

**A Case Study analysis to explore the
perceptions and experiences of patients,
carers and/or family members and
healthcare professionals in the management
of metastatic spinal cord compression
(MSCC)**

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**A thesis submitted in partial fulfilment of the
requirements of Edinburgh Napier University, for the
award of Doctor of Philosophy (PhD)**

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Declaration

I declare that this thesis is my own work, and that no material contained in it has been submitted for another academic award.

Siew Hwa Lee

June 2013

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Dedication

To my late father

Lee Giap Thung

Abstract

Background

Metastatic spinal cord compression (MSCC) can result in paralysis and is an oncology emergency. Prognosis is poor if not treated early. There are an estimated 1200-2500 new cases of MSCC per year in Scotland. At 2013 there are limited studies which have explored the issues experienced by patients, carers and/or family members and healthcare professionals in the management of MSCC.

Aim

The aim of this study was to explore the perceptions and experiences of patients, carers and/or family members and healthcare professionals in the management of metastatic spinal cord compression.

Research Design and Methods

A case study design approach involving two phases was used. Phase One involved three focus groups with healthcare professionals ($n=25$) and one-to-one interviews with healthcare professionals ($n=7$). Phase Two involved interviews with patients ($n=8$), carers ($n=6$) and healthcare professionals ($n=42$). Patients and carers were interviewed twice over a period of six months. Braun and Clarke's (2006) thematic inductive-data approach was used for data analysis.

Findings

Phase One identified an overarching theme of 'negotiating the care pathway' with four main themes: what can we do for patients with MSCC; what do we need to 'trade-off' to meet the needs of patients; how can guidelines help anyway; and how can we deliver optimum care in the midst of uncertainty? The majority of healthcare professionals viewed the existing National Institute for Clinical Excellence (NICE) guidelines (2008) as inadequate and lacking in a strong evidence base. Healthcare professionals acknowledged the importance of meeting the patient's preferred needs and goals given the nature of this condition and the short life expectancy of many patients with MSCC. Phase Two identified three main themes: facing uncertainty in MSCC; finding a

balance in MSCC and support beyond the treatment of MSCC. A focus on acute management is often at odds with the palliative nature of the patient's condition and this contributes to the complexity for patients, carers and healthcare professionals. The findings demonstrate the intricacies of uncertainty which affect all the key stakeholders when MSCC presents. There is a constant movement between uncertainty (of the future) and enduring inconsistencies (of information, treatment and advice for the future), which results in a struggle to find a balance.

Conclusions

Caring for patients with metastatic spinal cord compression is challenging with uncertainties surrounding the diagnosis of MSCC, spinal instability, treatment and support beyond the treatment of MSCC. A theory of collaborative decision making based on the findings in this thesis is proposed to help reduce uncertainty and enable key stakeholders to make decisions in their journey with MSCC.

Glossary of terms

AHP:	Allied Health Professionals: a health professional such as a physiotherapist (PT) or occupational therapist (OT) allied to medicine
CT:	Computed Tomography
DH:	Department of Health
EOL:	End of Life
EORTEC:	The European Organisation for Research and Treatment of Cancer
GP:	General Practitioner
HCP:	Healthcare professionals
IRAS:	Integrated Research Application System
MDT:	Multidisciplinary Team
MRI:	Magnetic Resonance Imaging
MSCC:	Metastatic spinal cord compression (MSCC) – metastatic is a general term used to describe the spread of a cancer from some other location in the body.
NHS:	National Health Service
NICE:	National Institute of Clinical Governance
PSA:	Prostate-Specific Antigen
QOL:	Quality of Life
QUORUM:	Quality of reports of meta-analyses of randomised controlled trials
RT:	Radiotherapy

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Chapter 1: Introduction and background to the study

1.1 Introduction

This thesis is an exploration of the perceptions and experiences of patients, carers and/or family members and healthcare professionals in the management of metastatic spinal cord compression (MSCC). The chapter starts with an account of my professional and personal interest in MSCC. This is followed by a mapping of the local and national developments and changes in relation to the management of MSCC. Within these changes, I focus on the rationale for a scoping exercise in two Scottish regions and how this current study fits in. A brief summary of the pathology, diagnosis of, and treatment for MSCC are presented to provide the background to the study. Finally, an outline of the chapters of the thesis is given.

1.2 A professional and personal interest in MSCC

In qualitative research, I feel it appropriate to write in the first person in order to explain the particular orientation I bring to this study (Webb 1992; Gilgun 2005). I acknowledge that I came to this study as a nurse having worked mainly in acute settings over the years. However, during my last seven years experience working in an acute urology ward setting, I have personally struggled with how to care for patients with metastatic spinal cord compression. In particular, I became interested in this condition because my previous discussions with colleagues revealed that a diagnosis of 'spinal cord compression' frightens people alarmingly. However, once patients were diagnosed with metastatic spinal cord compression in a urology setting, they were normally transferred very quickly to the cancer centre for radiotherapy. I could only think from my own perspective, how frightening all of this must be to them. My colleagues and I have discussed patients with this condition and have often questioned whether we have met their true needs.

My interest in research was formed over a number of years being involved in the development of a care pathway in transurethral resection of prostate

(TURP) and subsequently, in my Masters degree, I chose to evaluate two models of care in the management of acute urinary retention related to enlarged prostate. The opportunity to enhance my understanding of metastatic spinal cord compression was timely when I was offered a studentship at Edinburgh Napier University, Scotland. I acknowledge that the study was also driven by personal interest, as a family member had been diagnosed with cancer.

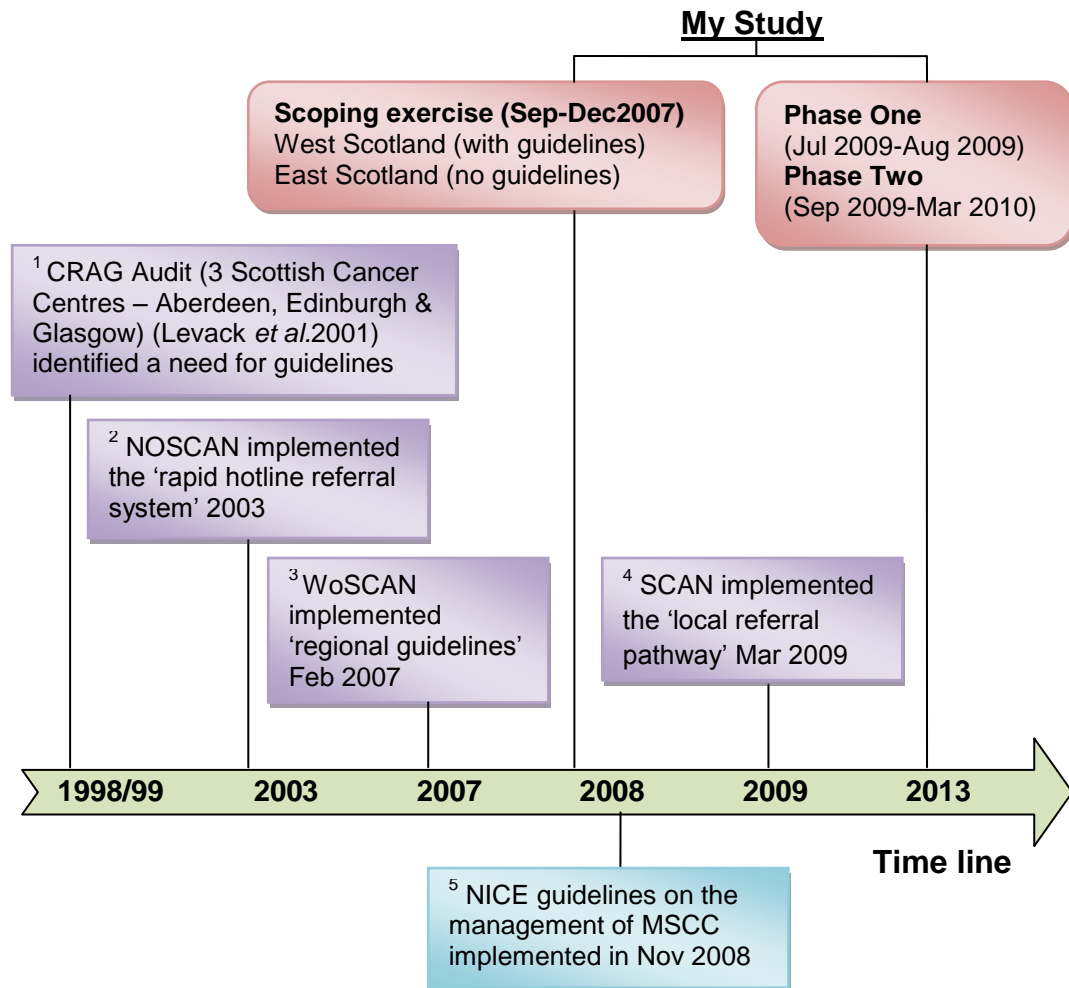
1.3 Metastatic spinal cord compression: context of local and national developments

In order to contextualise MSCC, it is necessary to provide firstly a definition and then outline the chronology of the Scottish and United Kingdom developments and changes that have taken place in relation to the management of MSCC. More specifically, I highlight where my study fits within these changes and provide the rationale for this study (Figure1).

Often cancer can spread to the other areas of the body such as lungs, liver and bones. Bone metastases to the spinal column are common and can compress the spinal cord and its surrounding structures (Aaron 1994; Bohm and Huber 2002; Coleman 2006). This necessitates immediate intervention to prevent permanent loss of neurological function. Progression of MSCC in the spine can have a devastating impact on the patients and their families. Metastatic spinal cord compression can be defined as:

“...compression of the dural sac and its contents (spinal cord and/or cauda equina) by an extradural tumour mass. The minimum radiological evidence is indentation of the theca at the level of clinical features. Clinical features include any or all of the following: pain (local or radicular), weakness, sensory disturbance and/or evidence of sphincter dysfunction.” (Loblaw and Laperriere 1998:1613)

Figure 1: Chronology of the local and national developments of MSCC



In the local context, a large prospective audit was conducted from January 1998 to April 1999, to examine the management of patients with MSCC in Scotland by the Clinical Resource and Audit Group (CRAG) in three Scottish cancer centres; Aberdeen, Edinburgh and Glasgow. The findings highlighted a lack of a referral process or clinical guidelines, causing delays in referral, diagnosis and treatment (Levack *et al.* 2001; 2002). In addition there was a lack of early identification of signs and symptoms of MSCC in both acute and primary care services and a lack of awareness on the appropriate method of investigation to detect MSCC (Levack *et al.* 2001; 2002).

¹ CRAG Audit (Levack *et al.* (2001); ² NOSCAN (North of Scotland Cancer Network); ³ WoSCAN (West of Scotland Cancer Network); ⁴ SCAN (South East Cancer Network) and ⁵ NICE 2008 (National Institute of Clinical Excellence)

Following the findings of Levack *et al.* (2001; 2002), the North of Scotland redesigned and implemented their service with a 'rapid referral hotline system' in 2003, where general practitioners, community nurses and hospital doctors refer patients suspected of MSCC to a designated senior clinician to discuss and arrange urgent MRI to improve the process of early diagnosis and treatment (Allan *et al.* 2009).

In the West of Scotland, an audit was carried out to examine any improvements following the CRAG recommendations in relation to symptom recognition, multi-professional care and rehabilitation of patients with MSCC (McLinton and Hutchison 2006). The retrospective data on patients admitted with MSCC, highlights poor pain assessment, poor ambulatory status and lack of a clear course of action to initiate mobilisation and rehabilitation. There was also a lack of a referral procedure for identifying patients suspected of MSCC. As a result, a regional guideline on the management of MSCC was established in February 2007 (McLinton and Hutchison 2006; Hutchison and Armstrong 2010).

Within the South East of Scotland, a local referral pathway was implemented in March 2009 (Appendix 1: Lothian MSCC Referral Pathway). An out-patient service with a protected MRI time slot for potential MSCC cases was piloted. SCAN MSCC audit from 2009 to 2010 showed improvements in patients remaining mobile on admission (Whigham 2012). An information leaflet and DVD was developed and distributed to GP surgeries.

As a result of the CRAG audit and subsequent developments (Levack *et al.* 2001; 2002), the three Scottish cancer networks have agreed on a standardised dataset for auditing purposes. An interactive DVD was developed and distributed to GP surgeries and clinical areas. Update reports from the implementation of these guidelines and referral pathways have found improvements in early presentation of patients with better outcomes (Hutchison and Garrett 2011; Whigham 2012). However, much work still remains with regards to referrals, education, patient positioning and mobilisation (Hutchison and Garrett 2011; Whigham 2012).

The national guidelines for the management of MSCC published Guideline CG75 (National Institute for Health and Clinical Excellence (NICE) 2008), aimed to improve the diagnosis and care of patients at risk of or with MSCC through the use of good evidence and a co-ordinated approach. The guideline recommends that each cancer centre commission appropriate services for referral and management of patients with MSCC. They recommend a single point of access to a MSCC co-ordinator who would then give clinicians advice and co-ordinate the care pathway.

The Scottish Government recognised the improvement of cancer care as a priority and addressed some barriers through various national policies, such as Better Cancer Care: Action Plan (Scottish Government 2008; 2010) and Living and Dying well (Scottish Government 2011). Having examined local and national developments in the management of MSCC, I now explain how my study contributes to the support and management of people affected by MSCC.

1.3.1 Rationale for a scoping exercise

There is little research into patients', carers' and healthcare professionals' perspectives in how MSCC is managed and these avenues therefore require further exploration. I undertook a scoping exercise, which involved individually interviewing 28 stakeholders on their current practice in two Scottish regions (West and East Scotland) from September 2007 to December 2007. The stakeholders were those directly involved in the management and care of patients and included Oncologists, Neurosurgeons, Radiologists, Palliative Medical Consultants, Orthopaedic Consultants, a Spinal Surgeon, Registrars, Managers, Ward Sisters, Nurses, Clinical Nurse Specialists, Physiotherapists, Social Workers and Radiographers.

1.3.2 Summary of findings from the scoping exercise

The scoping exercise from both regions showed similar key issues:

- Healthcare professionals in the acute setting perceived general practitioners lack identification of early symptoms of MSCC;
- Delay in referrals and treatment;

- Inconsistent patient management in positioning, mobilising and rehabilitation;
- Lack of verbal/written documentation of spinal stability / instability;
- Limited access to Magnetic Resonance Imaging (MRI) facilities;
- Limited use of bracing.

In the West of Scotland, healthcare professionals identified a continuing delay in referrals despite the implementation of local guidelines (WoSCAN 2007) for MSCC in February 2007. Some healthcare professionals felt that this information should be fed back to general practitioners in the region, while others said it was too early to see any difference from the implementation of local guidelines. Some respondents suggested that educating patients and staff to recognise the early signs and symptoms of spinal cord compression was essential. In the East of Scotland, the patient referral pathway from the general practitioner to the hospital was variable.

Inconsistencies in patient management were reported despite one region having guidelines in place. For example, respondents commented that instructions on whether 'to bed-rest' or 'not to bed-rest', were inconsistent for patients with suspected or confirmed MSCC. Advice about commencement of ambulation varied from the day of admission to five days after five fractions of radiotherapy. Decision making about positioning, mobilisation and rehabilitation was consultant led and sometimes their decisions conflicted with nursing management in relation to mobilisation to avoid complications such as chest infections, thrombotic episodes and caring for pressure areas. Nursing staff and allied professionals reported that patients on bed-rest regularly complained of boredom, feeling undignified during toileting, and having difficulty eating, watching television or reading. Nursing staff favoured early mobilisation but sometimes consultants considered early mobilisation might provoke a worsening of neurology, due to possible spinal instability.

Assessing whether the spine is stable or unstable is a grey area. There is difficulty in confirming spinal instability, as there are no agreed criteria. Images

can only be reported as 'not in alignment.' Some clinicians expressed difficulty in interpreting images as they had not had any training while others said that a plain x-ray has a place for determining spinal stability in compression of the cervical region, but not in the thoracic or lumbar region. There was a general absence of verbal or written documentation on the presence of spinal instability and this resulted in uncertainty and delays in mobilisation and rehabilitation. Some respondents felt MRI facilities were limited, especially on weekends, which meant a delay in treatment. Some felt neurosurgeons were reluctant or overly cautious about operating on patients with MSCC, while some neurosurgeons considered that the quality of life of the patients would be poor.

Most medical and nursing staff had limited experience in bracing. Bracing is generally prescribed for patients with infections of the spinal cord, not malignancies. There are differing opinions on bracing, as some respondents would fit a brace if the patient was not fit for surgery, and/or in cases with multiple site tumours, and/or with one or two column involvement. Generally, staff said patients complained of bracing aggravating pain and found bracing cumbersome.

This scoping exercise highlighted the variations in the management of patients with MSCC. The next section presents the concerns about delays in diagnosis and interventions for MSCC.

1.4 Pathology, clinical diagnosis, prognosis and treatment for MSCC

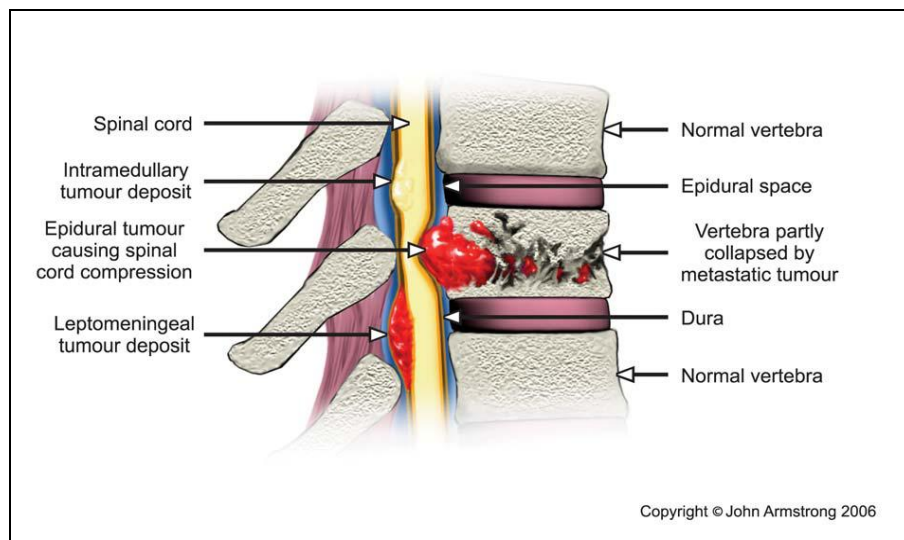
The difficulty in determining an accurate incidence of MSCC has been well documented (Loblaw, Laperriere and Mackillop 2003; Schiff 2003; Cole and Patchell 2008; Mak *et al.* 2011). A key population-based study carried out in Canada between 1990 and 1995, suggests that at least 2.5% ($n= 3458$) of all people with cancer experienced one or more episodes of spinal cord compression in the 5 years preceding death (Loblaw, Laperriere and Mackillop 2003). Post-mortem evidence indicates MSCC has a frequency of 5%-10% of all cancer cases (Barron *et al.* 1959). Studies have shown that metastatic

epidural spinal cord compression can occur by haematogenous spread to vertebrae; direct epidural spread or via the lymphatic system (Boyce, Yoneda and Guise 1999; Maccauro *et al.* 2011). Direct epidural invasion, from a paravertebral tumour through the inter-vertebral foramina, can cause compression of the spinal cord (Cole and Patchell 2008). Lymphatic spread is rare.

1.4.1 Origin of primary sites and spinal tumours

Patients, who present with MSCC, often have primary tumours of the lungs, breast, and prostate (Helweg-Larsen 1996; Loblaw and Laperriere 1998; Mak *et al.* 2011). Other less common causes are renal cell carcinoma, multiple myeloma, non-Hodgkin's lymphoma, colorectal cancers, sarcomas and unknown primary tumours (Helweg-Larsen 1996). Spinal tumour arises from inside the spinal cord (intramedullary) or outside the spinal cord (extramedullary) (Khanna *et al.* 2005). Tumours can spread to the vertebral column or surrounding structures. Figure 2 shows metastases to the vertebral column and the spinal cord.

Figure 2: Metastatic invasion of the spinal cord (Armstrong 2006)



The thoracic spine is the region most commonly involved with metastasis (70%), followed by lumbo-sacral (20%) and cervical (10%) (Kilmo and Schmidt 2004; Escalante *et al.* 2006). More than 50% of patients with spinal metastasis have multiple level involvements (Togawa and Lewandrowsky 2006). Lung, breast and lymphomatous metastases are more common in thoracic vertebrae; whereas renal, prostatic and rectal metastases are relatively more commonly found in the lumbo-sacral region (Boyce, Yoneda and Guise 1999; Mundy 2002).

1.4.2 Clinical diagnosis and prognosis

A diagnosis of metastatic spinal cord compression is an oncological emergency. New onset of back or neck pain along with a history of cancer, is a red flag that should prompt urgent investigation (Cole and Patchell 2008; Mavrogenis *et al.* 2009; Harel and Angelov 2010). However, 10-23% of patients with MSCC have no prior diagnosis of malignancy (Sciubba *et al.* 2010; Quraishi and Esler 2011; Eastley, Newey and Ashford 2012). The presentation of suspected MSCC can, however, be variable and depends on the vertebral level and the extent of involvement.

The most common symptom of metastatic spinal cord compression is spinal pain which presents as the first symptom in 83%-95% of patients, and more than 96% of patients at diagnosis (Helweg-Larsen and Sorenson 1994; Levack *et al.* 2001). It usually occurs at an average of 7 weeks before other neurological deficits (Levack, *et al.* 2002; Cole and Patchell 2008). The three classic pain syndromes are: local, mechanical, and radicular pain (Sciubba *et al.* 2010). Localised pain is confined to the region/segment of the spine that is affected by the metastatic disease. Mechanical pain (also known as axial back-pain) is aggravated with movement (axial loading of the spine) and can be relieved by lying down or in a supine position (Sciubba *et al.* 2010). Mechanical pain often indicates impending or established spinal instability. Vertebral body collapse may result in spinal instability. Radicular pain is caused by compression or invasion of the nerve roots and follows a dermatomal distribution (Eleraky, Papanastassiou and Vrionis 2010). Radicular pain is often

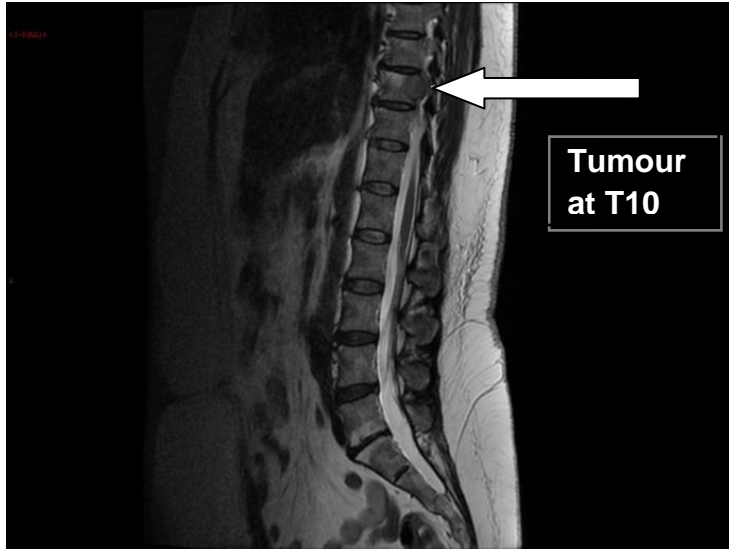
described as sharp, shooting or stabbing in nature (Sciubba *et al.* 2010). Pain may be unilateral or bilateral.

Motor weakness is the second most common symptom and occurs in 35%-75% of patients with MSCC (Bach *et al.* 1990; Helweg-Larsen and Sorenson, 1994). About 50%-68% of patients are unable to walk at the time of diagnosis. Autonomic symptoms occur late in the progression of MSCC and 50%-60% of patients suffer from bowel or bladder symptoms (Bach *et al.* 1990). This presents quality of life issues when there are bowel or bladder disturbances and a poor prognostic sign for preservation or improvement of ambulation status (Cole and Patchell 2008).

The prognosis for patients with MSCC is poor (Levack *et al.* 2001). The median survival in different series ranges from 3-7 months (van der Linden *et al.* 2005; Cole and Patchell 2008). In prostate and breast cancers, the survival is measurable in years, however, in lung cancer, the survival is measured in weeks or months (Coleman 2006). Patients who are paralysed pre-treatment or post-treatment, have a shorter life expectancy compared to patients who are ambulant. (Levack *et al.* 2001; Rades, Heidenreich and Karsten 2002).

Rapid access to magnetic resonance imaging (MRI) of the whole spine has had a significant impact on patient management in MSCC (Schiff *et al.* 1998; Levack *et al.* 2002; Loblaw *et al.* 2005, NICE 2008) and is superior to all other imaging modalities (Li and Poon 1988; Colletti *et al.* 1996; Jacobs and Perrin 2001). Accordingly, MRI should be performed immediately or within 24 hours for a definitive treatment plan. Figure 3 illustrates a sagittal view of a single tumour at thoracic level 10 causing impending cord compression.

Figure 3: Sagittal spine MRI scan showing a single metastatic lesion at T10 of a 50 year old patient with a known breast cancer (permission to use the image was given by patient).



NICE (2008) guidelines recommend targeted CT with three plane reconstruction to assess spinal instability if vertebroplasty or spinal surgeries are planned. Plain films are not recommended as a routine screening for suspected MSCC (Algra *et al.* 1992).

The researcher and colleagues have conducted two reviews and found no evidence-based guidelines on how to assess the risk of spinal instability in malignancy of the spine (Kilbride *et al.* 2010; Lee *et al.* 2012). Moreover, the definitions of spinal instability vary (Kilbride *et al.* 2010; Lee *et al.* 2012). White and Panjabi (1990: 89) defined spinal instability as “the loss of the ability of the spine under physiologic loads to maintain its patterns of displacement so there is no initial or additional neurologic deficit, no major deformity, and no incapacitating pain”. The difficulty in diagnosing spinal instability can lead to controversy in the choice of the treatment, especially the criteria for surgical intervention (Bilsky and Azeem 2007). Bilsky and Azeem (2007) propose three factors when making assessment on spinal instability: mechanical pain, neurological changes and radiologic findings. Sciubba *et al.* (2010) advised clinicians to make decisions around treatment from a practical perspective: to consider patient factors, stability, and neurology. Other authors suggest

mechanical pain can be an indication of spinal instability (Mercadante 1997; Coleman 2006; Izzo *et al.* 2012).

1.4.3 Treatment

The goals of therapy are pain control, preservation of functional status and quality of life. Current acceptable treatment approaches for MSCC include corticosteroids, radiotherapy and surgery (Loblaw and Laperriere 1998; Prasad and Schiff 2005; George *et al.* 2010).

The initial step when spinal cord compression is suspected is the routine use of corticosteroids, if there are no contra-indications. Corticosteroids, usually dexamethasone, are prescribed to reduce the oedema and cord compression and relieve pain. The optimal dose of dexamethasone is uncertain (Loblaw and Laperriere 1998; George *et al.* 2010; Harel and Angelov 2010). Two studies found no statistical difference between high and moderate dose dexamethasone treatment regimes; and recommend lower treatment dosages because side effects were fewer (Vecht *et al.* 1989; Graham *et al.* 2006). The usual dose recommended is 16 mg/d in divided doses over several days (NICE 2008).

Various scoring systems or algorithm have been developed to assist in decision making of surgery and/or radiotherapy (Bauer 1995; 2002; Tokuhashi *et al.* 1990; Tokuhashi *et al.* 2005; Tomita *et al.* 2001; Bilsky and Azeem 2007). Although some studies evaluated the scoring systems, the sample size and the clinical assessment alone may not be adequate in predicting survival in patients with MSCC (Leithner, Radl and Gruber 2008; Schultheiss 2008; Gakhar *et al.* 2012).

Radiotherapy alone is the most common treatment modality and is often the initial treatment for MSCC (Regine, Tibbs and Young 2003; Rades *et al.* 2006; Gerszten, Mendel and Yamada 2009). It may reduce the tumour mass, thereby improving pain and spinal cord compression. Patients who develop neurological deficits slowly have a better functional outcome after radiotherapy,

especially in radiosensitive tumours (Rades, Heidenreich and Karstns 2002; Rades *et al.* 2006). There are many reported studies on the different schedules of radiation therapy for spinal cord compression, ranging from 8-10 Gray (Gy) in 1-2 fractions to 30 Gy in 10 fractions (Kwok, Regine and Patchell 2005; MacBeth, Stephens and Hoskin 2005; Maranzano *et al.* 2005; Rades *et al.* 2005). The optimal dose remains controversial (George *et al.* 2010). Unlike the conventional radiotherapy, an alternative technique - stereotactic radiotherapy only targets the affected vertebrae (Ryu *et al.* 2001; 2004). The optimum dose is not known but a high dose delivered in 1-3 fractions has the potential for good control (Hall *et al.* 2011). The use of stereotactic radiotherapy is limited for patients with 1-3 metastases, with no more than 2 continuous vertebral bodies (Bhatt *et al.* 2012).

Surgery as a first-line treatment has shown promising benefits for patients, however, patient selection is important. Surgery may be indicated, particularly for those with spinal instability, intractable pain and rapidly progressing loss of neurologic functions, but the number suitable is small. The indication for surgery is usually limited to patients with one or two vertebrae involvement who have a good performance status and expected survival of more than three months (Rades *et al.* 2006).

A US-based randomised controlled multicentre trial, Patchell *et al.* (2005) reported that patients ($n=50$) who underwent direct de-compressive surgery in addition to radiotherapy (30 Gy in 10 fractions) were more likely to retain or maintain their ambulatory status longer than patients ($n=51$) who received radiotherapy alone (Patchell *et al.* 2005). The authors reported a significantly higher proportion maintained ambulation in the surgery plus radiotherapy group 84% versus 57% in the radiotherapy alone group (Patchell *et al.* 2005). This study has been criticised due to the small sample size and the highly selected patients (Knisely and Strugar 2006; Kunkler 2006). With the strict criteria in patient selection, used in Patchell's *et al.* (2005) study, few patients would be suitable for surgery.

Johnston and Smith (2005), reported that living with a terminal illness is a stressful and fearful experience which leads to feelings of a lack of control and defencelessness, affecting both the patient and their family. The threat of physical disability and carer dependency are most distressing to the patient and family (Pessin, Rosenfeld and Breibart 2002). Eva and Lord (2003), suggested that rehabilitation plays an important part in the management of MSCC. Spinal instability affects the decisions on how to care for patients in relation to positioning, mobilisation, rehabilitation and pain control. Held and Peahota (1993) recommend the use of a brace to support the spine and promote mobilisation, but Galasko, Norris and Crank (2000) reported that tumour metastasis to the spine can cause excruciating pain and the patient will be more comfortable lying down. As a result, healthcare professionals often face conflict in their decision making due to the lack of evidence-based literature.

1.5 Chapter summary and outline of the thesis

The context for this study shows that bone metastasis is a complication of a wide range of malignancies and the rate of recurrence is unpredictable. I have described the significance of MSCC in the international, the full UK and the Scottish context. Development of MSCC has major clinical implications and is an indicator of a poor prognosis. All literature on MSCC stresses the need for early diagnosis and treatment to prevent or minimise disability. However, early recognition of impending cord compression can be problematic (Husband 1998; Levack *et al.* 2001; Loblaw *et al.* 2012).

MRI is the gold standard imaging modality in identifying impending spinal cord compression, but is infrequently accessible in a timely fashion. Problems exist defining spinal instability in MSCC. Decisions on treatment, positioning, mobilisation, pain relief, and rehabilitation are complex, requiring multidisciplinary and multi professional discussion. Prognostic scoring systems to aid decision making are not consistently used and benefits are somewhat conflicting. There remains debate regarding surgery plus radiation versus radiation alone for patients in MSCC, despite a small randomised controlled trial, as the expertise may not exist for some complex spine surgery on the

thoracic spine. Moreover, major surgery is associated with morbidity and mortality and patient selection is important. It is not clear how clinicians make their decisions, when faced with multiple complex issues.

The scoping exercise revealed inconsistencies in the management of patients with MSCC which potentially led to delays in mobilisation and prolonged hospital stay. Management is variable and it is not clear how the patients are involved in decisions about their care. More importantly, it is not clear how the inconsistencies impact on patient care. There is limited research on how guidelines are translated into the clinical setting, therefore, it is timely to illuminate the patients' and carers' and healthcare professionals' experiences and to contribute towards the management of MSCC and towards the national agenda for Scotland's Patient Experience Programme: Better Together (Scottish Government 2008).

Outline of the thesis

This thesis is structured across seven chapters; an outline of each chapter is given. Chapter 2 presents a review of the current literature on the impact of MSCC on patients, carers and/or family members and the challenges faced by healthcare professionals in managing this group of patients. The rationale for the research design, methods, ethical considerations and analysis are presented in Chapter 3. The findings from Phase One and Two are presented in Chapters 4 and 5 respectively. Chapter 6 demonstrates the synthesis from the findings in relation to the literature. Chapter 7 offers the conclusion; suggesting recommendations for practice, policy and areas for future research in MSCC.

Chapter 2: Literature review

2.1 Introduction

In this chapter I provide an integrative review focussed on understanding issues and challenges faced by patients, carers and healthcare professionals in the management of metastatic spinal cord compression (MSCC) and identify the gaps in knowledge. The aims were to identify and synthesise:

- what is known about patients' experiences when diagnosed with MSCC;
- what is known about carers' and/or family members' experiences in supporting the patient with MSCC;
- what is known about the healthcare professionals' experiences in managing patients with MSCC.

Although systematic reviews are seen by some to be transparent as they use a predefined, explicit methodology (Webb and Roe 2007), Harden *et al.* (2004) caution that systematic reviews may distort, misrepresent or miss crucial service users' views or perspectives. However, an integrative review includes more diverse forms of evidence and would allow the synthesis of experimental and non-experimental research to provide breadth of perspectives, and a more comprehensive understanding of a particular phenomenon or a healthcare problem (Whittemore and Knafelz 2005; Gough, Thomas and Oliver 2012). I therefore applied this approach to carry out a structured integrative literature review.

The steps of this process are as follows:

- Identify the aim of the review;
- Identify the search strategies;
- Identify studies according to defined inclusion and exclusion criteria;
- Evaluate literature against defined criteria;
- Present a synthesis and summary of findings from the literature.

2.2 The aim of the review

The aim of this integrative review was to establish a clear focus for this study of MSCC. The background study on MSCC suggested that little is known about the patients', carers' and healthcare professionals' experiences in managing MSCC (Chapter 1). The findings from the scoping exercise revealed that inconsistencies in patient management persist and that there are concerns regarding the variations in the care that patients with MSCC receive. The body of research evidence that exists investigates the effectiveness and comparison of treatments for malignancies of the spinal cord from a positivist perspective. However, the dynamics of an illness experience and its relationship to physical pathology are extremely complex and relatively unexplored.

2.3 Search strategies

To enable effective critical review of existing evidence, patient experience was defined as the following:

“A patient’s experience of the care or treatment they have received. This included a patient’s wider experiences of health care service, perceptions, beliefs and issues about their journey of care” (DH 2007).

Therefore, literature about carers' and/or family members' experiences were also included, as their support is an integral part of the patient's experience. The patient's '*wider experiences of health care service*' (DH 2007) incorporates the perspectives of healthcare professionals and the multidisciplinary team in different health care settings involved in the management of patients with MSCC. To help to identify any gaps in research knowledge, refine research aims and inform methods, the terms regarding experiences, decision making, quality of life and end of life were added to the search strategy. Table 1 shows terms relating to MSCC and this was combined with patient, healthcare professionals and caregiver and their related terms. These were adjusted to suit the terminology of the database searched.

Table 1: Search terms used to identify studies on MSCC	
Main terms	Other related terms
Metastatic spinal cord compression	Spinal cord compression, spinal cord neoplasms, neoplastic metastases, malignant spinal cord compression.
Patient, Consumer	Participation; satisfaction; attitude; patient-centered care; experience; journey; perspectives; and decision making, patient.
	Palliative care; terminal care.
	Quality of life; coping; psychosocial aspects of illness.
Healthcare Professionals	Multidisciplinary teams; decision making, clinical.
Caregiver	Experience; perspectives; support.

The search strategy was carried out in consultation with a librarian and modified according to the electronic database. The search was focused on literature published between 1st January 2000 and 9th August 2012 to ensure findings were relevant to the review aims. Several electronic databases, paper-based sources and consultations were carried out as listed below:

- Medline 1st January 2000 – 9th August 2012;
- CINAHL 1st January 2000 – 9th August 2012;
- AMED (Allied and Complementary Medicine) 1st January 2000 – 9th August 2012;
- PsycINFO 1st January 2000 - 9th August 2012;
- EMBASE 1st January 2000 – 9th August 2012;
- Cochrane Library 1st January 2000 – 9th August 2012;

- Reference lists from relevant studies and reviews;
- Additional references were gained from experts in this field.

Initial literature searching was carried out in Medline using the Medical Subject Heading (MeSH) search terms, limited by adults, year of publication and English Language (Appendix 2). This strategy was adapted for use in other databases. Detailed search strategies applied to CINAHL, AMED, PsycINFO and EMBASE. As a result, comprehensive coverage of available literature was achieved. Although the language was restricted to English, two foreign articles with English language abstracts were retrieved. Both papers not being relevant to the research question were excluded.

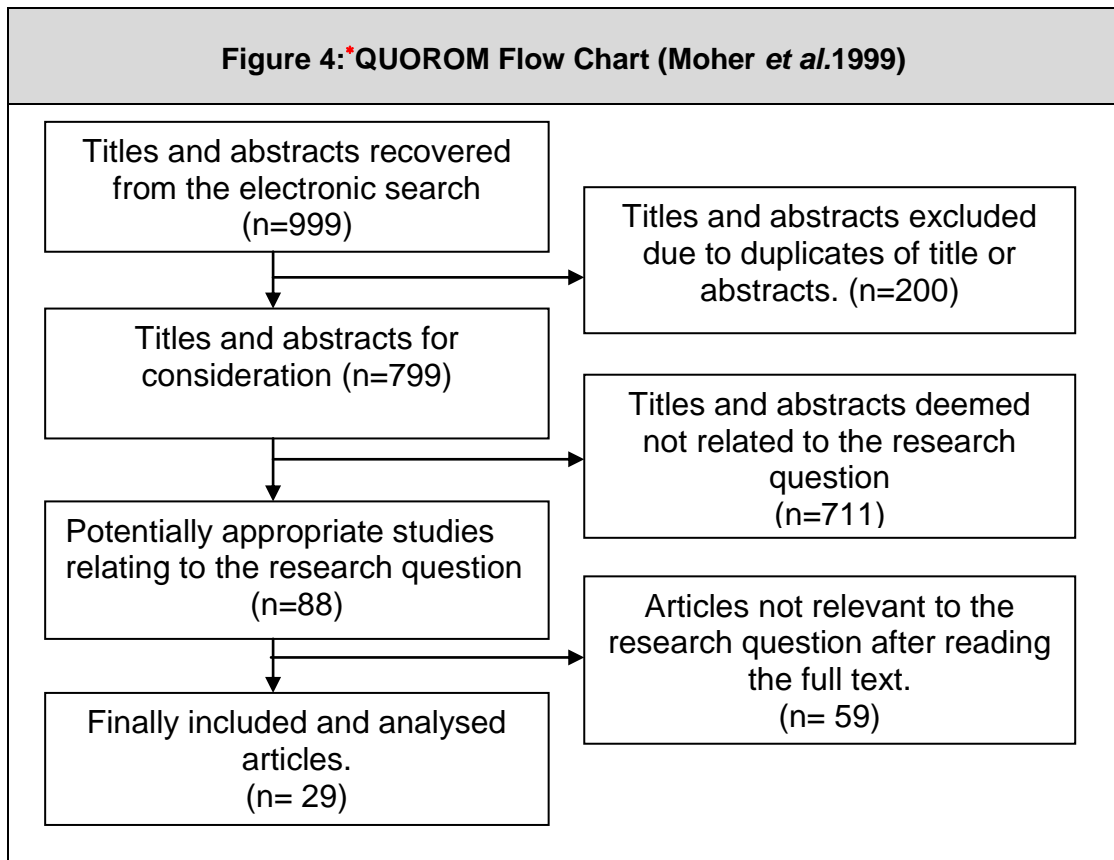
2.4 The review process

The retrieved titles and abstracts (395) from all databases - except the Cochrane Library - were entered into Endnote software to enable deletion of duplications. The titles and abstracts (604) from the Cochrane Library were checked manually and screened for relevance. Once this was established, efforts were made to obtain the full-text articles.

Three further articles were retrieved from relevant reference lists. Additional references were obtained from the research experts in this field. Once the abstracts were obtained from the search, they were reviewed for relevance to meet the criteria for this review. Published work has to be methodologically rigorous before any findings can be regarded as useful. The types of studies included are listed below:

- Meta-analysis and systematic reviews;
- Randomised controlled trials;
- Primary quantitative studies and qualitative studies.

The process of screening for the relevance of articles is illustrated in Figure 4 Quorum Flow Chart (Moher *et al.*1999).



The search yielded 999 articles: Medline 64 articles, CINAHL 210, AMED 54, PsycINFO 10, EMBASE 57 and Cochrane Library 604; 200 of which were duplicates resulting in 799 titles and abstracts being screened with 88 identified as being potentially relevant to the research question in accordance with the inclusion and exclusion criteria. The inclusion criteria were applied to the selection of abstracts and articles ($n=88$).

Twenty nine articles were deemed relevant. Papers identified by the searches were read and the data extracted and summarised under pre-determined headings: author(s); year; country of study; care setting; aim of study; type of study; sample; characteristics of patients or staff groups; methods; key

* Quality of reports of meta-analysis of randomised controlled trial (QUOROM) (adapted Moher *et al.* 1999)

messages and level of evidence in Scottish Intercollegiate Guideline Network (SIGN) (2012); see Appendix 3. The literature was scrutinised and issues and themes were synthesised.

The 29 studies retrieved included: one Cochrane systematic review; three other systematic reviews; one review, one qualitative study; 21 quantitative studies and two audits. A further two articles were retrieved from the reference list (Levack *et al.* 2002 and Patchell *et al.* 2005). The final total of studies is 31. Although these studies were assessed for quality, in this review, the purpose was not to exclude studies based on quality but rather to allow an overall judgement of the status of knowledge in the field. Three key issues or themes which consistently emerged from this review were identified and provided the framework for the following discussion and reporting of findings from the integrative review as follows:

- Impact of MSCC on patients' experience;
- Carers' experience in supporting the patient with MSCC;
- Healthcare professionals' experiences in managing patients with MSCC.

2.5 Impact of MSCC on patients' experience

There were 24 studies addressing various aspects of patients' experiences with MSCC which impacted on their daily lives. The review presents the evidence drawn from three systematic reviews, one randomised controlled trial, 12 prospective studies, seven retrospective studies and one qualitative study. A summary of the studies addressing the impact of MSCC on patients' experience can be found in Appendix 4. The patients' experience of MSCC are discussed under the following sub-headings: impact of MSCC on patients' survival; impact of MSCC treatments on patients' quality of life; information needs of patients about MSCC; structured rehabilitation on patients with MSCC; impact of MSCC on patient as a person and transition from curative treatment to palliative care.

2.5.1 Impact of MSCC on patients' survival

There is strong evidence reporting short survival times (median 59 to 120 days), as a major influencing factor when describing the experience of an individual with a diagnosis of MSCC (Cowap, Hardy and A' Hern 2000; Conway *et al.* 2007; Huang and Jatoi 2009; Guo *et al.* 2010). Cowap, Hardy and A' Hern (2000), reviewed the medical records of 166 patients and reported that the median survival from confirmation of MSCC was 82 days (range, 1-1349 days). Whilst in a larger study, Conway *et al.* (2007), in their prospective study of 319 patients at three Scottish cancer centres reported the median survival was 59 days from diagnosis of MSCC (95% CI 43-75). It must be noted survival post diagnosis can vary depending on the primary cancer groups.

In a recent US-based retrospective review of 88 patients' medical notes, Guo *et al.* (2010) reported the median survival was 4.3 months. As the majority of patients from these studies had radiotherapy and a minority had surgical treatment, studies looking at different treatment modalities need to be considered in terms of survival times.

Investigating 49 patients who had radiotherapy treatment only, Aass and Fossa (2005), reported the overall survival from the start of radiotherapy was a median of 3.5 months (range, 0.3-36.0). One limitation to their study was that it only included patients with hormone resistant prostate cancer who received radiotherapy. Estimated survival rates are important for people with MSCC as it can be influential in the decisions made regarding their treatment.

Some authors suggest that palliative surgery with or without radiotherapy is a valuable treatment for MSCC (Wai *et al.* 2003; Sandalcioglu *et al.* 2005; Falicov *et al.* 2006; Fujibayashi *et al.* 2010; Wu *et al.* 2010). For, example, Wai *et al.* (2003) reported the time to death ranges from 1-21 months. Whereas, Falicov *et al.* (2006) reported an overall 50% survival in their study of 85 patients was 39.1 weeks (95% confidence interval, 30.9-60.0 weeks).

Tomita *et al.* (2001), in their study used their surgical scoring system to determine the treatment for 67 of their patients. Their findings show that the mean survival for 28 patients who underwent wide or marginal surgical excision was 38.2 months; for 13 patients who underwent intra-lesional excision, mean survival was 21.5 months; the mean survival for 11 patients who had palliative surgery and stabilisation was 10.1 months and those treated with supportive care was 5.3 months. These findings may indicate that the survival of patients depends on the position of the incision in relation to the tumour and whether complete removal of the tumour was possible. In addition, survival also depended on whether patients went on to receive adjuvant treatment.

In contrast, Wu *et al.* (2010), in their prospective longitudinal study, did not demonstrate a prolonged survival in patients after surgery compared to the findings of the study by Patchell *et al.* (2005). Wu *et al.* (2010), compared patients who had undergone surgery plus radiotherapy to another group of patients who had radiotherapy alone; no statistically significant difference was found between the two groups in terms of survival ($P = .056$). The survival rates at 9 months and 18 months for the surgery group was 62% and 58.9% and for the non-surgery group 62% and 48% respectively. The authors reported there was a moderate decline in survival between 12 months and 22 months in the surgery group compared with that during the initial 12 months (Wu *et al.* 2010). Overall there is no conclusive evidence about the relationship between treatment modalities and survival rates.

2.5.2 Impact of MSCC treatments on patients' quality of life

As length of survival may not be the main aim of palliative treatment, other studies need to be taken into account when looking at the treatment of people with MSCC. For example, Falicov *et al.* (2006) stressed that reduction in pain levels, maintenance of independent function and avoidance of neurological compromise are the main goals of surgical intervention. The authors conducted a prospective study assessing health related quality of life (HRQOL) in patients who underwent surgery. Eighty five patients were given a detailed questionnaire at five time points: before surgery, at six weeks, three months, six

months and one year post surgery. Outcome measures were: the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ –C30) (Aaronson *et al.* 1993), Health Utility Index (HUI) (Torrance *et al.* 1996), European Quality of Life – 5 Dimensions (EQ-5D) (Dolan 1997), Visual Analogue Scale (VAS) (Jensen, Chen and Brugger 2002) and Eastern Cooperative Oncology Group (ECOG) (Jonsson *et al.* 1996) functional assessment. The authors reported surgical intervention had a positive impact on patients in the domains of pain relief and in overall health and function. One criticism of the study, Falicov *et al.* (2006), was the repetition in some of the domains, for example, pain in VAS, QLQ-C30 and HUI and the additional burden this presented for patients.

There was no definition of health related quality of life and no justification for the choice of measures used. The authors did not specify whether patients were prescribed analgesics and when they completed the questionnaires. The authors reported widely on the aspects of pain, however, there was less mention about the emotional domain. Although the authors reported no significant improvement in functional scale but improvement in overall health status, it is not clear whether these factors influenced each domain. With respect to the EORTC quality of life questionnaire, it is designed for clinical trials and it does not identify patients' problems or care needs in depth.

Wai *et al.* (2003), suggest the use of a multi-dimensional assessment of quality of life is more appropriate in palliative care. The authors prospectively evaluated a cohort of 25 patients after surgery at one, three and six months during follow up and by telephone using a patient-centered questionnaire Edmonton Symptom Assessment (ESAS) (Bruera *et al.* 1991) and a physician-determined assessment of the patient's physical disability, the Townsend Functional Assessment (Townsend, Rosenthal and Smalley 1994). ESAS is designed to assess a patient's quality of life with domains in pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, sense of wellbeing and shortness of breath.

The study demonstrates the most improved domain after surgery, was in pain. Significant improvements were also seen in the domains of tiredness, nausea, anxiety, appetite and overall wellbeing. There was no improvement in the domains of depression, drowsiness and shortness of breath. The authors reported the Townsend Functional Assessment showed improvement in 44% ($n=11$) of patients; therefore, neurological recovery is unpredictable (Wai *et al.* 2003). It is notable here that although surgery enhanced a patient's quality of life, it is not known whether those patients who were depressed, were mobile or did not regain their mobility or whether the patient had poor outcomes from surgery.

Wu *et al.* (2010), a Chinese-based study, compared two treatment groups (surgery, $n = 46$ patients versus non-surgery group, $n = 50$ patients) using a different quality of life measure. Patients self administered the Functional Assessment of Cancer Therapy-General (FACT-G) (Cella *et al.* 1993) quality of life questionnaire at baseline, one, three, six and nine months after surgery. The FACT-G questionnaire measures four specific life domains: physical wellbeing, social/family wellbeing, emotional and functional wellbeing and in addition pain assessment. Sixty seven (69.8%) patients completed all the five time point assessments. These include 33 patients in the surgery group and 34 patients in the non-surgery group. Their findings showed that patients who underwent surgery fared better and maintained their quality of life over the nine month assessment period compared to those patients from the non-surgery group (Wu *et al.* 2010). Although the authors acknowledged that surgery was suitable for all patients eligible for this study, the decision making of treatment was left to the patient and family members. It is not known what the patients' preferences were and whether the family members' preferences influenced the patient's decisions. It is also not known whether the patients had an understanding of their condition and the palliative intent of treatment.

Interestingly another study considered whether satisfaction with surgical intervention had an impact on patients' and family members' mental health and their quality of life (Fujibayashi *et al.* 2010). Thirty seven out of 71 patients

responded. Overall, 30 (81.1%) of the patients were satisfied or very satisfied with the surgical procedure. Pain relief was achieved in 27 patients and patients aged below 65 years with neurological improvements correlated positively with increased patient satisfaction. There is caution in the interpretation of these findings, as 16 patients had died by the time of completion of the questionnaire and responses were collated from family members. Hence, patient satisfaction may not correspond to of their family members. Although the response rate was slightly over 50%, there is a possibility that those who did not respond were not satisfied or had poor outcomes.

Another limitation reported was the period that elapsed between the surgery and the completion of the questionnaire (range, 3-69 months) which may have depended on unreliable memories to complete the questionnaire. Moreover, surgery is considered in generally fit patients with an expected survival of at least 3 months. In addition, patients who had total en bloc spondylectomy were excluded from the study and there was no explanation for the exclusion. It is not known whether patients who had major surgery had poor outcomes or suffered complications.

The above studies showed that improvement in pain is significant after surgery. However, the majority of patients who were not fit for surgery suffered from pain which may not have been addressed. For example, Huang and Jatoi (2009), on reviewing the medical records of 39 patients found 33 (85%) patients require pain relief. Whereas, Conway *et al.* (2007), found that almost half the patients in their study experienced ongoing pain because the therapeutic benefits of radiotherapy can only be felt around 2.6 months after treatment.

Not all patients regain their neurological functions after surgery (Schoeggel, Reedy and Matula 2002; Wai *et al.* 2003; Sandalcioglu *et al.* 2005). Wai *et al.* (2003), stated that stabilisation of the spine addresses the problem of pain but not necessarily neurological recovery and in some cases total tumour removal may not be achieved (Schoeggel, Reedy and Matula 2002; Sandalcioglu *et al.*

2005). Some studies have reported that complications as a result of surgery in MSCC can be distressing for patients (Murakami *et al.* 2010; Omeis *et al.* 2011). For example, Omeis *et al.* (2011), conducted a retrospective case control study of 162 cases; 65 patients developed post operative complications. The incidence of surgical site infections after surgery is significant (~10%) with risk increasing in relation to the number of co-morbidities. Previous surgery, complex plastic closures, and hospital acquired infections during primary surgery are also complicating factors. Murakami *et al.* (2010), reported a significantly higher frequency of respiratory complications and delirium occurring in the elderly patients (although the authors advocate that surgery should not be avoided solely because of the patient's advanced age).

Whilst the above studies looked at outcomes from surgery, Aass and Fossa (2005), assessed the impact of radiotherapy on 49 patients quality of life using a modified Barthel Activity of Daily Living Index (Barthel ADL Index) (Wade and Collin 1988) at the start and end of radiotherapy treatment and at follow-up to death. The authors reported radiotherapy (median target dose 30 Gy (range, 9-40)) may improve mobility, daily life function and sphincter control in patients with MSCC due to hormone resistant prostate cancer.

However, at the end of radiotherapy treatment, patients did not report improvement with regards to mobility, daily function and sphincter control. The authors suggest it could be because prostate cancers are slow to respond to radiotherapy. Radiotherapy was started at a median of 4 days (range, 1-66 days) and the authors highlighted that a delay in recognition of MSCC may be either due to patients' and/or doctors' delay. What's more, the authors could not confirm whether a patient's pre-treatment neurological status was an important parameter predicting good clinical outcome compared to other studies as the Barthel ADL Index may not be sensitive towards differentiating between paralysis and paresis. This study indicates the problems in the use of a measurement tool in evaluating physical function over a period of time.

Levack *et al.* (2004), carried out a prospective study ($n=180$) at three major cancer centres in Scotland of patients shortly after diagnosis, using the Schedule for Evaluation of Individualised Quality of Life – Direct weighing (SEIQoL-Dw) (O’Boyle *et al.* 1993) to measure the quality of life, Hospital Anxiety and Depression Scale (HAD) (Ibbotson *et al.* 1994) for emotional wellbeing, Barthel Disability Index (BDI) (Mahoney and Barthel 1965) for activities of daily living, Karnofsky Performance Score (KPS) (Schag, Heinrich and Ngnaz 1984) to measure functional outcome. The SEIQoL-Dw questionnaire was developed from the technique of ‘judgement analysis’ to measure patients’ levels of functioning; measuring from 0 (worst) to 100 (best) on patients quality of life.

This measure allows patients to nominate the five areas of life which are most important to them then rate their level of functioning or satisfaction with each, and indicate the relative importance of each area to their total quality of life. The study found that what the patients perceived was their quality of life did not match with healthcare professionals’ judgement about the patient’s quality of life. The majority of patients scored high on family life (91%). Health and mobility were nominated by 44%, 39% and 35% respectively, and independence at 29%. Physical disability was not significantly associated with quality of life as the majority of patients viewed family life as more important to their quality of life.

In the social/family domain, Levack *et al.* (2004), highlight that using SEIQoL-Dw quality of life measure can focus attention around what matters to patients. The authors acknowledge that although some cues were selected more commonly than others, no two patients nominated the same five cues (generally, a combination of physical and non physical issues), therefore, it was difficult to predict what the patient was going to say. The findings indicate that what contributes to quality of life varies widely between patients. Moreover, it is not clear whether the patients have a full understanding of the consequences of MSCC shortly after diagnosis. In addition, the authors stated that during the study, the majority of patients were actively receiving treatment with

dexamethasone, radiotherapy and analgesia and this can give a sense of optimism and hope. There may also be disparity in what the patients expect and the professionals' palliative intent. It is also notable that 81 patients were unable to complete the quality of life measure questionnaire; with 57 cases being unwell and 24 patients not giving a reason. Therefore, those who were ill or did not participate were under-represented.

In a follow up to the above study, Conway *et al.* (2007), interviewed 128 patients one month after diagnosis with MSCC. They reported patients rated their quality of life as good despite physical disability. The authors acknowledged that due to limited data on quality of life at one month after diagnosis, the poor performance status of patients was associated with a lower quality of life. However, when individual scores were analysed, not all patients with a low performance status had low quality of life. This indicates the difficulty in capturing the information around physical disability and quality of life in MSCC. Wu *et al.* (2010), found both groups of patients (surgery group and the non-surgery group) scored favourably on the social/family well being domain. One explanation offered was the Chinese tradition of attending to the patient's needs regardless of the patient's treatment. Further qualitative research may uncover whether support from family members or the health providers influences the patient's quality of life.

In the domain of emotional wellbeing, Levack *et al.* (2004), used the HAD questionnaire, and reported patients experiencing disability as a result of MSCC were not severely depressed and few were depressed shortly after diagnosis of MSCC. The authors cautioned that depression should not be confused with demoralisation and sadness. A follow up of the same group of patients at one month found similar results where most of the patients' moods were reported to be normal (Conway *et al.* 2007). Low mood correlated with low quality of life but the authors could not account for all patients who recorded low on the quality of life scores. Some patients rated their quality of life to be high and at the same time recorded high levels of emotional distress. Other patients who scored low in the quality of life scores had low levels of emotional distress. This

suggests the difficulty in capturing the emotional wellbeing of patients and the factors that influence the patient's emotional state with the use of this questionnaire.

In contrast to these findings; Wai *et al.* (2003), investigated the efficacy of surgery for MSCC patients in respect of quality of life. The ESAS scale was carried out pre and post-operatively to determine any differences in symptom control. This study reported that patients continued to have depression, drowsiness and shortness of breath post-operatively with no improvement. Similarly, Ruff *et al.* (2007a; 2007b) through their prospective evaluation of rehabilitation after radiotherapy for MSCC patients, found that 26 (86.7%) out of 30 patients who did not participate in a structured rehabilitation programme suffered clinical depression necessitating anti-depressants. Measurements in this study were carried out using the Beck Depression Inventory-Second Edition (BDI-II) (Beck, Steer and Brown 1996).

Findings from these four studies are disparate; this may be due to the fact that a variety of measurement scales are used, none of which is designed specifically for MSCC. Some authors argue that health related quality of life (HRQOL) measurements that are commonly used are not always viewed as helpful in identifying individual patient's needs as they are not specific to MSCC (Street *et al.* 2009; 2010; Mitera and Loblaw 2010). The reviewers stated that survival, pain, ambulation, neurological deficit and sphincter control are indirect measures of health status and utility and it is misleading to consider these as measures of quality of life (Street *et al.* 2009; 2010). These outcome measures are process variables; meaning a patient's condition can change over time. Therefore, they cannot give an insight into a patient's experience and the impact on their care. A qualitative approach may more effectively illuminate the cause and experience of depression for patients with MSCC.

Street *et al.* (2009), in their systematic review, analysed 141 studies that investigated patients HRQOL outcomes as a result of surgery, surgery and radiation, radiation only, vertebroplasty and kyphoplasty. The reviewers found

the most commonly used outcome measurement tools in general cancer studies are: Eastern Cooperative Oncology Group (ECOG), European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QCQ-30) and the European quality of Life – 5 Dimensions (EUROQOL 5D), and the most common patient self-assessment instruments used to assess health status were Short Form 36 (SF-36), Sickness Impact Profile 5 (SIP 5) and the Activities of Daily Living (ADL).

When the validity of the different HRQOL questionnaires was compared against the International Classification of Functioning Disability and Health (ICF) WHO (2013) benchmark, the reviewers indicated that none of the instruments specifically address the concerns and impairments of patients with metastatic spinal disease. The reviewers found that the inconsistencies, variability and disparity of findings on health related quality of life indicated a need for a disease-specific outcome tool for MSCC.

Subsequently, the reviewers published the same systematic review and this time they introduced a new patient-administered HRQOL outcome tool specific for metastatic disease of the spine – Spine Oncology Study Group Outcome Questionnaire (SOSGOQ) (Street *et al.* 2010). The reviewers claim the face validity of the questionnaire was assumed as the tool was developed in consultation with patients with metastatic spinal disease and by consensus from an international expert working group. This new tool consisted of 27 questions covering the following domains (physical function; neurological function; pain; mental health; social function; and post therapy) and was intended to measure the disease burden specific for metastatic spinal disease (Street *et al.* 2010). However, to date, there is no study validating its use. The reviewers mentioned social function however, only one vague question was found which asked whether the patient's condition impairs/compromises the patient's personal relationships. The patient is given a limited choice of responses ("never," "rarely" and "sometimes") and so the answer does not really address the interaction between the patient and their spouse and/or family members who are pivotal in supporting the patient.

In another systematic review, Mitera and Loblaw (2010), identified five studies that used quality of life measures (Schedule for Evaluation of Individualised Quality of Life –Dw (SEIQoL-Dw); Short Form 36 (SF36) (Garratt *et al.* 1993); Paediatric quality of life inventory (PedsQL) (Varni *et al.* 2002); and Functional Assessment of Cancer Therapy (FACT-G) in radiation therapy trials for patients with MSCC. The reviewers found the quality of life measures used across the studies were inconsistent and findings cannot be compared. They suggest the concept of quality of life measures must incorporate not just the physical aspects but also the cognitive, emotional and subjective components that are important to patients. Although the reviewers did identify quality of life measures that meet all the criteria (FACT-G and SEIQoL-Dw), it was thought to be time consuming for patients to complete these questionnaire and that they did not capture the distinctive disease components of patients with MSCC (Mitera and Loblaw 2010). Hence, this justifies the need for further research to explore patients' perspectives in MSCC.

The delay in recognising MSCC affects the outcomes of treatment. Pre-treatment neurological status is a predictor of functional outcome and prognosis is acknowledged by a few authors (Cowap Hardy and A' Hern 2000; Wai *et al.* 2003; Aass and Fossa 2005; Sandalcioglu *et al.* 2005). Cowap Hardy and A' Hern (2000), reported that at presentation, symptoms had been present for a median period of 10 days (range, 0-383 days). Limb weakness was the most common symptom, followed by back pain, sensory loss and sphincter disturbance.

In contrast, a prospective study of 319 patients conducted by Levack *et al.* (2002) found pain was reported by nearly all the patients (94%) and had been present for approximately three months (median = 90 days; IQ range 37-205 days) but the site of pain did not correspond to the site of compression. Although patients experienced leg weakness and/or sensory problems this was reported late and detected even later. Therefore, MSCC is an emergency condition and early recognition of the signs and symptoms of MSCC could reduce poor outcomes.

2.5.3 Information needs of patients about MSCC

Patient education about the signs and symptoms of MSCC is important to facilitate early referral and is linked to coping with the diagnosis (Hutchison *et al.* 2012). These authors recently conducted a survey in a cancer centre in Scotland to determine patients' and staff views on the provision of information to patients with a diagnosis of MSCC or potentially at high risk of developing MSCC. Questionnaires to patients and staff consisted of open and closed questions. Fifty six patients (50 of the 56 patients had metastases) and 50 staff responded. The staff comprised of: consultants ($n=29$); registrars ($n=7$); radiographer ($n=1$); senior ward/charge nurses ($n=6$) and clinical nurse specialists ($n=7$).

The authors reported that a large proportion of patients did not receive information on MSCC ($n=26$) (Hutchison *et al.* 2012). Thirty two per cent received information in verbal form, seven per cent in written form and 13% a combination of both. The majority of patients (82%: $n=46$) did not look for information from any other source. Forty eight per cent of staff said they gave verbal information to high risk patients prophylactic about MSCC; however, 45% ($n=13$) of consultants were not sure whether patients should be given this information.

Views on when it is the appropriate time to give information to patients varied from 'on a diagnosis of bone metastases' to 'disease progression' or 'when the clinician perceived the patient to be at high risk of developing MSCC'. Forty-two per cent ($n=21$) of staff felt that the appropriate time to give information on MSCC was to those patients in at risk groups (primary cancer of lung, breast, prostate cancer or bone metastases). However, the findings are unclear around which group of patients were given prophylactic information. Patients' views were also sought on whether it would be helpful for them to have the information about the signs and symptoms of MSCC. Forty eight patients agreed, three patients disagreed and five were unsure.

The authors highlight that those patients who felt the information on MSCC would not be helpful had metastases, however, there were no reasons given for this response (Hutchison *et al.* 2012). The authors categorised the patients comments into 'want to know', 'don't want to know' and 'neutral'. Those patients who commented 'don't want to know' did not give any explanation. Most patients were reported as wanting a combination of written and verbal information on MSCC. The authors noted there was a mismatch between what the patient wanted to know about MSCC (both when they were diagnosed with the condition and prophylactically) and those of the staff. They found that staff were unclear whose role it was to provide information to patients and at what stage patients should be given the information. The perception was it was 'either everyone's problem or someone else's problem'.

The rationale for the staffs' attitude was perhaps because patients with MSCC or those at high risk may be managed at a different site-specific cancer and care setting. The authors noted that four per cent of staff reported giving patients written information about MSCC whereas 20% of patients said they received it, and 77% of patients wanted it. Seventy eight per cent of staff reported giving verbal information on MSCC but only 45% of patients reported receiving any information.

One of the limitations of the Hutchison *et al.* (2012) study was that no information was given why the 45% ($n=13$) of consultants were not sure whether patients should be given prophylactic information on MSCC. The authors mentioned interviewing the participants, however, the findings seemed to be quantified. For that reason, the above study lacked an in-depth exploration of the patients and staff perspectives. The authors acknowledged that a limitation of this study was that the questionnaire was administered at different times by patients and staff and did not reflect the individual communication. In addition, there are questions on whether staff had awareness of the signs and symptoms of MSCC themselves. There was also a lack of clarity as to whose role it is to provide this information to patients or how and when the decision should be made to provide it. This is further

compounded by a lack of clarity as to where the patients are cared for and who managed them.

Although Hutchison *et al.* (2012) explored the views of healthcare professionals, it is noted that only the senior ward/charge nurses and clinical nurse specialists were involved. However, many of these patients are cared for by other level nurses on the wards. Furthermore, patients see their general practitioners in the community and their views were not sought. Therefore, further research is needed to explore their views and how they make decisions in communicating this information to the patients.

2.5.4 Structured rehabilitation for MSCC patients

Where patients became paraplegic due to MSCC, three studies reported that they benefitted from a structured rehabilitation programme (Ruff *et al.* 2007a; Ruff *et al.* 2007b; Tan and New 2012). For example, Ruff *et al.* (2007a; 2007b), a US-based study, compared 12 consecutive patients who received directed rehabilitation for two weeks with a historical control group of 30 paraplegic patients with 'no rehabilitation'. The rehabilitation programme was aimed at training patient and caregiver on transfers, bowel and bladder care, incentive spirometry, nutrition and skin care. To provide this rehabilitation, the authors suggested patients and their support network should be willing to participate in the programme, have expected survival of six months or more and resources should be available to educate and train the patients and their carers. However, it must be pointed out that the 'no rehabilitation' group received physical therapy three hours a week for at least two weeks.

The authors reported patients who underwent the directed rehabilitation lived longer (26 weeks compared to 6 weeks for patients who did not receive rehabilitation), were able to independently transfer compared (67%), were more likely to go home less depressed and had higher satisfaction with life scores than the 'no rehabilitation' group. Patients self-reported their symptoms; depression using the Beck Depression Inventory-Second Edition (BDI-II);

satisfaction with life scale (SWLS) (Diener *et al.* 1985); and mobility independence.

Twenty six of the 30 patients with 'no rehabilitation' (86.7%) compared to one patient (8.3%) suffered from clinical depression two weeks after completion of their radiotherapy and were treated with anti-depressants. All patients who participated in the rehabilitation were discharged home. The implication of rehabilitation seems to foster a positive focus for patients and carers to adjust and cope with the changes. However, it is not clear whether patients and their carers received any support at home.

In a follow up study of the same sample (see Ruff *et al.* 2007a as discussed above), Ruff *et al.* (2007b), the rehabilitation group of patients were studied until death. Their findings showed patients had reduced pain levels, with fewer deaths from myelopathic complications. The possible reason given was that the programme gave patients and carers time to adjust and cope with daily activities at home. It is also notable that patients who were depressed after radiotherapy continued to suffer from depression until death. The authors acknowledged that the rehabilitation group and the 'no rehabilitation' group were not evaluated at the same time. Moreover, there may be some differences in the outcome of the rehabilitation group that may be due to unrecognised changes in patient care.

In an Australian study, Tan and New (2012) reviewed the medical records of 108 patients between 1996 and 2008. The authors reported a focused rehabilitation programme for patients who suffered spinal cord injury due to tumour. Participants in this study were found to have reduced pain levels. The authors conclude that the programme brought functional benefit despite longer stay in the specialised rehabilitation unit (median 47.5 days, range 4-237 days). However, the authors suggest balancing the goals of rehabilitation with the short life expectancy of patients. A limitation to this study is the retrospective approach which includes inaccuracies and missing data in the patients' records. In addition, the authors did not describe the support, length and specific details

of their rehabilitation programme. It is also notable, as in the study by Ruff *et al.* (2007a and 2007b), patients who were perceived to have a prognosis of less than three months were not included in the study. Therefore, this might disadvantage those patients who were presumed to have a shorter life expectancy.

Huang and Jatoi (2009), retrospectively reviewed the outcomes of 39 patients between 1996 and 2006 who went home without support. Patients who survived beyond a year were patients who had regained their mobility. Twenty five patients (64%) did not gain back their mobility. More than half ($n=23$; 59%) required bowel care and/or bladder catheterisation and 33 (85%) needed analgesics. Thirteen patients (33%) went home without help. Others were transferred to a hospice or home with hospice or health facility. The authors acknowledged their retrospective study could not capture the emotional state of patients.

The authors suggest patients with MSCC who did not regain ambulation appear to have greater needs – physical, emotional and psycho-social. Similar findings were also reported by Cowap, Hardy and A' Hern (2000). In fact, the authors suggest the identification of patients performance status on admission may help to anticipate and plan the level of care patients required. However, how patients cope or make sense of their disability in the healthcare setting or in the community is not known.

2.5.5 Impact of MSCC on patient as a person

Literature reveals a lack of information on how patients perceive their disability and its effect on them as a person. Eva *et al.* (2009) conducted a longitudinal case study to ascertain patients' constructions on their disability as a result of MSCC. Semi-structured interviews were undertaken with nine patients, six carers and 29 professionals at intervals through the trajectory of the patients' illness. The time points were not specified. The authors' findings revealed that the patients' orientation to disability incorporated a twin-tracking manner; 'acknowledging the problem' and 'not acknowledging the problem'.

The authors described that patients 'acknowledged their problem' by trying to adapt to their unfamiliar and unpredictable body and at the same time were concerned about dependence on others and not wanting to be a burden. The patients then reassessed their daily life and reorganised their activities by taking practical steps to achieve their needs. The authors also described the patients' ambivalence towards getting information, with some patients fearing the worst. The other theme of 'not acknowledging the problem' indicates patients trying to maintain normality for fear of being labelled as disabled. In trying to manage this fear, the patients try to find solutions to overcome it. Another theme described by the authors was around the patients 'managing the tension' by twin-tracking between goals that are contradictory. Over time, the patients adapted to their disability but voiced concerns of future deterioration. Although patients regret their loss of independence, they looked to future possibilities. According to the authors, the patient's orientation of 'not acknowledging the problem' is self protective and has psychological benefits.

An explanation offered was the patient's adjustment to disability which has a temporal dimension where one takes time through a process of reconciling one's view of self and this requires support from others. This requires renegotiation in relationships with others and with the environment. However, patients may not live long enough to incorporate this adjustment into their sense of self, therefore, they try to resist the 'disabled identity'. Another explanation given for the concept of 'adjustment to disability' was comparable to the process of a person who has been bereaved. Although the authors used Pawson and Tilley's (1997) context-mechanism-outcome theory as a basis for data collection, the reason for the choice was not explained. Similarly, the authors did not give the explanation for the choice of George and Bennett's (2004) approach for within-case analysis and Glaser and Strauss's (1967) between-case methods of data analysis. Moreover, the responses of carers and healthcare professionals were not reported and it is not known whether the responses of healthcare professionals influenced the patient's understanding of their condition.

This study gave an insight into patients' views in juggling with the reality of their disability. It is not known whether the patients' twin-tracking attitude was influenced by the treatment they were receiving, for example, Levack *et al.* (2004) highlight that treatment may foster optimism. There may be disparity in patients' expectation and the professionals' intent. Further research is needed to explore the perspectives of the different stakeholders in decision making in the management of MSCC.

2.5.6 Transition from curative treatment to palliative care

There is a lack of literature exploring end-of-life care specific to patients with MSCC. Conway *et al.* (2007), reported that patients (65%; $n=21/33$) who are able to mobilise unaided had a higher chance of being discharged home. However, 69% ($n=31/45$) of those who were unable to walk at diagnosis were institutionalised at one month. The authors suggest healthcare professionals need to have a discussion about future care focussing on patients needs, for example, place of care. The majority of patients were reported to have a Karnofsky performance of 50 and the authors suggest patients need considerable nursing and medical care. Similarly, Cowap, Hardy and A' Hern (2000) stressed that treatment is palliation in the majority of cases and suggested it is likely that patients care needs will increase over time. However, it is unclear whether patients have autonomy or preferences in the choice of place for their end of life care.

Communication about end-of-life decisions is crucial and healthcare professionals should use the catastrophic event of a diagnosis of MSCC to have this conversation and initiate palliative care (Guo *et al.* 2010). Despite evidence showing patients median survival time of 4.3 months, Guo *et al.* (2010) found that patients were not aware of the urgency to have an advanced directive and Do-Not-Resuscitate (DNR) orders. The authors reviewed 59 patient records, 26 (46%) had a DNR note and for those who had the presence of an advanced directive, the median time between the date of the directive and death was 16.5 days. However, the authors acknowledge this was a retrospective review of patient medical notes and any expression of choice in having an advanced

directive can vary and moreover the reasons can be difficult to capture in a quantitative way.

Due to the limited sample size, the authors were unable to identify specific patient groups associated with lower advanced directive and DNR instructions. This study was carried out in the US; there is lack of literature on end-of-life issues in MSCC for comparison. Further research is required to explore the experiences of patients, carers and healthcare professionals in the communication of end-of-life issues.

Summary

In summary, the findings from this section indicate the life expectancy of patients with MSCC is short and varies across the different primary type cancers. The pre-treatment neurological status is a strong predictor of functional outcome and survival. It is highlighted that the sooner MSCC is detected and appropriately treated, the better the outcome. Treatment whether radiotherapy or surgery, is of palliative intent. The review suggests that not all patients are suitable for surgery and that the impact of surgery on patients is reduction in pain. There is controversy as to whether surgery could prolong survival and regaining mobility after surgery or radiotherapy is unpredictable. The review identified in older patients there is increase in surgical complications positively associated with the number of co-morbidities.

It is not clear how patients cope with the toxicity or side effects of corticosteroids, radiotherapy or recover from surgery or indeed manage the complications of treatment. Younger patients are perceived as more likely to want active treatment to regain functional improvement which contributes to quality of life. Besides, there is a lack of evidence on patient preferences or whether they have a say in their treatment.

Many of the studies reporting on patients' quality of life as a result of surgical, radiotherapy and rehabilitation interventions and have an international focus. It is apparent there are a variety of outcome tools used to measure patients'

health related quality of life but most of these questionnaires have limitations. The majority of studies looked for efficacy of interventions and generally reported positive outcomes as a result of treatment. There is disparity and inconsistency in their approach to variable assessments which made it difficult to compare their findings. Patients have their own definition of quality of life and it may not be what healthcare professionals or family members judge it to be.

Although these health-related quality of life tools are commonly used in general cancers, they are not specific to MSCC. Some measurement tools were not sensitive to detect the changes, for example, patients' physical functions, daily activities of living and emotional status. The review has identified that MSCC has a great impact on patients across all domains. However, the subjective aspects from patients and carers in the domains of cognitive, emotional and social/family are relatively unexplored. One study reported social/family support has a positive impact on a patient's quality of life; the authors suggest it could be from a cultural viewpoint.

The literature indicated provision of information on early signs and symptoms of MSCC to patients is important; there is a lack of studies around this area, making comparison difficult. More importantly, an in-depth exploration of patients understanding of their condition is needed as the review highlighted some patients 'disagreed' or were 'unsure' whether it would be helpful to have information about the signs and symptoms of MSCC.

The review suggested that planned or focused rehabilitation can improve patients' psycho-social wellbeing, coping mechanism and prolonged survival. There is patient selection bias as the authors recommend rehabilitation for patients who have a life expectancy of more than three months. Given the paucity of evidence and the small sample size, the effectiveness of rehabilitation cannot be compared. Moreover, there is a lack of studies exploring the patients and carers perspectives when participating in rehabilitation program in MSCC.

Patients seemed to have ambivalence between acknowledging the problem and not acknowledging the problem and trying to manage this tension (Eva *et al* 2009). The patient's attitude was thought to be self protecting and to have psychological benefit. However, there is limited information about what communications or discussions ensued between patients, carers and healthcare professionals during the transition from curative to palliative care. This illustrates the complexity of MSCC and an understanding of the dynamics involved needs to be pursued.

There is evidence highlighting that patients went home without support, however, it was not clear whether those patients were mobile or did not gain back their mobility. Others were transferred to a hospice or a home with hospice or health facility. There is a suggestion that patients who did not regain mobility appeared to have greater needs; physical, emotional and psychological. It was also noted that pain control should be addressed and that healthcare professionals need to have a discussion about the place of care. Moreover, there is a lack of evidence on end-of-life discussions on prognosis, advanced care planning and DNR orders. Therefore, further research is required to explore whether the patients preferences and support needs were met or not. As the carers and/or family members play an important role in supporting the patients with MSCC, the next section will explore the carers' perspectives about MSCC.

2.6 Carers' experience in supporting the patient with MSCC

There is no study dedicated solely to the carers' perspective in MSCC. The evidence for this section was also mentioned in the patients' experiences (Sub-section 2.5.2). However, to discuss this aspect on carers' experience about MSCC, I refer the article by Fujibayashi *et al.* (2010) - details in Appendix 5.

Fujibayashi *et al.* (2010), surveyed 37 patients and their families' satisfaction, three months after surgery. The mean age of patients was 60.1 (range, 31-85 years). Twenty one patients were male and 16 female. The findings showed: 18 carers and/or family members (48.6%) were very satisfied; nine (24.3%)

were satisfied; seven (18.9%)* were somewhat satisfied, and two (5.4%) were somewhat dissatisfied.

However, 21 patients were alive and 16 were dead at the time of completion of questionnaire. Those 16 responses were completed by family members. The authors found the patients satisfaction was due to neurological improvement, whereas the family members were more concerned with pain control and length of patient survival. The findings may not be a true reflection of the patients' perspectives, given 16 family members responded on behalf of the deceased patients. It is unclear whether there were other influencing factors; for example, support needs, rehabilitation, age of the patients and carers. Also, those who did not respond may not have been satisfied.

Summary

In summary, this review has identified a gap in the literature on the lack of views from carers and/or family members about MSCC. However, it is noted from literature in advanced cancer that carers and/or family members felt devastated when their loved ones had recurrent or advanced cancer and it was reported they had unmet needs (Hagerty *et al.* 2004; Sharpe *et al.* 2005). Carers and/or family members have an important role in supporting their loved ones in the cancer trajectory. Therefore, it is important to have an understanding of the carers' role and the dynamics around supporting the patients with MSCC. Moreover, there is also a lack of understanding on the interactions between carers and healthcare professionals in the management of MSCC.

* Note: Fujibayashi *et al.* (2010) reported as 7(18.9%) carers were satisfied with the surgery; however, on close examination, the results was 8(21.6%).

2.7 Healthcare professionals' experiences in managing patients with MSCC

This section will look at the healthcare professionals experience in the management of patients with MSCC. The evidence in this section is drawn from; one Cochrane systematic review, one review, two retrospective studies and two audits. Two of the studies were also mentioned in sub-sections 2.5.1 and 2.5.2 (Tomita *et al.* 2001; Omeis *et al.* 2011).

There is a lack of studies exploring the healthcare professionals' experiences in managing patients with MSCC. However, this section draws upon relevant studies and audits to identify the current knowledge relating to healthcare professionals' practice. A summary of the studies highlighting healthcare professionals' perspectives about MSCC can be found in Appendix 6.

Earlier in this review (section 2.5.2), I identified numerous studies which indicated the feasibility of surgery and its positive impact on some patients (Sandalcioglu *et al.* 2005; Falicov *et al.* 2006; Fujibayashi *et al.* 2010; Wu *et al.* 2010). However, the reviews indicate the pre-treatment neurological status of the patient should be taken into account when making decisions regarding surgery. In contrast to common knowledge that paralysis is predictive of survival, Tomita *et al.* (2001), suggest that even with paraplegia, patients may still have a long survival period if given the right treatment. Their rationale was that patients die not because of paralysis but because of disease progression. Tomita *et al.* (2001), proposed a surgical strategy based on treatment goals to assist the clinician in decision making. The authors proposed a scoring system to determine the type of treatment based on three prognostic factors: (1) grade of malignancy (slow growth, 1 point; moderate growth, 2 points; rapid growth, 4 points), (2) visceral metastases (no metastasis, 0 points; treatable, 2 points; untreatable, 4 points), and (3) bone metastases (solitary or isolated, 1 point; multiple, 2 points). Here, the treatment goal for each patient was set according to the prognostic score; long-term control, middle-term local control, short-term control and supportive care.

Tomita *et al.* (2001), in their phase two study (between 1993 and 1996), made their treatment decisions for 61 of their patients based on each patient's prognostic scores, the success rate of local control of the disease was achieved in 43 (83%) of their patients who were treated surgically. The authors found this strategy was practical and reliable. Although the authors have reported the accuracy and reliability of the prognostic score system, further trials are needed to validate its use. However, in this study there was no mention about taking into consideration patients co-morbidities. As I have previously identified in the review (section 2.5.2), the risk of patients developing surgical complications increases with the number of co-morbidities (Omeis *et al.* 2011).

Murakami *et al.* (2010) reported a retrospective review of a sub-group of elderly patients (32 patients > 70 years) who had undergone surgical procedure (since 1999) based on Tomita's prognostic scoring. In this analysis, it was noted that the pre-operative general conditions of the patients were assessed using the Eastern Cooperative Oncology group performance status and the Karnofsky performance scale. Respiratory complications and delirium occurred significantly more often in the elderly group. Despite the risk of complications in major surgical procedures in the elderly, the authors suggest en bloc excision (total en bloc spondylectomy) is feasible for selected patients with few systemic complications and surgery should not be avoided due to a patient's advanced age.

However, Yamasita *et al.* (2008), stated that surgeons need to have a treatment strategy for each individual patient with MSCC. The authors used the total revised Tokuhashi *et al.* (2005) scoring strategy to investigate 93 patients after surgery. The authors found those patients with higher total revised Tokuhashi scores and their primary cancer type proved helpful for predicting short-term functional improvement. Sixty per cent of prostate and breast cancer patients were free from neurologic re-deterioration at follow up. The authors highlight that a greater probability of benefit exists for prostate and breast cancer patients who still have effective adjuvant therapy.

In other primary cancer types, 70% ($n=37$) of colon, liver, stomach, and kidney cancer patients did not achieve the short-term functional improvement. The authors suggest it could be that the local spinal metastases were uncontrolled. Therefore, the authors believed the duration of improvement in physical function is strongly dependent on the presence or absence of major internal organ metastases. The authors indicate this knowledge would help healthcare professionals make decisions and also help patients and carers make informed decisions.

Likewise, Tancioni *et al.* (2010), suggest that no firm conclusion can be made regarding the superiority of one approach versus another because of the heterogeneity of the patient population. In their study, 89 patients underwent fairly conservative treatment followed by radiotherapy. With this approach, their patients achieved long-lasting remission of pain and recovery of neurological function of 80% and 70% respectively. The authors believed a multi-disciplinary team (oncologist, radiation oncologist and neurosurgeon) is important to choose the appropriate treatment. Less is known about how the healthcare professionals make their decisions based on the available evidence especially when care planning and treatment decisions are of palliative intent.

In an audit carried out in the UK, Pease, Harris and Finlay (2004) identified the issues encountered in clinical practice were centred on the difficulty in assessing the status of the spine. Although MRI is an accurate modality to detect spinal cord compression, it cannot reliably confirm spinal instability. The knowledge of spinal status is important to determine the treatment and care of patients and often there was confusion about when to start mobilising the patient. Patients were routinely nursed flat and commenced mobilisation after completion of radiotherapy (between 5-7 days). However, after the authors implemented their care pathway, the majority of patients began rehabilitation after 1-2 days.

With rehabilitation starting sooner, the authors reported increased survival and decreased complications such as chest infections and deep vein thrombosis

events. The authors recommended collars and braces to increase patient functional independence, comfort and a sense of control. Although the authors reported anecdotally that patients had an increased quality of life, little is known about the patients' experiences with regards to decision making in mobilisation. There is also lack of staff perspectives in how they faced the challenges in making decisions about each patient's care.

A similar evaluation was carried out by Warnock *et al.* (2008), investigating the staff perspectives with the use of a questionnaire and a retrospective review of medical and nursing documentation. The authors reported that the majority of patients who were unable to walk on admission did not regain mobility and patients' experienced significant physical problems as a consequence of developing MSCC. There was a discrepancy on issues of mobilisation between the healthcare professionals' response and the actual practice as identified from the documentation. In this study, 14 (66%) consultants, 10 (71%) specialist registrars and 32 (30%) nurses responded.

The findings showed 75% ($n=18$) of doctors did not recommend that patients should routinely be on bed-rest, versus 69% ($n=22$) of nurses reporting that patients were routinely kept on bed-rest for the duration of treatment. However, documentation revealed 88% ($n=44$) of patients were on bed-rest for the duration of their treatment and the rationale for this was not clear. Nurses identified that patients on bed-rest had difficulty eating/drinking, boredom, isolation, low mood and complications such as pressure sores, chest infections and deep vein thrombosis. Twenty one per cent ($n=7$) of nurses felt patients' psychological concerns were met most of the time, 55% ($n=17$) felt they were met sometimes, 18% ($n=6$) felt patient's concerns were rarely met and six per cent ($n=2$) said they were never met. However, findings from documentation identified common emotions were; low mood, anxiety and being tearful - specifically related to loss of independence, being incontinent, and in pain. In contrast, Huang and Jatoi (2009) found no patients appeared to have depression severe enough to refer for a psychiatric consultation or initiation of anti-depressants. Nonetheless, the authors acknowledged that patients may

have mild depression or the extent of depression was difficult to capture in the patients' medical records. This indicates reviewing patients' notes may not capture an in- depth understanding of the patient's psychological concerns and their needs may not be addressed.

The evaluation also highlighted the majority of patients (43 out of the $n= 50$ in the audit) were elderly (Warnock *et al.* 2008). Although the authors suggest a need to develop a clear guideline on mobility, assessing spinal stability and early referral to the physiotherapists, there was no suggestion to address the patient's psycho-social or support needs. The authors acknowledge that one limitation to their study was the low response rate from the nursing staff, despite repeated reminders and suggest that the use of other methods of data collection may encourage participation. This indicates the use of a qualitative approach may help to understand the similarities and differences in decision making amongst the stakeholders in the management of MSCC. However, there is an emphasis on providing treatment and care based on evidence on how best to care for this group of patients. Kilbride *et al.* (2010) reviewed practice and care on the issue of spinal stability, role of braces, positioning and mobilisation. The reviewers found a lack of guidelines and consensus in the literature on how to assess spinal instability as there are other variables to be considered (Kilbride *et al.* 2010).

To ensure that patients are cared for effectively Lee *et al.* (2012), in their Cochrane systematic review investigated what treatment approaches can help provide healthcare professionals with their decision making in MSCC. The review indicates disparity in evidence regarding stabilisation, positioning and initiation of mobilisation. Moreover, there is a lack of evidence in the use of bracing to relieve pain or vertebral collapse to support the recommendations of guidelines. Furthermore, there is a lack of current research literature about the preferences of patients with a poor prognosis and their quality of life needs to be taken into consideration in care decisions.

Summary

In summary, the literature identified studies which have proposed a scoring system to assist clinicians to determine a patient's suitability for surgery or supportive care. However, there is a need for more randomised controlled trials to validate its accuracy. It is notable that there is controversy in the type of approach in surgery, and/or with radiotherapy. The complexity in decision making in MSCC is around selecting appropriate patients for treatment. Patients with prostate and breast cancers as primary type cancers respond better if there are still adjuvant treatments. Other cancers may not respond well and there are other factors to consider such as; local progression of cancer in the spine and spreading to the other major organs. Other issues in clinical practice include the difficulties in identifying spinal instability, however, it is deemed important to assist healthcare professionals make decisions in treatment and care. The review also highlights the discrepancies in instructions on positioning and mobilisation and the use of braces. There is a lack of guidance to help healthcare professionals make decisions based on evidence. Therefore, further research is required to explore healthcare professionals' experiences in meeting these challenges and managing patients with MSCC.

Nurses perceived the majority of patients' psychological needs were either met most of the time or met sometimes but some evidence suggests a quarter of patients' psychological concerns were not attended to (Warnock *et al.* 2008). Documentation revealed patients suffered emotional, psychological and physical problems. However, evidence also suggests documentation may not capture information on depression or the extent of depression. It is not known how patients coped with the impact of MSCC and whether they had ongoing concerns.

The review indicates prognostication is crucial in initiating discussion about end-of-life care and can empower patients in decision making. However, little is known about how healthcare professionals approach this issue with the patients, carers and/or family members.

2.8 Collaborative decision making in relation to the complexities of MSCC

It is apparent from the integrative review there are controversies and uncertainties surrounding the optimal treatment and care for patients with MSCC. Treatment for MSCC is normally palliative, and healthcare professionals need to meet and support patients and carers during this challenging period (Cowap, Hardy and A' Hern 2000; Conway *et al.* 2007). Tancioni *et al.* (2010), suggest a multi-disciplinary team that comprises of an oncologist, radiation oncologist and neurosurgeon choose the appropriate treatment for patients. However, healthcare professionals cannot automatically assume what patients value when lifespan is limited (Levack *et al.* 2002). Evidence showed that often discussions around end-of-life decisions occur late for people with MSCC (Guo *et al.* 2010). Moreover, the inclusion of patients and/or carers and other healthcare professionals in the decision making was not discussed.

In wider literature on decision making, Menard *et al.* (2012), conducted a selected literature review to identify strategies to improve the decision making process in oncology. They identified a difference between uncertainty reduction and management of uncertainty approach in cancer care. The uncertainty reduction strategies discussed involve the physician making an evaluation of the patient's medical condition; giving thorough evidence based medical information; and management of the likely consequences of the medical decision. Blanch *et al.* (2009) and Politi *et al.* (2011), found poor patient satisfaction about treatment decisions when giving information on uncertain treatment. Additionally there appeared to be little focus on a patient's psychological status, imbalanced flow of information, and lack of relationship building between physician and patient. This approach results in decisional conflict, especially when the strategy was focused on medical uncertainty. Menard *et al.* (2012), argues that uncertainty occurs at medical, psychological and social levels. Therefore, they recommend uncertainty management approach in decision making.

Another strategy the 'shared decision making approach' was also considered to have limitations (Menard *et al.* 2012). Shared decision making strategies involve patient-centred communication where the patient is encouraged to participate in decision making through information exchange and negotiation. This is drawn from an individualised assessment of the patient's medical, psychological and social status. It is thought that this shared decision making approach lacks the focus on patient and physician psychological characteristics which can potentially alter the decision making process. For example, patients who are anxious or distressed may not process and exchange information with their physician (de Haes and Bensing 2009). Similarly, the patient's physician may not be sensitive towards detecting the patient's distress.

Menard *et al.* (2012), also highlight that shared decision making can lack the focus of multi-disciplinary input. According to Legare *et al.* (2010) and Stacey *et al.* (2011), shared decision making approaches predominantly use decision aids to assist patients with treatment decisions. Other authors argue that decision aids are designed and implemented without conceptual clarity, lack communication processes and the behavioural components for active participation in decision making (McCaffery, Irwig and Bossuyt 2007; Nelson *et al.* 2007; Street 2007).

Based on their review, Menard *et al.* (2012), recommended a collaborative decision making approach with a 'three-step' model. This model comprises a collaborative evaluation interview between the physician and the patient, a collaborative multi-disciplinary meeting focused at supporting the medical decision and a collaborative decision interview for a final decision, taking account of the patient's preferences and values. This model is based on a literature review within oncology in general (genetics, screening of cancers and in some cancers where there are treatment options) and lacks supporting empirical work. In another review, using a meta-narrative approach to explore inter-professional collaboration models in cancer management, Gagliardi, Dobrow and Wright (2011), reported confusion as to whether collaborative decision making is a process or intervention or an intermediary outcome. It was

suggested that further research is needed to explore how or whether various conceptual models with common elements and outcomes can be blended to support collaborative decision making.

This section shows that a lot of work on decision making in cancer is focussed around uncertainty management, shared decision making, team decision making and collaborative decision making. Literature has demonstrated a lack of definitions on the concepts or that the existing definitions lack theoretical clarity. In order for policy to decide on action, there is a need for stakeholders to agree on and define these concepts. Therefore empirical data from this current study can help to clarify the theoretical concepts in collaborative decision making drawing on experiences of managing MSCC.

2.9. Conclusion arising from the integrative literature review

This integrative review indicates there is limited evidence to inform an understanding of the patients' experience when diagnosed with MSCC and the type of care they need or prefer. MSCC is a dynamic condition that is unpredictable and impacts on patients across all domains. The review indicates controversies and uncertainty in the treatment outcomes. However, there are quite a considerable number of studies investigating patient outcomes, for example, survival, pain, mobility and quality of life. The challenges lie in the difficulty in evaluating patient outcomes. Most of the evidence is also focused on delivering an intervention or outcome of an intervention for a set period of time, not about the influence that ongoing support might have or how patients are managing with end of life issues.

It must be acknowledged that the data collection for this thesis was carried out before some of the studies were published. However, in keeping with qualitative enquiry, literature searching has been an ongoing and reflexive process. The findings of this review demonstrate there remains a lack of representation of the patients' experience in MSCC. Similarly, there are gaps in knowledge on carers' experiences about MSCC. Moreover, little is known on the role of the healthcare professionals and their experiences in managing and

caring for this group of patients. The review also highlights the trajectory of cancer for many of these patients and little is known about where they are managed and who manages them.

2.10 Chapter summary

This integrative review shows that MSCC is a devastating event and can cause severe morbidity and compromise survival in patients. Early recognition and treatment is important to preserve neurological function. Patients who develop MSCC suffer from issues in several domains: information needs, physical function, emotional, social, and end of life. There are various studies investigating treatment outcomes such as survival, pain, neurological status, activities of daily living, ambulation and sphincter control. Other studies look at quality of life including physical functioning, emotional wellbeing, and social/family wellbeing. However, all these assessment measures are complex. Patients with MSCC are often elderly, ill and depressed and frequently have more than one co-morbidity and the survey can be a burden for them to complete.

Furthermore, it is difficult to capture the concept of quality of life as patients may have their own definition of what quality of life means to them and this can change with time. Some of the questionnaires, for example, the EORTC are made to measure quality of life constructs in clinical trials but it does not identify patients' problems or needs. Therefore, the assessment tools are not specific to MSCC and are not sensitive to detect the changes in a patient. Although Street *et al.* (2010), proposed a health-related quality of life questionnaire, there is no publication validating its use or accuracy. In addition, little is known about how these findings help to inform the patient's needs. The subjective component, the patient's experience with MSCC, is lacking.

There seems to be disparity in the findings around emotional wellbeing. Some studies show a minority of patients were depressed whilst others show patients suffered clinical depression and were treated with anti-depressants. It seems that the patients' psychological issues were not fully addressed or were neglected. Therefore, there is gap in the literature to provide a comprehensive

understanding of the impact of MSCC on patients. Qualitative approaches to data gathering may help to uncover and provide evidence of patients needs.

Levack *et al.* (2004), and Wu *et al.* (2010), highlight that the social/family wellbeing domain scores favourably, indicating that family is important to a patient's quality of life. However, little is known about the patient's interaction with their spouse and/or family members and the impact the family support has on the patient. There was one study with minimal information about family members' satisfaction after patient's surgical procedure (Fujibayashi *et al.* 2010). The findings showed differences in the factors that influence satisfaction between patients and their family members. The reasons for this were not explained in depth, therefore, there is a gap in knowledge about carers' and/or family members' perspectives in MSCC. They are, after all, pivotal in supporting patients.

Literature highlights the complexity and controversies in treatment outcomes. Patients' suitability for surgery depends on their age, co-morbidities, site of tumour, extent of tumour and any spread to other organs. Younger patients seem to want active treatment to retain functional improvements, being related to quality of life. Older patients with increased co-morbidity have an increased risk in acquiring complications. However, Murakami *et al.* (2010), suggest treatment should be offered despite advanced age. Patients are faced with poor prognosis and are dealing with a decline in their health status. Treatment is of palliative in intent and it is not clear what the patients' expectations, preferences and choices are and their experiences as a result of the interventions. It is noted that patients are managed in different disease-specific sites, but little is known about where these patients are managed and who manages them. There is also a gap in the literature in the perspectives and experiences of healthcare professionals as to how they make these decisions with regards to treatment and care.

There is evidence that indicates that focused and structured rehabilitation programmes benefit patients and their carers. One setback was that this

programme was recommended for patients with a survival expectation of more than three months. It is not clear what the current practice is with regards to rehabilitation in the UK - although one study shows only four per cent of patients (5 out of 166) went to a rehabilitation unit (Cowap, Hardy and A' Hern 2000). Further research is required to explore the patients and carers experience of the impact this has on their care and support.

The review highlights the need to provide patients with information on signs and symptoms of MSCC to encourage early referral and treatment. There is a need for research to explore how patients process information when diagnosed with MSCC and translate it into what it means for them. However, the signs and symptoms were not specified. There is also a lack of information about whether staff have awareness of the signs and symptoms of MSCC. Likewise, there is a lack of clarity on when, how and by whom the information about MSCC should be given to patients. Issues in clinical practice are centred on spinal stability, patient positioning, mobilisation and bracing, however, there is lack of best evidence-based recommendations. The review indicates that the evidence around spinal stability, positioning, mobilisation and bracing is limited. There is apparent disparity in the findings on positioning and mobilisation. This indicates the need to explore the healthcare professionals' perspectives in how they interpret guidelines and assess patients' needs and preferences.

There is a gap in the literature on end-of-life issues. For example, there is a lack of evidence demonstrating initiation of conversations or discussion on prognosis. There is also a lack of information on end-of-life needs and place of care. It is not known whether patients have a choice or autonomy in end-of-life matters. Guo *et al.* (2010) reported evidence from patients' medical notes which demonstrated patients were not aware of the urgency to have an advanced directive or do-not-resuscitate orders. This illustrates there is a lack of knowledge on what patients understand or perceive regarding their condition and treatment in MSCC. Besides, Eva *et al.* (2009) identified that patients' construction of their disability seemed contradictory. The patients seemed to twin-track between 'acknowledging their problem' and on the other hand 'not

acknowledging their problems'. However, this study did not discuss end-of-life issues or how this can help identify patients' needs. Although the authors used the case study method, they did not report on the interaction between patients, carers and healthcare professionals. Therefore, further research is required to explore the similarities and differences in decision making between the key stakeholders in the management of MSCC. Cowap, Hardy and A' Hern (2000), Conway *et al.* (2007), and Huang and Jatoi (2009), recommend that healthcare professionals should assess the patient's prognosis and performance status at the time of admission to anticipate and plan palliative care and place of care. There were recommendations but the authors did not expand on them. Therefore, there is a need to explore if patients have any autonomy or choice in the place of care.

On the whole, the review demonstrated that evidence is of an international focus and the issues on the impact of MSCC on patients are similar. However, the majority of evidence is of a quantitative approach. Therefore, using a qualitative approach can illuminate patients', carers' and healthcare professionals' perspectives in the management of MSCC. Recognising the short survival times, interventions need to focus on the individual patient's preferences and choice. Issues on end-of-life and support needs require to be explored. Given the complexity of managing MSCC and the lack of current evidence to underpin practice, I therefore identified the research aims and questions for this thesis and these are presented at the beginning of Chapter 3 (Sections 3.1.1 and 3.1.2). In the next chapter, I then discuss the rationale for case study design, research methods and data analysis in order to enhance our understanding of MSCC.

Chapter 3: Research design and methods

3.1 Introduction

This chapter presents an account of the research design and the rationale for the choice of methods. The ethical aspects of this study will be discussed. I then discuss the process of recruiting participants, the data gathering and analysis. I conclude by examining my position as a researcher and how I ensure trustworthiness of the data.

3.1.1 Overall aims and research questions of the study

The overall aim was to explore the patients', carers' and/or family members' and healthcare professionals' perspectives and experiences in the management of metastatic spinal cord compression (MSCC). It is noted that for the purpose of this study the word carer will be used to refer to the family caregiver whether it be the wife, husband, daughter, son or significant other. Four questions were formulated.

3.1.2 Research questions

The questions that this study set out to explore were:

- What are the patients' perspectives and experiences when diagnosed with MSCC?
- How do carers and/or family members perceive support when coping with the patient with MSCC?
- What are the healthcare professionals' perspectives and experiences in the management of patients with MSCC?
- What are the similarities and differences in the perspectives and experiences of key stakeholders?

3.2 Research design

This section reflects upon some of the philosophical underpinnings with the aim of understanding and developing new knowledge of MSCC. The choice for adopting a qualitative approach and the case study research strategy will be discussed.

3.2.1 Research Paradigm

A paradigm can be defined as ‘a basic set of beliefs that guide action’ (Guba 1990:17). Denzin and Lincoln (2005), explained further that beliefs can never be established in terms of their definitive truth. Perspectives, on the other hand, are not as solidified, nor as well unified, although they may share elements with a paradigm. When discussing what constitutes knowledge and reality, this has been classified into two paradigms, ‘positivist’ paradigm and ‘post-positivist’ or ‘naturalist’ paradigm (Guba and Lincoln 1994; Saks and Allsop 2007).

According to Bryman (2012), quantitative research can be construed as a research strategy that is characterised by quantification, and has incorporated the norms of the natural sciences model. The quantitative paradigm embodies a view of social reality as external and objective and knowledge can be produced through rigorous deductive methods (Bryman 2012). In contrast, the post-positivist paradigm, commonly referred to as qualitative research, is influenced by naturalism, embodies a view that knowledge is socially constructed and reality is emphasised in words, is constantly shifting and cannot be understood by precise measurement (Bryman 2012).

Guba (1990) suggests a researcher has three key questions to answer when choosing a qualitative approach: what is the nature of reality and how is it studied? (Ontology); what is the relationship between the researcher and knowledge? (Epistemology); and how should the researcher go about finding out knowledge? (Methodology) and demonstrate the assumptions by identifying the strategies that are seen as exemplifying these assumptions.

My intention was to have an in-depth understanding of the patients', carers' and healthcare professionals' experiences about MSCC; what was their experience and what other factors may have influenced their experience (Ontology).

Epistemology is about how we come to know things, the relationship between how the researcher comes to know the world and to justify how they gain that knowledge (Guba 1990). In this study, the background study, the scoping exercise and the integrative review informed the nature of knowledge of MSCC and shaped the design of this study. The literature review highlights the need to explore; the patient's views, those of the carers who support them and the actions or decisions made by key healthcare professionals (Epistemology).

Therefore, it is justified to use focus groups and individual interviews with the participants (Methodology).

3.2.2 Rationale for the choice of qualitative approach

The majority of studies in the integrative review used a quantitative approach to investigate the treatment outcomes, health-related quality of life and satisfaction with life. The strict criteria in the recruitment of participants to the studies, the patient's eligibility for treatment and rehabilitation meant that quantitative research was seen as the appropriate approach. A focus on patients' preferences and needs was not evident. There was one qualitative study that explored the MSCC patients' interpretations of disability, however, there was no report about the carers or the healthcare professionals views about this condition (Eva et al. 2009).

According to Hopkinson, Hallett and Luker (2001), and Green and Thorogood (2009), the benefit of qualitative approaches is to provide an understanding of different perspectives and to examine how reality is constructed rather than assuming or presenting one reality. Creswell (2009), provides some clarification that qualitative research is an inquiry process of understanding based on distinct and methodological inquiry which explores a social or a human problem. The intention is not to present generalised findings, but rather to draw from the understandings of the research subjects (Saks and Allsop 2007). Qualitative research is also useful to influence clinical practice where

the topic of study relates to service provision (Barbour 2008). Therefore, my role as a researcher is to build a complex, holistic picture, analyse words, documents and perspectives of the participants and conduct the study of the phenomenon MSCC in its natural setting.

The guiding design for this thesis is the qualitative approach where there is no pre-defined theoretical perspective. Although the patient's perspective of experience is central to the study, multiple perspectives can exist within a phenomenon which can be dynamic, complex and influence that experience (Lincoln, Lynham and Guba 2011). I considered it important to provide patients and carers an opportunity to report their experiences in a healthcare environment which can be framed by healthcare professionals' assumptions of what is best for the patients (Stiggelbout and de Haes 2001).

It is equally important to explore the healthcare professionals' perspectives as their actions and decisions influence the patients' and carers' experience and is very much part of the phenomenon under study (Barbour 2008). Therefore, using a theory or theories may constrain my findings; instead, I chose to allow the themes to emerge based around my research aims and questions.

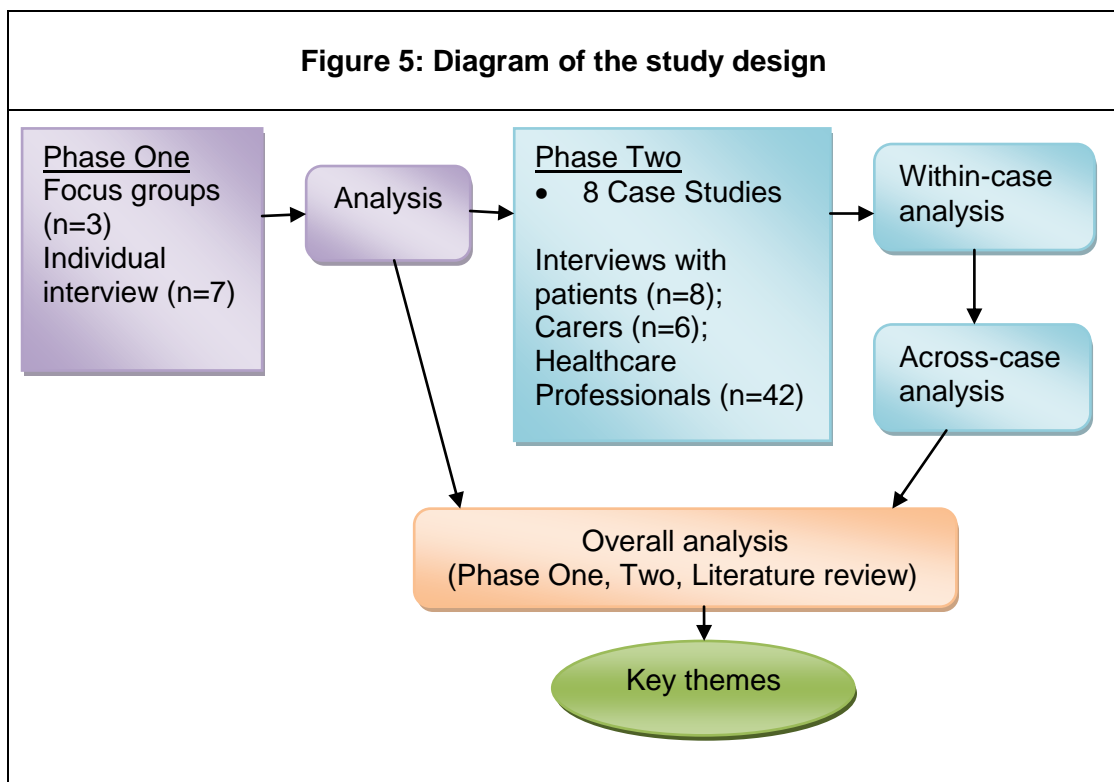
3.2.3 Choosing the research design

The research design provides the logical sequence of steps and procedures in data gathering in order to gain an understanding or gain new knowledge on the phenomenon. Some authors suggest that in qualitative research, there are a number of designs such as grounded theory, ethnography and phenomenology that are necessary to explore their research questions (Morse and Field 2002; Denzin and Lincoln 2011). In the early stages of this study, the use of action research was considered (McNiff and Whitehead 2011). However, action research was not deemed a suitable choice as it became clear that little is known about the patient's experience of MSCC.

Both grounded and phenomenological theories insist on a higher degree of interpretation and were not suitable as the ways patients interact with their carer

and healthcare professionals were not understood. Ethnography was discarded as it is associated with an understanding of a culture; however, this study is about a phenomenon of MSCC. Although case study approach has similarities to other qualitative methodologies, it remains relatively realistic and true to the data (Sandelowski 2000).

Therefore, a case study approach was appropriate to understand the patients' experience of MSCC and the problems surrounding approaches to treatment, how patient/family preferences are accommodated, and how the team works. It is equally important to understand the unpredictability of a condition such as MSCC as it is life threatening for the patients (Chapters 1 and 2). The researcher needs to elucidate clearly what is being done to elicit rich narratives from the participants about MSCC. The research design for this study is illustrated in Figure 5 (phases, methods and participants).



The study development and the research process, was undertaken in Scotland during my PhD study from September 2007 to September 2010. The data

collection for this study was planned into two phases. It was anticipated that all data collection would be carried out over a period of six to eight months. Phase One, took place between July and August 2009. Phase Two data gathering took place from September 2009 to March 2010.

3.3 Rationale for the Case Study as a research strategy

The case study research strategy was judged to offer a beneficial approach for this study as it placed emphasis on the examination of a phenomenon – MSCC – as a current reality for patients, carers and healthcare professionals and the context of MSCC in its natural setting, taking into account the dynamic process with all its complexity. The case study strategy can be used within the quantitative or qualitative paradigm or even mixed methods (Cavaye 1996).

According to Yin (2009), the case study as a strategy is the intention to find out more about a subject, the subject of inquiry is the case which is made up of many parts which is investigated within context. Stake (1995), gave a slightly different view. He contends that case study is not so much a methodological choice but a choice to study something and that when we effect that choice we are in essence studying a case (Stake 1995). Yin (2009:18) defined the case study as:

“...an empirical inquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and the context are not clearly evident; and in which multiple sources of evidence are used”.

Basically, a case study should be considered when: the focus of the study is to answer ‘how’ and ‘why’ questions; the researcher cannot manipulate the behaviour of those involved in the study; the intention is to cover contextual conditions as they are relevant to the phenomenon under study and the boundaries are not clear between the phenomenon and context.

The case study enables the researcher to use a variety of research methods and multiple sources of data to explore the research questions which then give

a deeper understanding and holistic view of the phenomenon (Hancock and Algozzine 2006; Yin 2009; Swanborn 2010; Thomas 2011). For example, D'Souza (2001) used a case study approach to understand the dynamics of the waiting list on how their radiation therapy shortage developed. The findings highlighted an interplay of factors; rising cancer incidence, increasing demands for radiation therapy, strained patient-doctor relationship, and an incompatible relationship existing between moral and legal responsibility – the government was viewed as morally responsible but the physicians were given the responsibility without the authority to change the waiting list situations.

Yin (2009) stressed the importance of identifying the five key elements for designing and implementing a qualitative case study approach.

- Study questions;
- Study propositions, if any;
- Its unit(s) of analysis;
- The logic linking of the data to the propositions;
- The criteria for interpreting the findings (Yin 2009: 27).

Through addressing these components, the researcher is able to establish the suitability of the case study approach.

Study questions

In the first component, Yin (2009), suggests that the form of the study questions should indicate the relevance of the methodological design; questions pertaining to 'who', 'how', 'what', and 'why' may be suited to a case study approach. The research questions in this study sought to gain an insight into the subjective experiences of patients (in relation to '**who**'); and '**how**' they experienced the phenomenon of *MSCC* (in relation to '**what**'). Similarly, the study aimed to understand the experience of carers ('**who**'), and in '**how**' they perceived support when coping with their loved ones with *MSCC* ('**what**'). Seeking understanding of '**how**' the patients, carers and healthcare professionals ('**whom**') experience *MSCC* ('**what**') allowed me to explore this from an inclusive and 360 degree perspective. Therefore, a qualitative case

study approach was best suited to answer the 'who', 'what' and 'how' questions in this study, as the event of interest is MSCC, how MSCC is managed at the acute stage and the patients' and carers' experiences will be traced over time (Yin 2009; Swanborn 2010).

Study propositions

According to Yin (2009), research questions alone do not point to what a researcher should study; there is a need to develop 'theoretical propositions' which reflect the importance of theoretical issues. Yin (2009), stresses that 'theory proposition' should not be associated with the formality of grand theory as in social science. Theoretical proposition can be described as a statement developed from relevant literature or from generalisation based on empirical data (Nieswiadomy 2002; Wells *et al.* 2012). Miles and Huberman (1994) and Yin (2009), suggest that the researcher draw up a pre-determined guide to what should be studied within the case and at the same time remain realistic in its scope. To ensure the credibility of this study, I developed the topic guides, using questions and propositions that had emerged from the background study of MSCC, the findings from the scoping exercise, the literature review and through consultation with my supervisors (Appendices 7-12). Therefore, theoretical propositions help to ensure that the research questions can be adequately answered. The theoretical propositions for this study are:

1. The context within which the communication and information about treatment and care is crucial to understanding the impact on the patient and/or carers to manage uncertainty about end-of-life issues.
2. The communication of uncertainty is unique to individual circumstances (age, capacity, coping, attitude and decision making). How healthcare professionals manage the issues of uncertainty depends on their knowledge, experience, skills, guidelines, evidence, practice context within the unit, role and responsibilities. These two fundamental factors for healthcare professionals have a bearing on the experience and perceptions on the individual (patient/carer).

3. Decision making by healthcare professionals is influenced by the above factors and will vary according to the changing status of the patient's condition, effectiveness of treatment, and the response of the patient. I argue that the lack of on-going communications around uncertainty between healthcare professionals and patients/ carers is affecting their coping, adjusting and management of MSCC.

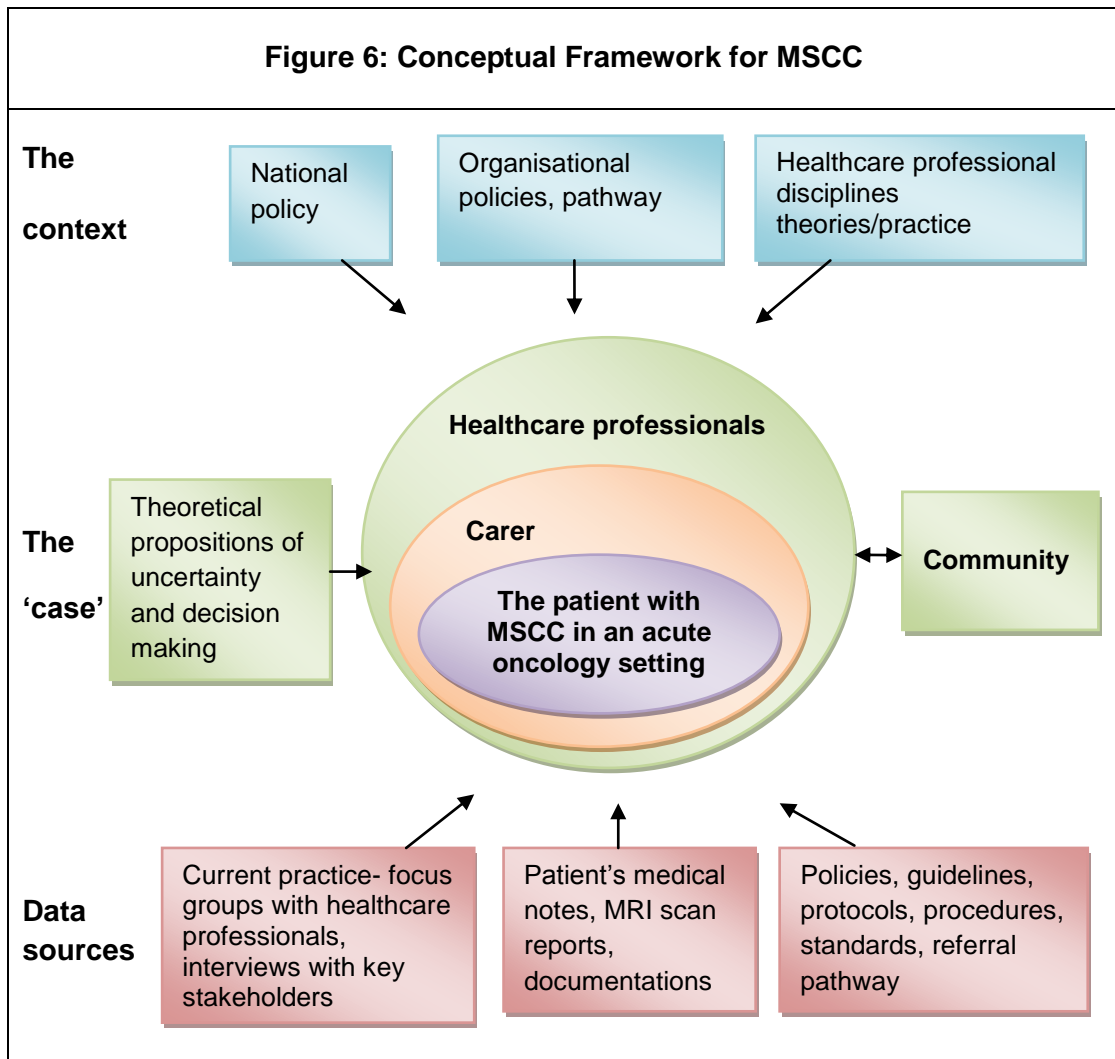
Miles and Huberman (1994), also recommend that the direction, structure and boundaries of the study be supported by a conceptual framework which explains the unit of analysis to be studied.

The unit of analysis

The unit of analysis - 'a case' - may be an individual, process, event, entity or an organisation (Yin 2009). Case study can also be done about decisions, programs, implementation process and organisational change. Yin (2009:29), explained that 'in each situation' an individual person is the case being studied and the individual is the primary unit of analysis. For each individual, relevant information was collected and several individuals (cases) included in a multiple-case study. In this study, a unit of analysis comprised of a patient with MSCC, their carer, and key healthcare professionals involved in the patient's care. This research adopted a multiple-case study; in total eight cases were explored. This allowed variations and complexities around managing this group of patients to be obtained from different perspectives in real-time (Anthony and Jack 2009; Yin 2009; Bryman 2012).

Miles and Huberman (1994: 18), suggest that a conceptual framework serves several purposes for the researcher: it specifies who and what will and will not be studied; assumes some relationships are based on logic, empirical findings and/or personal experience; and provides the opportunity to gather constructs (for example, organisational guidelines) into intellectual 'bin's (to help in making sense). My conceptual framework clearly identifies 'the patient with a diagnosis of MSCC' (the heart of this study) and the patient's experience was explored within the immediate acute oncology setting, in relation to their carer, key

healthcare professionals, unit, organisation, national policies/guidelines and the professional disciplines associated theories/practice context. As this study explored the patients' and carers' experience over a time period, this framework included the community context linked to the case. Figure 6, below shows the case, the context and the data sources to inform this study.



The various data sources were from focus groups, interviews, patient's medical notes, MRI scan reports, and nursing care plans. The rationale for the choice of methods and data sources will be discussed in detail in section 3.4.

The logic linking the data to the propositions and the criteria for interpreting the findings

In the fourth and last components, Yin (2009), suggests that researchers return to the propositions to ensure data analysis is within the scope of the study and to provide structure for the report. According to Baxter and Jack (2008) and Thomas (2011), this may limit the inductive approach when exploring a phenomenon. To safeguard against becoming deductive, I kept field notes and memos of my thoughts and decisions to help with data analysis.

In this thesis, I utilised Braun and Clarke's (2006) thematic framework for within-case and across-case analysis to capture broad issues in MSCC (details in Section 3.8). For example, Kennedy *et al.* (2008a; 2008b) used within-case and across-case analysis to evaluate a new bereavement support service for families where a parent was dying from cancer. This brought out rich information about the delicate and dynamic family experience of a parent dying of cancer.

3.3.1 Development of theory in Case Study strategy

Case study research can be used to describe a phenomenon, develop theory or test theory (Darke, Shanks and Broadbent 1998; Yin 2009; Lacono, Brown and Holtham 2011). Eisenhardt and Graebner (2007), state that to justify theory building, the researcher has to clarify why the research question is important and why there is no existing theory that offers a feasible answer. In the current study, the scoping exercise and literature review indicate that MSCC is an unpredictable condition and there are complexities surrounding its management. In this situation where there is a lack of evidence and theory, case study can be used to provide the evidence and in the process of analysis, a theory can develop or generate hypothesis (Cavaye 1996; Smith 2002). The use of multiple cases and across-case analysis allows the synthesis of concepts embedded in theories; thus the varied evidence, the constructs and interactions between the stakeholders are more accurate and robust (Dooley 2002; Eisenhardt and Graebner 2007).

3.4 Rationale for the choice of research methods

In this case study, I used focus groups, individual interviews, field notes and document review to illuminate the experiences and perceptions of the patients, carers and healthcare professionals around MSCC. Fundamental to this exploration was a decision or set of decisions made, why they were taken, what factors informed these and how care decisions were implemented and the perceived outcomes. I believed that these methods would give all the stakeholders an opportunity to voice their experiences.

Ragin (1997), Marshall (1999), Denzin and Lincoln (2011), suggest that where research interest involves a large number of variables and a limited number of cases, evidence is needed from various sources, such as documents, artefacts, interviews and observations to enable an in-depth inquiry into a social phenomenon. Methods such as in-depth, semi-structured or unstructured interviews and focus groups observations are some of the recommended methods (Rubin and Rubin 2005).

3.4.1 Rationale for focus groups with healthcare professionals

I considered focus groups relevant in order to gain insights into the health professionals interaction and their decision making process in clinical practice. Focus group interviews were deemed most appropriate to explore and understand the group dynamics as well as individual views and experiences of phenomena and abstract concepts about MSCC (Barbour 2008; Krueger and Casey 2009). This would be useful at Phase One to provide the platform for comparison with the narratives of participants in Phase Two of the study. There is evidence of using focus groups within the context of a quantitative study for refining research instruments, but there are also many studies which have used focus groups in the preliminary phase of qualitative study (Barbour 2009). In focus groups, the interviews contain open-ended questions to allow responses without setting boundaries (Krueger and Casey 2009).

Bloor *et al.* (2001), stressed that focus groups are valuable only if the purpose of the research is to study group norms, meanings and processes. In my study, I wanted to have an insight and understanding of the different health professionals practice (norms), issues in their oncology area (meaning of their social context), their working as a team and the decisions they make (their social processes of communication and decision making processes).

My plan was to conduct three focus groups: two in the hospital setting and one in the community setting. A manageable group would consist of between 6-8 participants. Although it is possible to still run a discussion with a smaller group the desire for diversity of opinions will not be elicited (Hoyle, Harris and Judd 2002; Barbour 2008). However, more than 10 may be difficult for participants to express their opinion fully (Hoyle, Harris and Judd 2002).

3.4.2 Rationale for individual interviews with healthcare professionals

I discussed having individual interviews with healthcare professionals with my supervisors when some of the participants were unavailable for the focus groups, but expressed an interest in having an individual interview. Barbour (2008), argued that there are no hard-and-fast rules and suggested giving people a choice as some are less inclined to discuss difficult or sensitive topics in a focus group. Although the group dynamics may be missing, I took into consideration that some of them were policy makers and could contribute their views and experiences.

3.4.3 Rationale for interviews with patients, carers and healthcare professionals

I made the decision to have semi-structured interviews with patients once they were diagnosed with MSCC (Rubin and Rubin 2005). Dialogue with a purpose contributes to the understanding of realities of an event, an experience, or an emotion (Lincoln and Guba 1985; Yin 2009). During this process the participant's perspective of the phenomenon under investigation will emerge

with the researcher's role of a facilitator. Pre-determined interview schedules were used and depending on the patient's response, prompts were used to get a better understanding.

Similarly, carers were interviewed individually rather than in a focus group to avoid disruption in their routines and being mindful of the psychological upheaval suffered by them and their loved ones as a result of the illness.

The literature review identified that patients had unmet needs, therefore, I also considered a longitudinal element to capture the patient's experience during their transition from hospital to home or to the hospice setting to establish an understanding of their experience after treatment. I also sought to capture their carers' and/or family members' views on their support to the patient during the transition from hospital to home or hospice. The time frame for follow-up was based on the estimation of the reported evidence on prognosis. For example, in lung cancer cases, the life expectancy after diagnosis of MSEC was around 4 to 8 weeks (Loblaw, Laperriere and Mackillop 2003).

As a nurse, I had relatively well developed interviewing skills but I was going to interview vulnerable people towards their end-of-life, I attended a workshop and also talked to a Macmillan nurse about interviewing cancer patients. It was necessary for me to adopt reflexive subjectivity to all aspects of this research (Finlay and Gough 2003; Roth and Breuer 2003).

3.4.4 Field notes

I considered that field notes might add to the data gathering. For in-depth focus groups and interviews, field notes provide useful information. For example, what the researcher observes or hears immediately after the discussion or the dynamics of the group can contribute to ideas or issues that can be included at the analytical stage (Ritchie and Lewis 2006).

3.4.5 Document review

In keeping with case study methods, this study included reviewing documentation; for example, patients' demographic information, their diagnosis, treatment, observations and care plans in order to gather background information about the patient. Other key documents included imaging reports such as Magnetic Resonance Imaging (MRI). This approach can be used to corroborate and augment terms, names or different aspects of the problem and explain the variations in the data (Sandelowski 1995; Yin 2009). I sought clarification and explanation from relevant health care specialists especially about the treatment and MRI reports to determine the links and gaps in understanding the case (Hancock and Algozzine 2006).

3.5 Ethical approval and permissions process

Ethical approval was obtained from Edinburgh Napier University Research Ethics and Governance Committee and Lothian Research Ethics Committee (Appendix 13). The purpose of the Research Ethics Committee was to review the research, provide advice, and ensure that the participants' dignity, rights, safety and well-being were protected. The sample size was increased from six to eight patients and eight carers as suggested by the Lothian Research Ethics Committee. There were some changes to the patient information sheet in line with the National Research Ethics Service (NRES 2009) guidelines.

In this study, the Lothian Research and Development Office felt that application to the Caldicott Guardian (NHS 2010) was not necessary as access to patient information was required only after they had agreed to participate in the study. The study was granted ethical approval by the Lothian Research and Development Office in April 2009 (Appendix 14).

The participants were informed they could withdraw from the study at any stage and reassured this would not affect their care and treatment (Royal College of Nursing (RCN) (2011)). All the participants were informed that the interviews were confidential and information provided would be anonymous and kept in

accordance with the Data Protection Act (1998). Data were coded and stored in password protected computers in secured, locked premises. Data will be stored for 5 years and destroyed after that. Only the researcher and her supervisors had access to the data.

The risks of a breach of confidentiality were minimal as pseudonyms replaced the participants' identities in the transcribed data. Additionally, data were grouped and narrative quotes were kept gender neutral to protect healthcare professionals' identities.

In addition, I also considered the key principles of beneficence, which encompasses 'the sum of the potential benefits and the importance of the knowledge gained outweighing any risk or harm' (Kvale 1996: 116), as well as the principle of autonomy which places an emphasis on respecting the rights of individuals (Green & Thorogood 2009; Beauchamp and Childress 2009).

3.6 Sampling

In a qualitative study, sample size is not meant to be representative or large in number. A minimum of 6-10 participants was recommended by Morse (1994) and Creswell (2009). Purposive sampling aims to select information-rich cases for in-depth study to examine meanings, interpretations, process and theory (Liamputtong and Ezzy 2005: 46). Silverman (2000), identifies that purposive sampling allows a researcher to choose a case because it illustrates features or process of the phenomenon in various abstract dimensions, for example; conflicts, tensions, and human relations. It can be an illness, a treatment, type of care or professional decision making.

In this study, purposive sampling was used to identify those patients and carers who were well placed to discuss the phenomenon under investigation, which was their experience and perceptions of MSCC. The sample selection was based on the following criteria: patients diagnosed with metastatic spinal cord compression; were undergoing treatment; were willing to reflect on their experience and willing to participate. Patients were recruited once the diagnosis

of spinal cord compression had been confirmed and they had been seen by the consultant.

The criteria for carer selection to this study were: supporting the patient with a radiological diagnosis of metastatic spinal cord compression; eighteen years of age and above and able to give consent. I obtained patients' permission to approach their carers once they had agreed to participate in the study. Key healthcare professionals were identified once the patients were recruited to the study.

3.7 Recruitment of participants to the study

In this section, I discuss how I recruited healthcare professionals for the focus groups and individual interviews in Phase One. Access to stakeholders was through the Consultant of Oncology, Head of Cancer and Palliative Services and Heads of Departments. Access to nurses and allied professionals was through their head of department and line managers. However, because of the many disciplines involved, and not being personally familiar with the professionals, I discussed with my supervisors options towards identifying access to them. I secured the opportunity to attend the team meetings of the different disciplines. I 'tagged' along during some of the oncology ward rounds in four clinical areas. In addition, I attended ward managers meetings and negotiated access to staff nurses. I approached the general practitioners during one of their seminars and the district nurses during their monthly meeting.

The process of data collection was not without its problems and challenges. My initial dilemma was during the recruitment of patients to the study. When I approached the urology consultant to recruit his patients and healthcare professionals to this study, he felt that his team did not have the time. However, he asked me to send him a copy of my research proposal. As indicated in my background study, lung, breast and prostate cancer patients are common groups at risk of developing a recurrence of cancer. However, I received a negative reply which was a blow to me. I felt as though I had already failed before I even started data collection.

On one hand I did not want to be seen to be coercing healthcare professionals into participating in this research, but I would be doing a disservice to the patients in this group, who are one of the common groups at risk of developing MSCC. I therefore reflected on my approach, and thought that a review of my research proposal in terms of length and details may alter the decision making. I wrote back to the consultant citing that the small sample size meant I only needed one patient from his speciality, giving a short explanation why it was important to have representation from this group of patients and that only two to three healthcare professionals would require to be interviewed for about 30 to 60 minutes considering their busy schedule. I was elated when I got a reply allowing me to have not one patient but two patients from this speciality. On hindsight, I should have written a more structured letter with very clear information of what I needed rather than an overview of the whole study from the start.

3.7.1 Phase One

This phase of the study took place from July to August 2009. Table 2 shows that I approached 66 healthcare professionals, of which 25 participated in the focus groups and seven in the individual interviews. I recruited healthcare professionals personally and followed this up with emails. The participants were recruited to reflect the range of expertise within a multi-disciplinary team which provided useful insights. I provided the healthcare professional with an information sheet about the study and a consent form (Appendices 15 and 16).

Table 2 : Phase One - recruitment of healthcare professionals						
	Approached	Agreed	Focus group	Individual interview	Withdrawn due to work	Other reasons/No reply
Oncologist	12	7	3	3	1	5
Neurosurgeon	4	1	1	-	-	3
Neurologist	1	1	1	-	-	-
Radiologist	4	3	3	-	-	1
Registrar	4	3	-	-	3	1
Staff Grade Doctor	1	1	1	-	-	-
Charge Nurse	4	4	3	-	1	-
Palliative Care Nurse	2	2	2	-	-	-
Nurse Practitioner	1	1	1	-	-	-
Project Manager	1	1	1	-	-	-
Staff Nurse	5	4	2	-	2	1
Discharge Planning Co-ordinator	1	1	1	-	-	-
Education Co-ordinator	1	-	-	-	-	1
Physio Superintendent	1	-	-	-	1	-
Physiotherapist	2	2	2	-	-	-
Occupational Therapist	2	1	1	-	-	1
General Practitioners	10	5	3	2	-	5
District Nurse	5	2	-	-	2	3
Head of Cancer Services	1	1	-	1	-	-
Hospice Medical Director	1	1	-	1	-	-
Consultant Palliative Medicine	1	1	-	-	1	-
Consultant Neuro Imaging	1	-	-	-	-	1
Head of Radiotherapy	1	-	-	-	-	1
Total	66	42	25	7	11	23

3.7.2 Phase Two

The interviews with patients, their carers' and key healthcare professionals were conducted from September 2009 to March 2010. Before I recruited the patients, carers and key healthcare professionals to this study, I made appointments to see the different oncology consultants and neurosurgeons to seek their help in recruiting the patients. The treating consultant would ask the patient whether he/she would like to participate in the study. When the patient had confirmed, I arranged to have an initial discussion with the patient.

At the same time I asked the patient whether their carer would like to participate. I allowed the patients and carers 24-48 hours to determine if they wished to take part in the study and informed consent was obtained. An invitation letter, information sheet and consent were given to the participants (Appendices 17 - 19). The patient's general practitioners were informed once the patient had consented (Appendix 20). The patients were also informed of the second interview after their discharge from the hospital.

In total I approached 20 patients and recruited eight patients in line with the ethics requirements (Table 3). Seven patients declined due to various reasons: one was too breathless to talk; one was transferred to a high dependency unit; five gave no reasons. Five of the patients who had initially agreed to the interview did not participate due to: one patient died quite suddenly due to gastric bleed; one patient's condition deteriorated and was transferred to a hospice; two withdrew as they were transferred back to the district hospitals; and one patient was a poor historian due to his intellectual ability.

Table 3: Phase Two - recruitment of patients, carers and healthcare professionals					
Participant	Approached	Agreed	Interviewed	Declined	Other reasons
Patient	20	13	8	7	1 died 1 condition deteriorated 2 withdrew 1 poor historian
Carer	7	6	6	-	1 withdrew
Oncologist	6	6	6	-	-
Neurosurgeon	2	2	2	-	-
Radiologist	8	5	5	-	2 did not reply 1 withdrew
Palliative Doctor	1	1	1	-	-
Registrar	7	6	6	-	1 did not reply
Senior House Officer	1	1	1	-	-
Charge Nurse	1	1	1	-	-
Palliative Care Nurse	1	1	1	-	-
Nursing staff	8	8	8	-	-
Physiotherapist	2	2	2	-	-
Occupational Therapist	2	2	2	-	-
General Practitioners	8	4	4	-	2 busy 1 busy with swine flu vaccination 1 did not attend to patient
District Nurse	2	1	1	1	-
Community Nurse	2	2	2	-	-

Note: 1 carer was not approached as the patient did not want his wife to worry.

Carers were recruited following the agreement of the patients. If the carers were not with the patient, I would arrange to see them when they visited the patient. I was aware of the patient's rights to confidentiality and would not approach their carer without their permission. I approached seven carers after obtaining permission from the patients and only six carers participated in the study (see Table 3). One of the patients did not want his wife to participate as he felt she was a worrier. Another carer agreed initially but later felt that she did

not have a full picture of what was happening and opted out. My approach to obtaining informed consent gave the participants the choice and they did not feel obliged to participate in the study as demonstrated by the decision of one carer to opt out.

Key healthcare professionals involved in the management and care of the patients with MSCC were invited to participate in the study following the interviews with the patients. For example, I invited six treating oncologists and two neurosurgeons to participate in the study to explore their experience in managing the patient. One of the oncologists managed three patients and I interviewed him twice. The participation of key healthcare professionals from different disciplines was important to help verify information and to understand their complex roles, norms, values and the cultures of the oncology wards and the hospital system (Morse, 1994: 67).

3.8 Data gathering process

In this section I describe how I conducted the focus group sessions and individual interviews with the healthcare professionals in Phase One of this study. I also provide my reflection on the process. Table 4 shows the data sets for both phases in this study.

Table 4: Data gathering phases			
Dataset	Method	Participants	Data obtained
Phase One			
Dataset 1	Focus group 1 (n=9)	Radiologist (n=2) Neurologist (n=1) Palliative Care Nurse (n=1) Nurse Practitioner (n=1) Project Manager (n=1) Discharge Planning Coordinator (n=1) Occupational Therapist (n=1) Physiotherapist (n=1)	1 transcript
	Focus group 2 (n=12)	Radiologist (n=1) Oncologist (n=3) Neurosurgeon (n=1) Senior House Officer (n=1) Charge Nurse (n=3) Physiotherapist (n=1) Staff Nurse (n=2)	1 transcript
	Focus group 3 (n=4)	General Practitioner (n=3) Palliative Care Nurse (n=1)	1 transcript
	Individual interview (n=7)	Oncologist (n=3) Head of Cancer Services (n=1) Hospice Medical Director (n=1) General Practitioners (n=2)	7 transcripts
Phase Two			
Dataset 2	Case study (n=8) 1 st interview with patients (n=8) 2 nd interview with patients (n=6) 1 st interview with carers (n=6) 2 nd interview with carers (n=5)	Patients (n=8) Carers (n=6) Oncologist (n=6) -7 transcripts Neurosurgeon (n=2) Registrar (n=6) Senior House Officer (n=1) Charge Nurse (n=1) Palliative Care Nurse (n=1) Staff Nurse (n=8) Physiotherapist (n=2) Radiologist (n=5) Community Nurses (n=2) –1 transcript District Nurse (n=1) General Practitioner (n=4) Occupational Therapists (n=2) Palliative Care Doctor (n=1)	67 transcripts
Other sources of data included documents such as patient's demographic details, field notes, magnetic resonance imaging reports, nursing care plans and medical notes.			

3.8.1 Phase One

Phase One involved three focus groups and seven individual interviews with healthcare professionals in a cancer centre and three other* health boards in East Scotland (Focus group 3 and two general practitioners who participated in the individual interviews were from other NHS Health Boards). Phase One data gathering generated 10 transcripts.

3.8.1.1 Focus groups with healthcare professionals

Focus Groups 1 and 2 were conducted on the 27th July 2009 and the 30th July 2009 at a neutral venue - a nearby clinical research facility in a major teaching hospital in South East Scotland. Nine participants attended the Focus Group 1 session. In Focus Group 2, 12 participants attended. Focus Groups 1 and 2 comprised healthcare professionals from a multidisciplinary team in a cancer centre (See Table 2). Focus Group 3 was conducted on 8th September 2009 in a healthcare centre in South Scotland. Four participants attended this session: three general practitioners and one palliative care nurse.

For Focus Group 1, my supervisor with a medical background was there as a co-facilitator and contributed on the medical aspects of the discussion. My colleague researcher helped in taking notes and assisted in identifying the speakers in the seating plan for transcribing purposes. In Focus Group 2, my director of study was the note-taker. A colleague of mine helped to take notes for Focus Group 3. As lunch was provided, I mingled with the participants, making them feel at ease before the discussion.

The discussion started with an introduction of the participants followed by background information of the study. I started the discussion with a topic guide (Appendix 7), using prompts to establish flexible dialogue between the participants. The session was audio recorded. The discussions lasted approximately an hour. I felt that I had facilitated the discussion in an engaging manner.

* Health Board: There are 15 National Health Services (NHS) health boards in Scotland.

Focus Group 2 was a much bigger group, comprising 12 participants, and with so many members I did seek to draw in participants who were rather quieter. I was aware that a larger group with members from different disciplines may be intimidating (Barbour 2008). However I felt that the members were genuinely interested in this area of study and I was able to capture their similarities and differing opinions. Focus Group 3 was in a general practitioner surgery with three general practitioners and a palliative nurse participating in the discussion.

Reflecting on the focus groups discussions, I felt I was able to encourage interactions between the members and made sure the participants had the opportunity to express their views. I had provided blank paper for the participants to write what their thoughts were about the focus group session and what they thought would be best for patient care. This allowed them to reflect on their participation, as a way of summarising their thoughts. This gave each participant an opportunity to state what, otherwise, they might not voice in a group session.

3.8.1.2 Interviews with healthcare professionals

Seven individual interviews were carried out with healthcare professionals who were unable to attend the focus group sessions. Six interviews took place in the participant's office and one interview was via Skype.

I used the same topic guide as in the focus groups (Appendix 7). The interviews were conducted in a fairly relaxed conversational way, allowing the participants to discuss issues that they were concerned about which they may not have brought up in a focus group discussion.

3.8.2 Phase Two

The data gathering in the Phase Two generated 67 transcripts (Table 4 in Section 3.8).

3.8.2.1 Interviews with patients

The first interview was carried out after the patient had received their five fractions of radiotherapy as it was anticipated that the patient might have some response towards the treatment by this point. The patients I recruited were from four oncology wards and one neurosurgery ward in a cancer centre. Six patients were interviewed on oncology wards, one in a neurosurgical ward and another in one of the private rooms in the radiotherapy unit where the patient attended his radiotherapy treatment as an out-patient.

In order to develop rapport with my participants and to gain their trust, I explained why I was carrying out the research, and my background (Morse1994). Each individual interview was semi-structured to ensure the discussion was participant-led and flexible according to the general condition of the patient (Appendix 8). The interviews lasted between approximately 40-80 minutes.

I provided privacy and a relaxed atmosphere to make patients comfortable so that they could share their experience. As participants were drawn from a vulnerable group, the interviews at times engendered feelings of sadness, depression, discomfort, and dissatisfaction for the participants. I was able to respond sensitively on these occasions in a supportive and empathic way; by enquiring whether they wanted to continue or needed to contact anyone. The participants fully engaged in responding to questions and provided rich descriptions of their experiences.

Nurse/researcher role conflicts can be challenging during data collection. I struggled whilst listening to patients' anxieties, thinking all the time whether I should intervene. As a nurse I was trained to help patients and yet I had to be impartial as a researcher. This challenged the fundamental core of my professional code of practice (Nursing and Midwifery Council (NMC) 2010). For example, the interview with my second case study stood out prominently in my mind. The patient told me that a patient next to her bed caused her anxiety as she talked about being paralysed and dying. She had apparently spoken to a

couple of nurses about the anxiety of the patient next to her but did not say it was affecting her. I asked the patient whether she wanted me to inform the nurse to move her to another bay, she declined saying she was alright.

However, I later learned from the registrar that the patient had a nightmare the night before her discharge home. I was very concerned and talked to my supervisors, not knowing whether I had done the right thing. However, they reassured me that I had taken the right steps. I later heard from the patient during the second interview that her nightmare was built up over the days and not as a result of talking to me.

In total, six patients were followed up and were interviewed at various locations: one at the local hospital; one at the radiotherapy department; one at the hospice, two patients were interviewed at their own home and one was a telephone interview. One patient was ill and did not take part in the second interview and another died in a community hospital. All interviews were conducted face to face except in case study 2 as the patient lived far away in the countryside. As some patients were still on treatment, I undertook the interviews when each patient felt able and comfortable. As a precaution, I always informed a colleague that I was away for an interview and contacted her when the interview was over.

The second interview gave me the opportunity to validate the findings from the first interview (Appendix 9). However, I could not validate the second interviews findings as seven patients had by then died. As I got to know the patients and carers, they were very welcoming when I conducted the second interview with them. Although I initially planned to have the second interview 4-8 weeks after the first interview, realistically, this was not possible as patients and carers have a lot going on in their life.

3.8.2.2 Interviews with carers

Interviews with carers were also semi-structured to allow for being participant-led and for flexibility (Appendix 10). Interviews lasted between 40-80 minutes. The location for interviews was according to the choice of the carers. Three

carers preferred to be interviewed in the ward private interviewing room whilst two others wanted the session in their homes. One carer could not leave his home as he had to tend to his farm and was willing to have the first and second interview via telephone.

The follow up interviews allowed clarification of previous discussions and explored new concerns the carer might have (Appendix 11). Two carers had the follow up interviews in their home and one at the local hospital. In one case, I interviewed the carer after the death of her husband as she was still keen for the second interview. However, she suggested I gave her time to grieve and arranged the interview two months later when she felt she was comfortable to talk.

I was touched to hear the carers' stories as they related the turmoil they went through in making sense of the patient's end of life and grieving before the passing of their loved ones. For example, one carer described how she got a memory box for each of her daughters with treasured items to remember their dad. I felt sadness when she described the funeral of her husband and showed me his urn containing his ashes. I felt I was able to deal with the carers when they became emotional and provide support and empathy.

3.8.2.3 Interviews with key healthcare professionals

Participants were recruited after identifying the key healthcare professionals involved in the patient's care. The healthcare professionals were recruited in the cancer centre when the patient was admitted in the acute stage. The individual interviews with healthcare professionals were carried out following the interviews of patients. I interviewed six oncologists and two neurosurgeons (where two patients were referred to them) in their offices. I also interviewed six registrars and one senior house officer as they may be the first person to see the patient before the patient's consultant. Efforts were made to identify those who made decisions on the care of patients so that the data collected was meaningful. Interviews with healthcare professionals were semi-structured (Appendix 12).

The interviews with eight nurses, five registrars and one senior house officer generally took place in a private room on the wards or the doctors' room. A registrar from a district hospital was interviewed due to a further test done for case study 8. The five radiologists' interviews took place in a nearby seminar room with access to a computer as I explored specific information about MRI scans. Two allied professionals were interviewed in their department; the other two were interviewed on the ward.

General practitioners were recruited via telephone calls and letters. Eight general practitioners of the patients in the study were approached. Four general practitioners participated in the study. Two general practitioners were interviewed via Skype video, one via a telephone call and one was a face-to-face interview.

Overall, my interviews with the healthcare professionals were very encouraging. Some of them said that the focus group session and the interviews gave them an opportunity to reflect on their practice and also to hear other team members' views.

3.9 Data analysis

There are different types of qualitative data analysis software available for managing and storing data, for example, NVivo 8. I attended training on the use of NVivo at the beginning of my study. As I had spent a lot of time transcribing, I had limited time to enter them in NVivo. Moreover, NVivo only helps in managing and organising data but the researcher still has to analyse it. I took great care to organise my transcripts for easy access and for reference. I initially found it cumbersome to make entries in NVivo during the workshop and made the decision that I would feel more comfortable with manual qualitative data analysis as it got me closer to the data through using colour codes via highlighter pens and linking the themes.

3.9.1 Transcribing

In total I had accumulated 10 transcripts for Phase One and 67 for Phase Two (See Table 4). All the taped interviews were transcribed verbatim (Gibbs 2007). All transcripts were done on Word Documents. For confidentiality reasons, I assigned their professional role followed by a number for easy identification of the transcripts. For the patients and carers, pseudonyms were given. I transcribed all three focus groups; patients, carers and most of the healthcare professionals' interviews. Due to time constraints I sent four taped recordings to a professional transcription service. I checked the transcripts against the taped recordings for accuracy.

As there was a limited financial fund for professional transcribing services and time constraints, a friend helped to transcribe some of the professionals' taped recordings. In some of my own transcribing where I had difficulty making out the Scottish accents, I asked my friend to check the words against the recording.

3.9.2 Justification for data analysis framework

I chose to use thematic analysis because it is a method aimed at transparency and allows for the identification, analysis and reporting of patterns of the experiences, meanings and realities of patients, carers and healthcare professionals in the management of MSCC. Thematic analysis translates qualitative information into themes and sub-themes which appeal to a broad audience (Miles and Huberman 1994; Boyatzis (1998). It is not strongly attached to any pre-existing theoretical framework and can be used to achieve different aims within them. The general approach in thematic analysis is inductive, although it can allow for the inclusion of a priori as well as emergent concepts (Ritchie and Spencer 1995). Barbour (2008), and Krueger & Casey (2009), suggest that the choice of framework or procedure depends on the purpose of the study and there is no 'right or wrong' framework. I initially tried using Strauss and Corbin's (1998), technique, which was described as flexible. However, I encountered difficulties in identifying the common issues in the

different healthcare professionals' perspectives due to my inexperience in qualitative analysis.

My director of study suggested I draw up the advantages and disadvantages of the different analytic techniques and identify which technique would help me best explore my questions. The distinction became clear that the difference between thematic analysis and Strauss and Corbin's (1998), grounded theory approach is at the selective coding stage. In the grounded theory method, it aims to develop a grounded core category at the selective coding stage and pulls the other categories together to form an overarching theory to explain the findings within the data.

However, thematic analysis generates broad themes to summarise the data but does not necessarily aim to develop a theory to explain it (Braun and Clarke 2006). In thematic analysis, an in-depth analysis for a single case is done first, then cross-checks for the development of themes and domains linked to the single case (Flick 2009). Thematic analysis also preserves the meaningful relationship between the participants and the distribution of perspectives on the topic under review (Flick 2009). This then allows cross-analysis with other focus groups to show the similarities and differences of the topic under study, and to report the patterns within the data set. Ritchie *et al's* (1995), Framework Analysis, also formed my early understanding in the process of identifying descriptive codes, elements and categories. However, this framework is more suitable for a priori-research driven coding approach. Hence, I chose Braun & Clarke's (2006), thematic analysis framework as it is suitable for an inductive-approach to analysis and can be taken further to develop theories, models, and explanations which can help better understand the experiences of our stakeholders.

Braun and Clarke's (2006) thematic framework has been widely used. For example, Crawford, Brown and Majomi (2008), used this approach to explore how community mental health nurses in the UK perceived their working lives; Bedos *et.al.* (2009), explored how people on social assistance perceived,

experienced and improved their oral health; Wong *et al.* (2009), examined the positive aspects of caring as subjectively constructed by bereaved informal cancer carers.

3.9.3 Data analysis using Braun & Clarke's (2006) thematic framework

In this section I will explain the approach to data analysis of the three focus groups data and seven individual interviews of healthcare professionals (Phase One data). According to Braun & Clarke (2006), thematic analysis provides a flexible tool but it can lack clear concise guidelines. Researchers need to clearly report the process of their data analysis and be explicit on how they use the method to draw findings (Attride-Stirling, 2001; Braun and Clarke, 2006; Sandiford and Seymour, 2007).

To ensure the clarity of the interpretation in this study I will describe the process of analysis using the six phases approach by Braun and Clarke (2006). I will describe the approach as steps so as not to confuse with the phases of my data collection. The recommended steps are listed in Table 5. Whilst the main steps of my data analysis were based on Braun and Clarke (2006), I also used some other approaches to help me make sense of the data. These steps are indicated by an asterisk (*).

Table 5: Phases of Thematic Analysis (Braun and Clarke, 2006)	
* My additional approach to the process	
Phases (described as steps)	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. *Narrative summary
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme. *Identify the conflicts, tensions and dilemmas
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions, and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

3.9.4 Phase One analysis

Here I will describe the analysis of the focus groups and the individual interviews in Phase one, which occurred throughout the data collection as a continuous process, as is common in qualitative research.

Step1) Familiarisation with the data

Analysis is 'the process of bringing order, structure and interpretation to the mass of collected data' (Marshall and Rossman 1999:15). My first step in the

analytical process was to familiarise myself with the data by listening to the digital recordings and transcribing the text. For easy reference, I numbered the lines leaving a space on the right hand column for coding purposes.

I highlighted my questions or comments in bold to distinguish between the participant conversation and mine for easy reading and referencing. I identified the issues by highlighting text or segments of the text with coloured marker pens. The aim was to understand the range of issues, variations of perceptions and attitudes regarding the management of patients with metastatic spinal cord compression. Coding proved challenging as a novice researcher in qualitative data analysis, I found this task daunting and coded some of the issues as themes straight away thereby missing this first important stage. Sandelowski (2007), recommended underlining key phrases 'if they make some sense'. In the early stages of coding, I found myself doing rigid descriptive coding which resulted in my focus being distracted from what the data was saying.

Step 2) Generating initial codes

This stage involved coding the interesting features of the data and collating data according to each code. At this stage I was helped by my supervisor's suggestion to code the transcript and write a narrative summary for each focus group and then amalgamate the dataset for all the focus groups. Three of us, my supervisor (CK), a psychologist researcher (CG), and I took the transcript of Focus Group 1 to do the coding and a narrative summary. Then together but blind to each other's coding and narrative summary, compared and cross-checked our findings. There were similarities with most of our coding but obviously my supervisor and CG had more experience and consequently they were more analytical. Cross-checking with other experts will also help to give credibility to the analysis of this study. I also found Grbich (1999)'s questioning useful. For example, read all the data including the researcher's journal and in a critical manner pose questions such as 'Why? How? What if?' and as the themes emerge identify the gaps in the data. Similarly, I have also utilised the process of identifying codes advocated by Ritchie *et al.* (1995).

I illustrate how I gave names to the codes which reflect the context of the participant's words. I quote for example, one phrase:

"...if patient needs further input from the therapist...." was coded as **'continuity of care'**.

Another example:

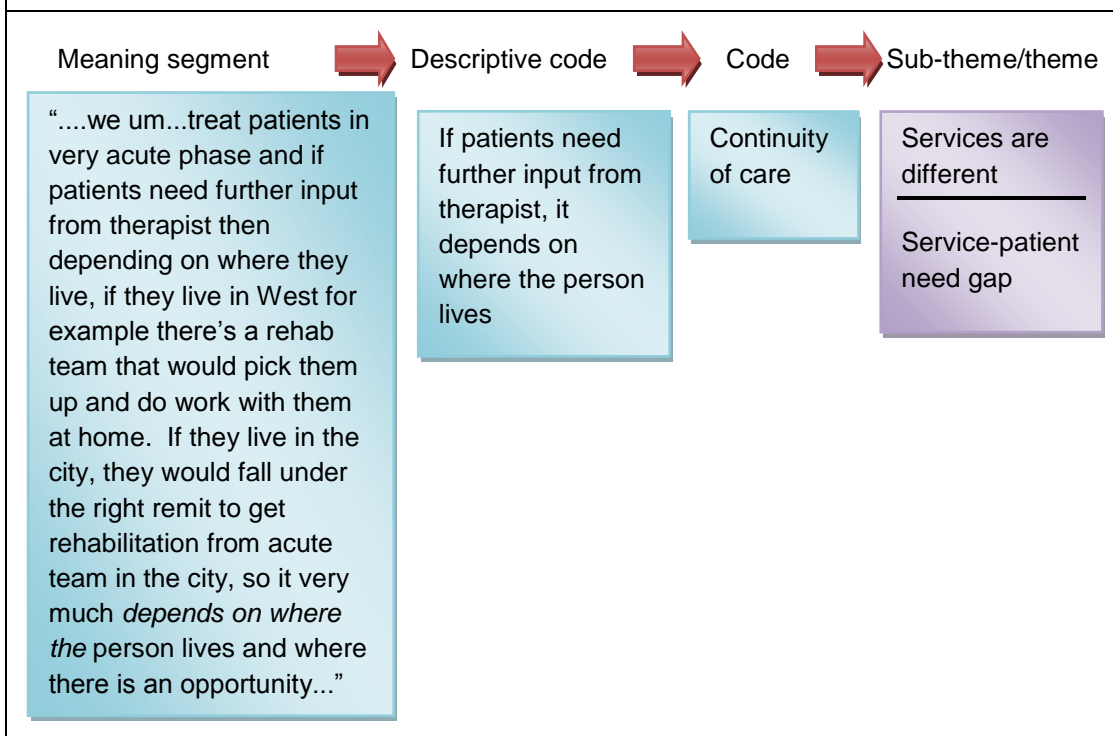
"I think even the way doctors introduced the physio... We'll get the physio to come in and see. [Laughter] They will get you up on your feet, you know! And they just expect that that's what we are going to do ...and it's not always possible. Sometimes we do...we can't always...." was coded as **'unrealistic expectation'**.

To move to a higher level of abstraction I constantly asked questions about what is going on in the data, why is this happening, and how the issues compare with other issues in the data. I used the participant occupational therapist's phrase in Focus Group 1 to illustrate the abstraction from the meaning unit, a descriptive statement, coded and then identified as a sub-theme and subsequently a theme:

*"....we um...treat patients in very acute phase and if patients **need further input** from therapist then **depending on where they live**, if they live in under the West Health Board for example there's a rehab team that would pick them up and do work with them at home. If they live in the city, they would fall under the right remit to get rehabilitation from acute team in the city, so it very much depends on where the person lives and where there is an opportunity..."*

Here, a description statement is given; *'need further input; depending on where they live'*. This is coded as: **'continuity of care'**. The sub-theme and theme can be identified as: **'services are different'** and **'service-patient need gaps'** respectively (see Figure 7).

Figure 7: Coding process – Focus Group 1 (excerpt from Occupational Therapist)



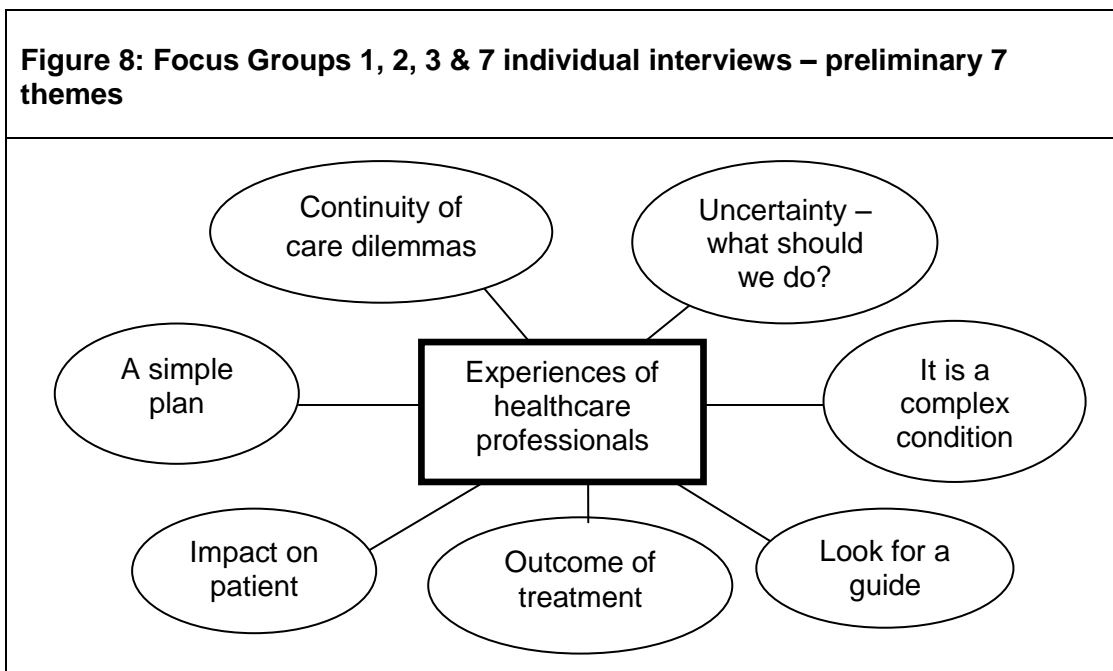
Step 3) Searching for initial themes

Step 3 is the stage where the analysis should focus on the emergence of themes rather than the codes. According to Braun and Clarke (2006), this is the stage to check if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2); to search for some form of patterns, associations and explanations, this can be presented in a diagrammatic construction. I also try to identify conflicts, tensions and dilemmas from both ends of the spectrum For example, there were views from ‘uncertainty’ to ‘certainty’; participants said ‘do not want to take away hope from patient’ and yet said ‘be honest with patient’.

Miles and Huberman (1994), suggest a ‘data display’ in the form of a text, diagram or matrix would allow the analyst to see some systematic patterns and inter-relationships to give a new way of arranging and thinking about the embedded data. Table 6 shows my initial matrix of codes assigned to the theme: uncertainty – what should we do?

Table 6: Matrix of theme, codes and main focus of findings		
Theme	Codes	Main focus of findings
Uncertainty – what should we do?	<ul style="list-style-type: none"> • Presentation of patient • Varied opinions • Consultant makes decisions • ‘play safe’ • Lack of knowledge on spinal instability • Communication problems 	<ul style="list-style-type: none"> • Need information to carry out care • Awareness of the impact of MSCC on patients • Delay in treatment • Challenging in an acute environment • Management does not match reality

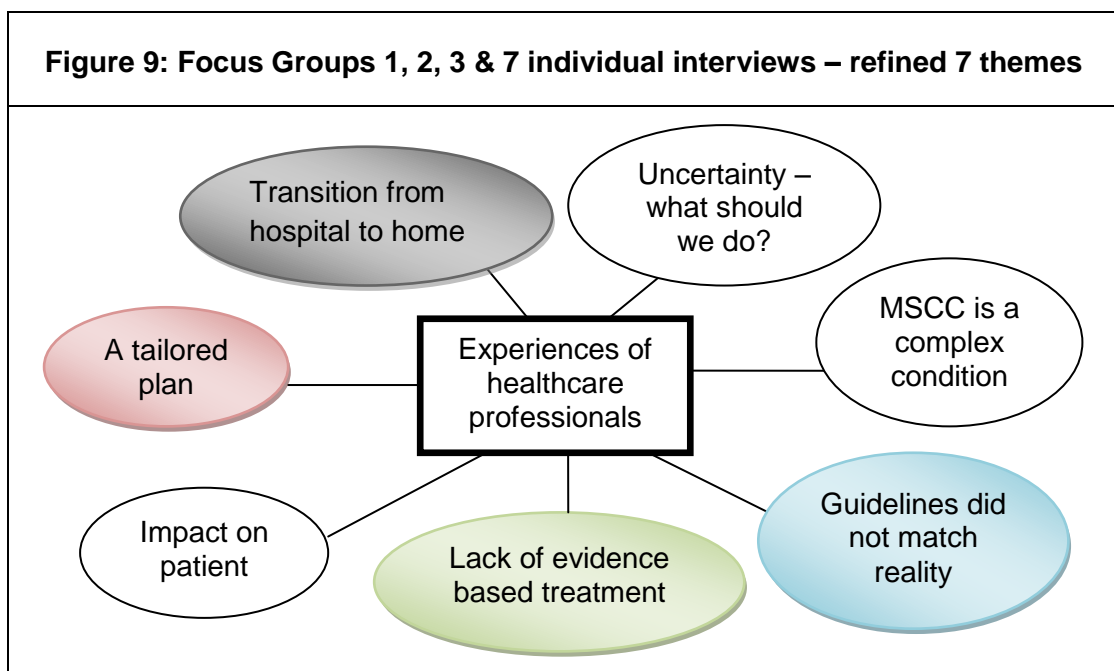
In addition to the matrix, I generated data in a thematic map for Focus Group 1 and repeated the process for Focus Groups 2 and 3 and the 7 individual interviews. An overall display of the 7 themes is shown below (Figure 8): uncertainty – what should we do; it is a complex condition; look for a guide; outcome of treatment; impact on patients; a simple plan; and continuity of care dilemmas.



Step 4) Reviewing themes

In step 4, some themes may need to be refined, some may not have enough supporting data and some may collapse into each other. Other themes may have to be further broken down and separated. At this stage, there are two levels of reviewing and refining the themes. Level one is to view the level of the coded extracts.

The extracts for each theme need to form a coherent pattern. The second level involves looking at the whole dataset. For example, in Figure 9, the theme 'look for a guide', was changed to 'guidelines did not match reality' because there were guidelines available. Similarly, the theme 'outcome of treatment' was changed to 'lack of evidenced base treatment'; 'a simple plan' was changed to 'a tailored plan' and 'continuity of care dilemmas' to 'transition from hospital to home' (highlighted).



Step 5) Defining and naming themes

In step 5, Braun and Clarke (2006), suggest defining and further refining the themes to present the findings. This involves identifying the essence of what the themes are all about and how they fit together. In refining the themes, an overarching theme emerged 'negotiating the care pathway'. Themes were then changed into a question format to reflect the challenges and conflicts the healthcare professionals experienced (Figure 10).

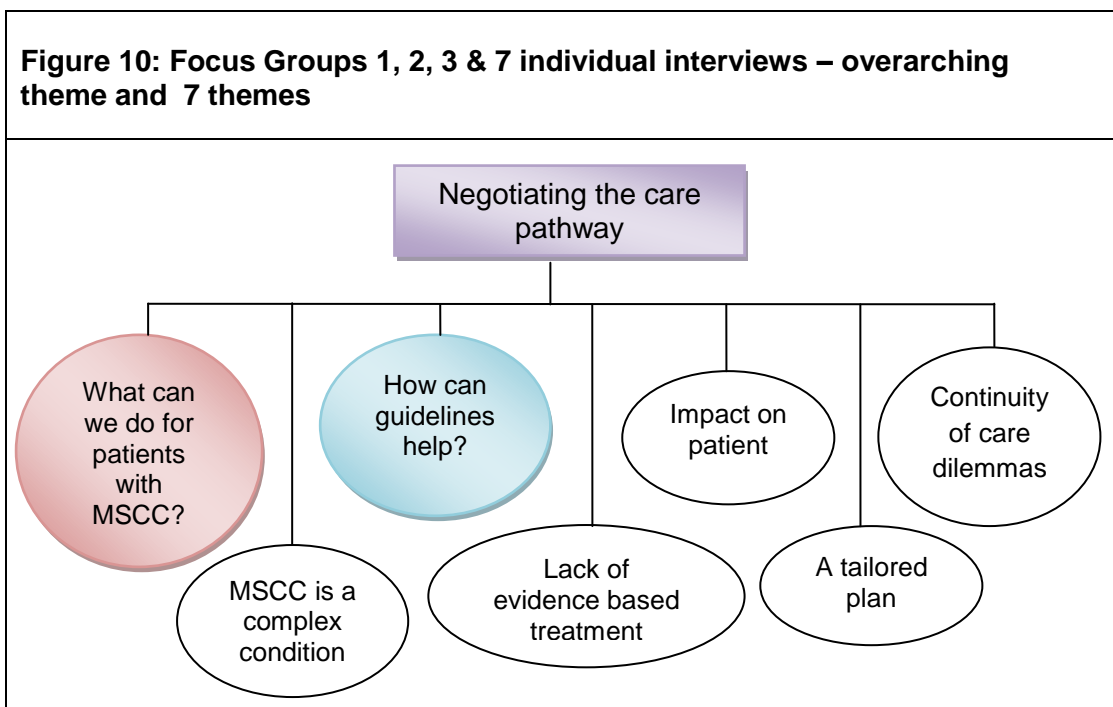
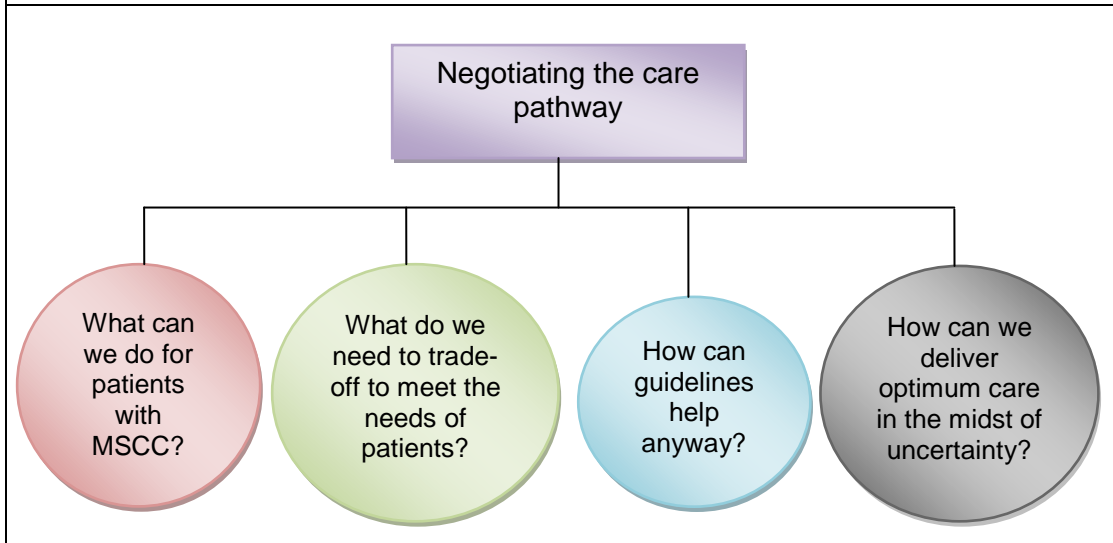


Figure 11 shows the final themes: 'MSCC is a complex condition' was collapsed to 'what can we do for patients with MSCC?'; 'lack of evidence based treatment' was changed to 'what do we need to trade-off to meet the needs of patients?'. The other three themes were joined to 'how can we deliver optimum care in the midst of uncertainty?'

Figure 11: Focus Groups 1, 2, 3 & 7 individual interviews – final themes



Step 6) Thematic findings

As I began to write the story of the findings, I kept going back and forth, from the transcripts. The findings will be discussed in the next Chapter 4.

3.9.5 Phase Two: Across-case analysis

In Phase Two, I analysed the data using the same framework as described in Phase One (Braun and Clarke 2006). I illustrate using a phrase from Case Study 2 (Figure 12):

*“I am confused and concerned and the anxiety would come from **not knowing what’s going to come next**. You know...you don’t know what pathway the illness is going to take” (Patient 2, 1st interview, p1/11)*

The description code is; “*not knowing what’s going to come next*”. This is then coded as: “*Not knowing the future*” and themed as ‘facing uncertainty’.

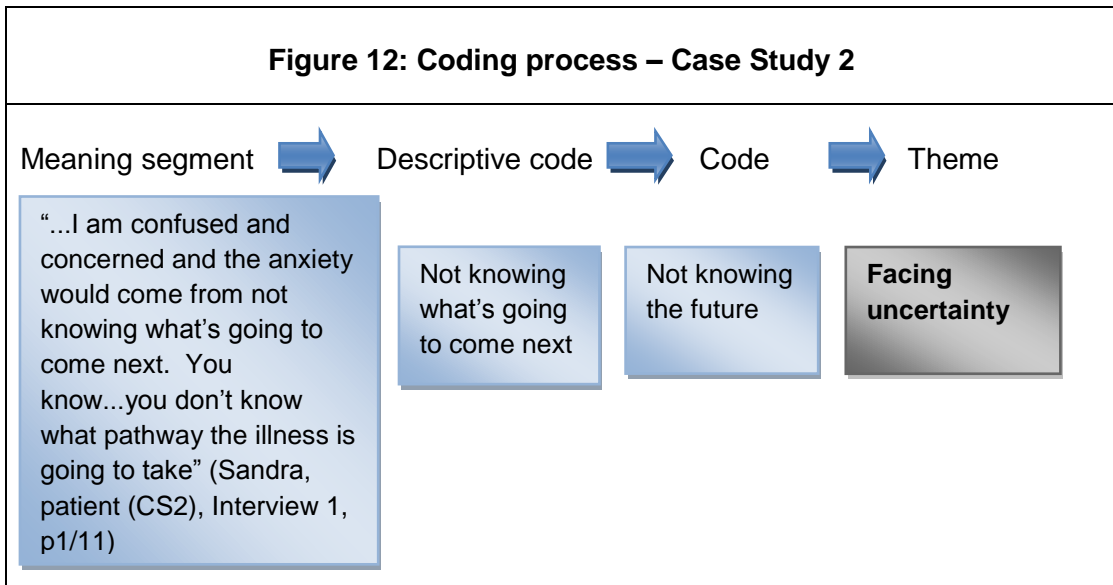
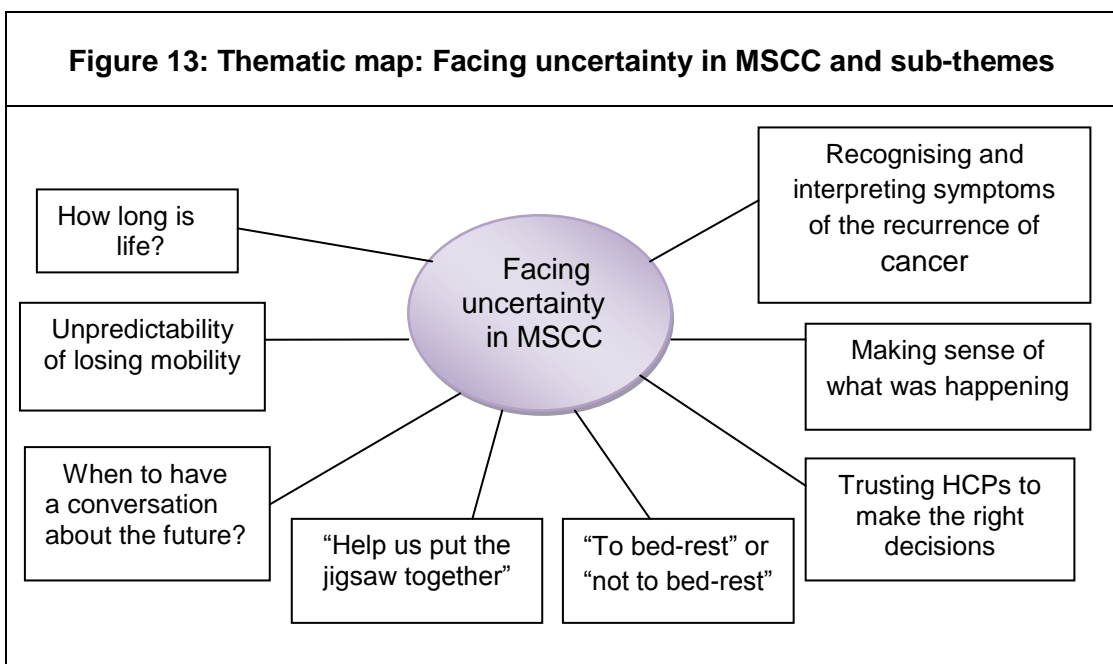
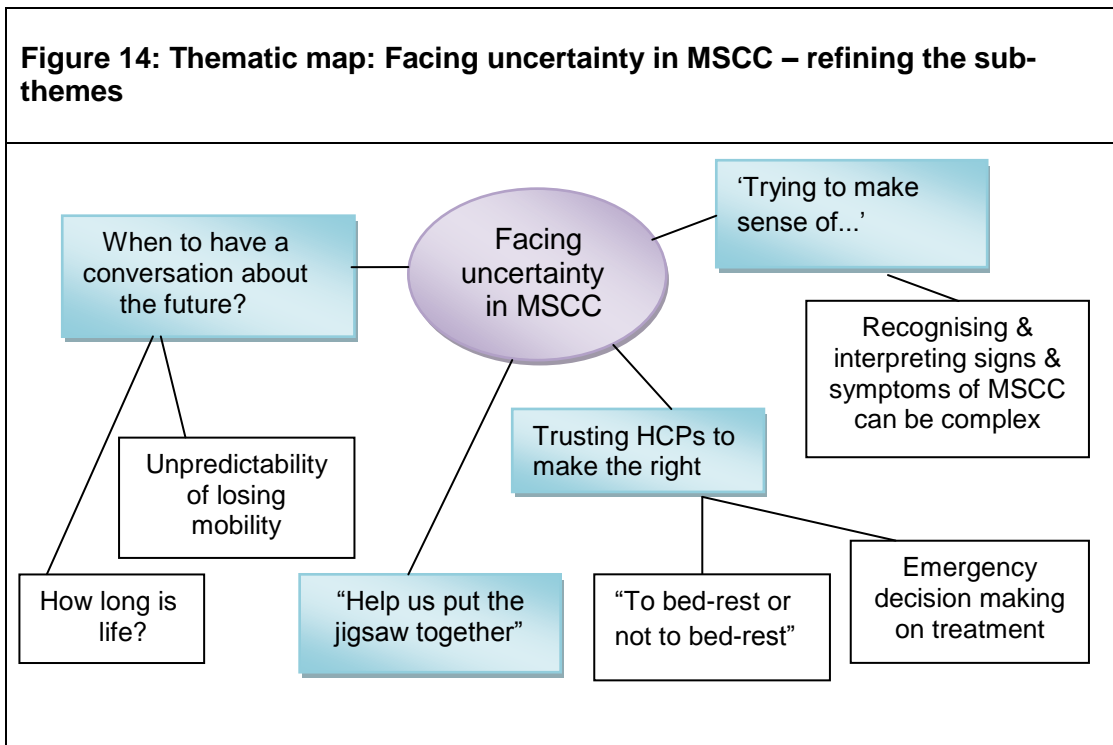


Figure 13 shows the across-case thematic display on the theme ‘facing uncertainty in MSCC’ with the sub-themes: recognising and interpreting symptoms of the recurrence of cancer; making sense of what was happening; trusting healthcare professionals to make the right decisions; to ‘bed-rest’ or ‘not to bed-rest’; help us put the jigsaw together; when to have a conversation about the future?; unpredictability of losing mobility; and how long is life?



The previous illustration is further refined by collapsing 8 sub-themes to 4 sub-themes: 'trying to make sense of...'; trusting healthcare professionals to make the right decisions; help us put the jigsaw together; and when to have a conversation about the future (highlighted in blue) (Figure 14).



In addition, I organised the data into case datasets and the supporting data sources of key healthcare professionals for easy reference when writing the findings (Yin 2009) (Table 7).

Table 7: Patients', Carers' profiles and 'case-related' data sources

Case study	Patients and Carers	Other data sources
Case Study 1	<p><u>Betty (Patient 1)</u></p> <ul style="list-style-type: none"> Betty (68) was diagnosed with MSCC with unknown primary cancer site. She was a widow. Her husband died 6 years ago. Mary (48) is Betty's daughter who has 2 young adult daughters and 2 grand-daughters 	<p>Oncologist Registrar Charge Nurse Staff Nurse Physiotherapist Radiologist Community Nurses</p>
Case Study 2	<p><u>Sandra (Patient 2)</u></p> <ul style="list-style-type: none"> Sandra (52) was found to have MSCC on routine follow-up scan for breast cancer John (55) is Sandra's husband Sandra and John have 2 sons aged 23 and 21 	<p>Oncologist Registrar Staff Nurse</p>
Case Study 3	<p><u>Jimmy (Patient 3)</u></p> <ul style="list-style-type: none"> Jimmy (74) had lung cancer and later developed MSCC. He was retired Jimmy did not want his wife to worry and requested that I did not interview her Jimmy and his wife have two grown up sons 	<p>Oncologist Radiologist Staff Nurse</p>
Case Study 4	<p><u>Robert (Patient 4)</u></p> <ul style="list-style-type: none"> Robert (78) had recurrent MSCC Jane (78) is wife of Robert Robert and Jane's two sons are married with children 	<p>Oncologist Registrar Staff Nurse General Practitioner District Nurse</p>
Case Study 5	<p><u>Richard (Patient 5)</u></p> <ul style="list-style-type: none"> Richard (61) was diagnosed with metastatic prostate cancer and it has spread to his spinal cord. He had retired and did odd jobs Linda (50) is wife to Richard. They have 2 grown up sons 	<p>Oncologist Senior House Officer Staff Nurse Physiotherapist Occupational therapist Palliative Care Nurse Palliative Care doctor</p>
Case Study 6	<p><u>Emma (Patient 6)</u></p> <ul style="list-style-type: none"> Emma (32) was diagnosed with MSCC while still on clinical trial chemotherapy for bowel cancer Matthew (32) is husband to Emma Emma was diagnosed with bowel cancer shortly after they got married. They have no children 	<p>Oncologist Neurosurgeon Staff Nurse Physiotherapist General Practitioner</p>
Case Study 7	<p><u>Tony (Patient 7)</u></p> <ul style="list-style-type: none"> Tony (42) was diagnosed with bowel cancer and later developed MSCC during clinical trial chemotherapy Gail (42) is Tony's wife. She works part-time Tony and Gail have two young girls aged 5 and 3 	<p>Oncologist Neurosurgeon Registrar Staff Nurse Occupational Therapist General Practitioner</p>

Case Study 8	<u>Jock (Patient 8)</u> <ul style="list-style-type: none"> • Jock (76) was admitted with unknown primary site cancer and after radiotherapy was investigated further and found that that cancer had spread from his prostate • Jock's wife did not participate in the study citing that she was not sure what was happening 	Oncologist Registrar (District Hospital) Registrar (Cancer Centre) Staff Nurse General Practitioner
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Initially, I wrote a narrative summary for each case noting down the main issues for each. A narrative summary was a way to systematically study a person's narrative of experience and perspectives (Bury 2001). An overall summary was then written for one dataset providing a way for me to reflect and make sense of how the patient with MSCC negotiated his/her way through treatment regimens, changing physical functions and disrupted lives, and the challenges faced by healthcare professionals.

As I was finding difficulty in analysing across cases, it was agreed I should start with an analysis of a single case to tease out the themes in my progress review. To make sense of the across case data, I drew up a matrix identifying different groups – patients, carers and healthcare professionals (Miles and Huberman 1994). Fetterman (2010), described data analysis in qualitative research as "...finding your way through the forest". I was lost in the maze and at times felt overwhelmed with so much data. My supervisors asked me to stop searching for a pre-determined framework and said that data analysis is achieved through making sense of my data. The next strategy was to write a narrative summary across case without looking at my raw data. I then made a few decisions:

- 1) To include the case which I had earlier intended to highlight as a single case;
- 2) To include my previous sub-theme 'vague signs and symptoms' and change it to 'making sense of...' - which was initially excluded as one supervisor thought that was too medical, and did not capture the range of issues emerging from the patients and carers perspectives, and
- 3) To write as a patient's trajectory of cancer.

The use of narrative analysis helped to bring out the salient phenomenon related to the core theme and at the same time illuminate the broader social context of the participants (Morse and Field 2002; Thomas 2011). On reflection of my interviews with patients and carers, (they would ask ‘where do you want me to start?’), their story seemed to have an event that triggered their experience. Creswell (2009), described this as “issue-relevant meaning or significance of the story”. So, it was befitting I start the story with patients making sense of their symptoms, as all these happened during the acute stage. Other subtle themes emerged during my writing of the narrative summary, for example, ‘trusting the healthcare professionals to make the right decisions’. It became clear that not only the patients were putting their trust in the healthcare professionals; the healthcare professionals themselves were also trusting their colleagues to make the right decisions.

Although the findings of ‘to bed rest’ or ‘not to bed rest’ was an issue for the healthcare professionals, their decisions impacted on patient care. Another transformation was to amalgamate two previous sub-themes ‘preserving/losing mobility’ and ‘how long is life?’ to ‘when to have a conversation about the future?’ It became clear that based on the patient’s trajectory of cancer there were only three main themes: ‘facing uncertainty in MSCC’; ‘finding a balance in MSCC’ and ‘support beyond the treatment of MSCC’. Table 8 is an example of my across-case development on the sub-theme ‘trying to make sense of...’ which was later refined to ‘trying to make sense of it all’. The words or phrases highlighted in bold show the descriptive codes.

Table 8: Across-case analysis illustrating the sub-theme 'trying to make sense of it all'	
Meaning segment	Codes
<p>"Because I was on a trial drug, I thought it was a mixture of everything between the chemotherapy, the trial drug. I didn't know what to expect with everything so I just thought I'll wait till Monday and see what happens" (Emma, patient (CS6), p7/1)</p>	<p>On trial drug</p> <p>Not knowing what to expect</p> <p>Wait and see</p>
<p>"The fact that she had had a few falls and was, it seemed to me, she was losing the use of her left leg. It was just a kind of worry seeing that" (Matthew (CS6), interview 1, p24/21)</p>	<p>Falls</p> <p>'Trying to make sense of...'</p> <p>Anxious</p>
<p>"...I was worried this pain I had for 2 years. I mean the pain keeps carrying on, it doesn't go away. Yes, aha...it comes right through, it's like bugs inside here [pointing to his chest], creeping about and you can feel all this. Very...oh I was crying. I was crying. A 74 year old man and there were tears running down my eyes" (Jimmy, patient (CS3), Interview 1, p3/20)</p>	<p>Continuous pain</p> <p>Make sense of symptoms</p> <p>Distress</p>
<p>"I had an x-ray that told me there was something wrong with his lungs, but it didn't give me a firm diagnosis. He did, at that point, start to have some pain in the left side of his chest and – that, I think, was around the nipple area. But events were dictating that he had to go to hospital, more on the account of his breathlessness than any pain at all. It was more of a localised pain, rather than a radicular one. Pain has never been a huge feature for him" (GP (CS8), p5/21)</p>	<p>'Trying to make sense of...'</p> <p>Decision</p> <p>Pain</p> <p>Not classical pain</p> <p>Symptoms</p>
<p>"...his chest x-ray was very abnormal, it looked like metastatic deposits but the radiologist felt he [the patient] may have a mixture of cardiac failure and infection. Erm, but certainly spinal lesions were not expected because he didn't have any symptoms at all, he didn't have back pain, he didn't have weakness in his legs, he didn't have any bowel or bladder problems, erm, so yeah, that was a surprise and also his PSA was normal" (Registrar (CS8), p3/17)</p>	<p>Making sense of signs</p> <p>Decision</p> <p>Making sense of presenting signs and symptoms</p>

3.10 Position of the researcher

When I engaged in this research, I faced quite a number of dilemmas and challenges. Ballinger (2006), recommended the position of the researcher should be accounted for to ensure that this is consistent with the research methodology. In qualitative approach, a researcher adopting a relativist perspective would focus on how the researcher's presence and positioning might influence the research process and its outcomes. Consequently, I continuously reflected and balanced between neutrality and sensitivity (Roth and Breuer 2003; Lincoln and Guba 1985). In many ways, I considered that my background in urology helped me approach and communicate effectively with patients, carers and healthcare professionals as I was accustomed to working with people who experienced acute illness.

3.11 Issues of trustworthiness

In qualitative research, the researcher has to address issues of credibility and trustworthiness to ensure the research paints an accurate picture of the participants' experiences of the phenomenon under study (Lincoln and Guba 1985; Streubert and Carpenter 2011). However, it is difficult to ensure integrity within qualitative research as reality is what participants perceive and events were captured at the moment in time within the context. To establish credibility, Lincoln and Guba (1985), suggest 'member checks'; asking the participants whether the researcher has captured their perspectives. I had the opportunity to confirm and clarify the first interviews' data during my second interviews. This was not possible for the second interviews, as seven patients had died by then. A decision was made after consultation with my supervisors to present the main findings during one of the MSCC steering group meetings thereby establishing of the account rang true for those used to working with this patient group.

3.12 Chapter summary

In this chapter I have provided a framework of the research design and the research process. There is a lack of evidence on the impact of a diagnosis of MSCC and the views of all the stakeholders regarding its' management. A qualitative approach with case study methodology was undertaken to provide the accounts of all stakeholders in the management of MSCC in East Scotland.

The use of case study was applicable to capture the range of data from different perspectives over a period of time. The five components in designing a case study were discussed and applied to this study. A conceptual framework for MSCC field study was drawn up to define the unit of analysis, the context and the sources for data collection. Braun & Clarke's (2006), thematic framework for data analysis was utilised. Several strategies were employed to make sense of the across-case analysis, for example: matrix of patients, carers and healthcare professionals' codes; thematic displays; a table of themes, sub-themes and main focus of findings and a narrative summary.

The use of narrative summary helped to contribute a clear understanding of the intricacy and multi-faceted issues faced by all stakeholders in the management of MSCC. The writing up, using the patients' trajectory of cancer has resulted in an in-depth description and a unique story about MSCC.

Throughout the research process, an awareness of reflexivity and my position as a researcher was constantly discussed with my supervisors and colleagues to ensure credibility of the findings. The findings from Phases One and Two will be discussed in Chapters 4 and 5 respectively.

Chapter 4: Phase One findings

4.1 Introduction

In this chapter, it is necessary to recap the purpose for Phase One and how this relates to the overall case study approach. The current study takes the form of an exploratory, descriptive and explanatory case study (Gray 2004; Yin 2009). The inquiry can change over time (Robson 2002). Below is the explanation on the phases:

- Phase One – the focus groups and individual interviews with healthcare professionals provides the exploratory aspect – what is happening in the local context; assessing the phenomena of MSCC; what are the current issues facing healthcare professionals in the management of MSCC. As suggested by Eisenhardt (1989) and Yin (2009), this phase was to test the theoretical propositions that emerge from the current study and compare whether they support or contradict the literature.
- Phase Two (In Chapter 5) – an example of a single case study with multiple perspectives of a theme illuminates the descriptive framework giving a clear picture about MSCC (Yin 2009).
- In Chapter 5, Phase Two – across-case findings from eight case studies provides the explanatory aspect – explaining the causal relationships between the stakeholders and how events unfold. As Yin (2009), states this is an examination of the different explanations of the participants.

In the next section, the views of the three focus groups and seven individual healthcare professionals are presented. The aim of this first phase of the study is to explore and set the scene to the perspectives and experiences of healthcare professionals in their current management of patients with metastatic spinal cord compression. The emergence of the overarching theme ‘negotiating the care pathway’ and the other four themes: what can we do for patients with MSCC; what do we need to ‘trade-off’ to meet the needs of patients; how can

guidelines help anyway; and how can we deliver optimum care in the midst of uncertainty? is detailed (Figure 11).

4.2 Negotiating the care pathway

The overarching theme 'negotiating the care pathway' illuminates the main perspectives of the healthcare professionals that the care pathway was not prescriptive and required complex negotiation. Negotiating the care pathway was described by some of the participants as the need for guidance, criteria, or pathways to enable them to identify, diagnose and prescribe treatment in the management of patients with MSCC. However, not all participants saw guidelines as being helpful with some seeking more autonomy to understand the patient as an individual with a short life expectancy. This overarching theme permeates through the four themes.

For example, the theme 'what can we do for patients with MSCC' is about how establishing the spinal status is important and why the information can help healthcare professionals make decisions on the care of their patients. The theme 'what do we need to 'trade-off' to meet the needs of patients' highlights how the uncertainty about treatment outcome and prognosis results in why trade-off decisions are made. The next theme 'how can guidelines help anyway' provides a basis for understanding how guidelines might influence the management of patients with MSCC or why they might not be helpful. The last theme 'how can we deliver optimum care in the midst of uncertainty' describes healthcare professionals acknowledging how MSCC can impact on patients and discusses why strategies are important to support them. Hence, the themes were labelled in a question format as healthcare professionals were exploring what challenges each discipline faced and they discussed strategies in overcoming those challenges.

4.3 What can we do for patients with MSCC?

The focus groups discussions and the individual interviews were centred on healthcare professionals' interactions with MSCC patients and their carers. Uncertainty was experienced by some of the participants and described as

feeling confused or indecisive about what actions to take in caring for patients with MSCC.

A nurse expressed her frustrations:

"...it has been a very grey area with regards to how you nurse patients with spinal cord compression because nobody ever told you 'this is how you care for these patients'" (Discharge Planning Co-ordinator, FG1; p3/12)

For some participants, this influenced their ability to decide how they should position patients with MSCC and when they should start mobilising the patient. One of the participants explained the variations in instructions:

"There's different ways everybody sort of deals with patients differently, some people like their patients to lie flat, some people don't mind them getting up to toilet, some people don't mind them mobilising at all" (Charge Nurse 2, FG2; p2/1)

The nurses were caring for the patients under the care of different medical staff, all with their own views, and this added to the uncertainty about what to do for any particular patient. This sense of uncertainty and confusion affected how the participants responded to their patients. The charge nurse added:

"...how we go about telling them how to go about daily, you know, it's getting a concrete...answer, you know, what we actually do to these patients when they come in certain ways" (Charge Nurse 2, FG2; p2/5)

They identified the need for information and decision about how to carry out care. They needed to be able to inform patients about their care, and this could be difficult. The uncertainty of what to do would impact on patient care. A member of the focus group explained and gave an example of her interaction with a registrar:

Neurologist: Who makes the decision in practice on the ward, do you think?

Nurse Practitioner 1: Normally, a consultant. But then you're waiting for the registrar to speak to the consultant. The consultant, depending on which consultant it is, will maybe only do a ward round once or twice a week, and you're like well you can wait until, you know, the next morning '[mention name of doctor]' have you spoken to the consultant?' 'No, I will find

out today, you know, 'but just keep them on bed rest'"
(Nurse Practitioner 1, FG1; p6/5).

This account suggests the nurse needed information to make a decision about the care of the patient. Meanwhile, the registrar was waiting for a decision by the oncologist and as a result played safe and kept the patient on bed rest. This indicates decision making was often characterised by playing safe and as a consequence patients were left immobilised. There is a line of decision making and this could potentially delay the patient's rehabilitation needs. However, at times consultants relied on their colleagues to establish whether the patient's spine was stable to allow mobilisation. One oncologist gave his views:

"...if it was a question of spinal instability, we would expect a neurosurgical opinion on that, frankly, you know. And in the meantime, we might keep the patient's spine as immobile as we could while we were making that decision, whether movement was going to, err, cause further issues, yeah" (Oncologist 5, Individual interview, p8/17)

This indicates that information about the patient's spinal status is important for decision making about treatment and care. The oncologist may have to depend on the neurosurgeon or the radiologist for guidance on whether mobilisation should be allowed.

Although there is a notion of playing safe to avoid the consequences reported, some consultants would mobilise their patients immediately they start their radiotherapy sessions:

"...there is no evidence base for this, but it has been our habit here that, um, if a patient has cord compression, you ask them just to take it easy and keep –until you've actually started their radiotherapy, you know once the radiotherapy's started you're likely to have them mobilise"
(Oncologist 6, Individual interview, p5/20)

This account suggests 'enduring' what was thought to be the appropriate decision in the absence of evidence. However, the existence of guidelines did not necessarily help as illustrated below:

"I think mobilisation is definitely one area we struggle with and the NICE guidelines...um...very much towards immobilising everybody and that's clearly completely inappropriate for lots of patients who just come in with some neuropathic pain and the pathway (local referral pathway- see Appendix 1) is looking at picking up people earlier, so we are seeing

people with very early signs or people who are completely asymptomatic and to lie on their back and log rolling” (Oncologist 2, FG2; p2/33)

Variations in the patient’s neurological status and function on admission meant that complete bed rest as recommended by the NICE guidelines was inappropriate. There was consensus and certainty that participants needed information about the status of the spine, but it was acknowledged that assessing information about the stability of the spine was difficult. However, there were communication issues:

“I think sometimes there’s difficulty in the communication as to whether somebody has a stable spine or not, you know, whether it’s unstable - that is not always filtered through, you know, from obviously when the scans are looked at and the doctor’s advised...but then it’s not always filtered through to nursing staff. So, therefore the patients are invariably just getting left alone...umm...because and if you don’t know if it’s stable or not, you just keep them in bed and that obviously is not good for the patient.” (Nurse Practitioner1, FG1; p3/33)

Efforts to commence rehabilitation can be delayed due to a lack of information or sharing of it and this has consequences on the patient’s care and quality of life. Participants also suggested that patients sometimes were confused as to what they should be doing in regards to mobilisation and commented that they were allowed to get up to sit on the commode but were not allowed to do anything else.

Examples of uncertainty about steroid therapy were also reflected as quoted:

“Even things like steroid therapy, you know...different doctors have different sort of ideas of...you know...how long people should be on steroids or how much steroids...” (Nurse Practitioner 1, FG1; p4/19)

The excerpt suggests variations in the treatment of MSCC with corticosteroids in terms of dose and duration.

In summary, the descriptions provided by the participants reflected a dynamic state where there were periods of uncertainty and a tendency to play safe. There was a sense of the need for information about the spinal status in decision making around management and care of patients with MSCC. Due to the lack of information on the spinal status, there is confusion and indecision on the part of nurses on how to position the patients and initiate rehabilitation.

There is a line of decision making between the junior doctors, registrars and consultant oncologists on the spinal status of patients which results in playing safe in the care of patients. The participants found the NICE guidelines (2008) inappropriate for the care of some patients in clinical practice due to the variations in their presentation. Lack of evidence and guidance makes the healthcare professionals decide what they think is best for patients. For examples, uncertainty was also reflected in steroid therapy management. The participants talked about the inconsistencies in weaning off the dose of steroids. However, healthcare professionals are aware of these issues; they recognise the needs of patients, the stage of disease and what treatment has to offer.

4.4 What do we need to ‘trade off’ to meet the needs of patients?

The input from the participants highlighted the complexity of caring for patients with MSCC and the uncertainty surrounding their clinical decision making was striking. They recognised the importance of identifying spinal instability to inform interventions and care. There are instances where some factors were ‘traded off’ to take into account the patient’s shortened life expectancy.

Magnetic Resonance Imaging (MRI) is the preferred diagnostic investigation for MSCC. One of the participants offered this explanation as to why the findings may not help to determine appropriate actions. A radiologist explained:

“...we can comment as to how...whether different bits of this spine involved and therefore the likelihood that something is affected is likely to be stable or lots of it is affected might be unstable but again as I said, it’s a whole spectrum and imaging doesn’t tell you the function of the patient, ...so...so...we can describe what we see but we can’t make a conclusion from that whether the patient is definitely stable or definitely unstable and so...so, again it’s all ...all shades of grey” (Radiologist 3, FG2; p5/27)

This indicated that MRI is a static image and cannot capture the functional status of patients. This account highlights that even when the spine appears stable radiologically, it can still be unpredictable. With the lack of criteria to determine spinal instability, another radiologist explained:

“...a lot of what we do is based on trauma [agreed by Radiologist 1] and making that decision about what is stable – there is no...um...evidence” (Radiologist 2, FG1, p7/21)

Healthcare professionals expressed the uncertainty of their decision making and reported being cautious and basing their management on traumatic spines. This uncertainty seemed to cause anxiety, as suggested by a member of the group:

“Umm, I think the problem is partly...err...everyone is frightened, you know, lump them together with trauma spines and think, oh well, unstable... nobody has told me its stable, therefore must keep them utterly immobilised until I get...you know some permission to move them. But these patients are usually moving before they come to hospital and its rare, people, you know, unless you got a significant imaging finding like adisplacement” (Radiologist 1, FG1; p 5/3)

There seemed to be a notion of fear in initiating mobilisation because of the unpredictability of the spine status. This resulted in playing safe in the management of patients with MSCC. However, one radiologist stressed that one should try not to assess the spine of a patient as unstable unless certain. Explaining that one has to consider both the clinical and radiological perspective when assessing the patient and take into consideration the patient’s shortened life span when making decisions. The radiologist explained further:

*“It is complex because imaging is one aspect of it and there is clinical assessment...err...are they getting *L’hermitte’s phenomenon? Are they getting problems when they mobilise, that suggest that they are getting some sort of neural compression; were the symptoms worst with movements? Does imaging have any particular concerning features? If not, I don’t see why you couldn’t mobilise them gently” (Radiologist 1, FG1; p 6/20)*

To trade-off the difficulties in giving information and making decisions about spinal instability, the participants rationalised the consequences on the patient if they were immobilised. For example one of the participants highlighted:

* L’hermitte’s phenomenon: L’ hermitte’s symptom is described as electric shock-like sensation, spreading down the spinal column and the lower and/or upper limbs when flexing the neck. It can be brought on by extending the head or by coughing, sneezing, bending forward, laughing and moving the limbs (Ventafredda et al. 1991).

“These patients...um...may have technical definition of instability, but they often have...um...have a relatively short life span. The consequences of immobilising are often higher than the consequences of mobilising if you know what I mean” (Radiologist 1, FG1, p4/34)

This indicated that patients are at risk of complications such as deep vein thrombosis and chest infection if left immobilised. Also it was suggested that patients may be aware if they were to experience symptoms of cord compression.

“Most patients will know very quickly if they’re getting neural compression, you know, it’s not many episodes where they suddenly become quadriplegic out of the blue, having had...err...you know, having been perfectly normal up to then, most patients won’t let you move their neck if it’s impinging on their cord. [...] try to avoid the assumption of instability for very long if not careful end up with a lot of them immobilised DVT’d” (Radiologist 1, FG1; p5/23)

One of the participants stressed his decision making by highlighting that what a healthcare professional sees as important may not be what the patient wants. A neurosurgeon gave an example:

“...even if they have cord compression, the attitude of the patients towards being paralysed is different depending on where the illness is. There are lots of other things going on in their lives: what prognosis; how long they are going to be living for and it may be quite different if your life expectancy is a matter of only a few weeks compared with, you know, how many years”(Neurosurgeon 1, FG2; p4/5)

This example suggests patients perceive their disability may be influenced by other more pressing issues, such as, their life expectancy. He went on further describing what matters to the patients:

“Interesting, this Scottish study we did...their (patients’) concern is not about diagnosis but all about their family and their finances, not about whether they can walk again which is bizarre. You know, from a medical perspective we are obsessed about whether they are stable or not (referring to the patient’s spine). They are worried about their money in the bank; they are worried about their wives and their kids. So, we have to think broadly what’s best for the patients and certainly not just from my perspective what operation is best for them. It is a huge problem and some can go by very quickly changing day by day.” (Neurosurgeon 1, FG 2; p17/10)

This account suggests that what healthcare professionals perceive as important may not necessarily meet the needs of the patient. The healthcare professionals need to explore the patient's preferences and priorities as their condition can deteriorate rapidly.

The unpredictability of MSCC and the complexities surrounding information about spinal instability is challenging. Lack of evidence encouraged suggestions for further research to obtain information about the spine. One oncologist suggested:

"I would have thought stability would be a very good basis for a prospective observational study of a patient's...err...state but you don't...you have to have more information about what the natural history of the disease was." (Oncologist 3, FG2; p6/31)

Another member added:

"Well, I think what would be useful is ...would be to test a predictive clinical radiological tool that would give the probability and then see whether that comes anywhere near to what actually happens obviously depending on how they stabilise and such thing" (Neurosurgeon 1, FG2; p7/7).

The account suggests an assessment tool may provide some information on the mechanics of the spine and outcomes for the patient.

Furthermore, data also illuminates the uncertainties, conflicts, and dilemmas and the trade-off in trying to get a balance of treatment decisions not only related to spinal stability. Treatment here refers to steroids, radiotherapy and surgery for MSCC. Healthcare professionals were aware of the lack of evidence on the effectiveness of treatment; on the other hand there was this notion of giving hope to patients by offering them some 'trade-off' in treatment decisions.

A radiologist noted:

"Radiotherapy is not going to heal their bones in a week. Nor is it going to heal their bones in four or five or six weeks, probably. So, [pause] but if you assume everyone is unstable then you get a lot of immobilised, bed-bound patients" (Radiologist 1, FG1; p7/26)

This quote acknowledges the limitations of radiotherapy and challenges the assumption that all patients with MSCC have unstable spines.

An oncologist highlights his experience in terms of steroid therapy:

“In my practice, we generally stop the steroids if they have been on it for a week because the toxicity of continuing with steroids often significantly impairs mobility of the patient, [...]...particularly if there’s been no evidence of any response to steroids, it’s difficult to know what the contribution of radiation is going to be” (Oncologist 3, FG2; p8/1)

These interpretations suggest the treatment outcome with steroids and radiotherapy is uncertain. Another member gave an example where treatment with steroids is justifiably prolonged:

“But where there’s significant pain you might find somebody on steroids maintained for quite a long time because that is helpful for that as well so they can be on for much longer” (Charge Nurse 3, FG2; p8/10)

On the other hand, sometimes there is a need to continue steroids for pain relief. Treatment decisions are further complicated when there is recurrent MSCC. An oncologist expressed his uncertainty:

“...but as the systemic therapies have become more effective we are now seeing patients living now a year or more after cord compression with breast cancer and then returning later with secondary cancer. This has caused uncertainty as to how they should be treated” (Oncologist 3, FG2; p9/27)

Although there is reported effectiveness of systemic treatment in breast cancer and in prolonging life expectancy, there are many challenges around making treatment decision in MSCC. For example, a decision for surgery depends on two factors. A neurosurgeon stressed this point:

“Um...now, it is a difficult assessment but two things we need to know are the functional status and the disease response to treatment. So, the treatment of breast cancer for instance has changed because we want to know how responsive the tumour might be, you know, what oncological treatments might be available for deciding whether surgery is necessary to do and...um...so, it needs to be a decision that’s a team decision not just a surgical decision” (Neurosurgeon 1, FG2; p10/5)

This excerpt suggests that the neurosurgeon needed information about the patient’s functional status and whether the tumour would respond to any further

treatment. However, treatment decisions should be shared between oncology and neurosurgery practitioners. The oncologist added that a decision also depends on whether it was soft tissue or bony involvement:

“Generally, the decision depends on whether there is soft tissue or bony involvement to decide what is better, whether it is radiotherapy or surgery and where we get a neurosurgical opinion” (Oncologist 3, FG2, p10/13)

This suggests the treatment decision depends on the extent of the tumour, whether it involved just the soft tissue or the vertebrae. However, to arrive at a definitive decision, the oncologist had to seek the opinion of the neurosurgeon. Another oncologist felt that the first assessment should be done by the neurosurgical team:

“I think if you’ve got someone with cord compression, the first contact, you know, reasonably should be a neurosurgeon, but I don’t think that’s quite the same thing as saying, every patient should then be treated neuro-surgically” (Oncologist 5, Individual interview, p12/4)

The interpretation from the account suggests that a neurosurgeon would be best placed to make the initial assessment; to enable a balanced decision on what is appropriate for the patient. However, some medical staff felt less supported by their neurosurgical colleagues. There was sometimes a delay in decision on definitive treatment. The doctor commented:

“Um...it’s not been in place a long time [meaning the referral pathway]...I think probably neurosurgery, it has been one of the issues...neurosurgery department... maybe not always been hugely helpful to us in the past, and because they have, you know, they are representation of the Steering Group there’s a much greater ‘buy in’ if you like than there was previously. [...] Neurosurgery’s been difficult to get assistance...advice from neurosurgery and...often difficult to actually get hold of someone senior. (Oncologist 4, Individual interview, p2/33)

The account suggests the difficulty in getting a neurosurgical opinion to assist in treatment decisions. However, there is evidence of good outcomes from surgical intervention leading to the oncologist to question the clarity of the local referral pathway:

“I mean with surgery there is actually...not sure whether it is in the pathway, but there is a decision making tool for when surgery is appropriate or not. I’m not sure whether neurosurgeons are actually using it or not. In the literature I’m sure you may have read, it’s about 10-20 per cent of patients who surgery is appropriate, based on various

things underlying malignancy. Haematology cancers, you know, by and large they are quite a reasonable prognosis [interrupted by phone call]. I don't know but it is in...there's a long English document – the NICE document ...as you know, there is a role for surgery with a better outcome in selecting patients for surgery” (Oncologist 4, Individual interview, p7/32).

This excerpt indicates that the referral pathway may not be explicit in the decision making process. Patients with haematological cancers have good prognosis and surgery may be appropriate for them based on evidence in the literature and the NICE guidelines. However, the decision making depends on the neurosurgeon but whether any assessment tools are used to make surgical decision is not clear in the referral pathway.

When surgical treatment is not appropriate, there may be issues around the treatment dose of radiotherapy. Another oncologist gave an example of haematological cancers:

“Well, it really depends, erm, the difficulty, I think, is that if they don't have histological diagnosis, they would tend to give what would be five fractions, yeah. If they have a histological diagnosis and they want to give radical treatment, then it could be anything up to twenty fractions” (Oncologist 5, Individual interview, p3/1)

The above interpretation indicates the complexities regarding decisions around treatment dose; it depends on the case, type of cancer and whether histology result is available.

In summary, there are many uncertainties surrounding treatment of MSCC, and with limited options to offer patients, there may be a balancing act in deciding what is best. The notion of 'trade-off' in treatment decisions is evident from the healthcare professionals' perspectives. Oncologists expressed a need to know what neurosurgeons decided with regards to a patient's suitability for surgery. Similarly, neurosurgeons required information from the oncologists about patient's functional status and prognosis in order to make those decisions. These data are focussed around medical decision making with few insights to whether this was shared decision making with patients and the implications for them.

4.5 How can guidelines help anyway?

Overall, participants identified the difficulties in decision making and acknowledged that management of MSCC guidelines exist, but there were mixed views about how useful these were. A guideline refers to a formal or government policy or an outline on which a course of action may be based.

Some participants were looking for a guide specific to patients with lumbar metastatic spinal cord compression:

"...patients with, who have the lumbar sacral the whole lot just - is there a guideline that is more specific to people with lumbar spinal cord compression? It used to be bed rest and that was it but now it's a bit different" (Charge Nurse 2, FG2; p2/12)

Some members found discrepancies in the existing NICE guidelines unhelpful.

"I suppose we only have the pathway (referring to the local referral pathway), we haven't really come up with a set protocol on what we're doing and I think part of that is the concern that the NICE guidelines don't quite fit with how we should align ourselves is...um...difficult" (Oncologist 2, FG2; p3/7)

A sense for the need for some guidelines, criteria or care pathways appeared to permeate through some of the data-set although there was no consensus in this aspect:

"Well, we've got a referral pathway for patients to come in but that...um...neurosurgery and oncology referral pathway is something that is being audited at the moment, .there is no consistency here [Pause]. It would be handy to have, you know, more helpful to have a guideline that could help you guide decision making" (Project Manager, FG1; p4/14)

Another member commented that things kept changing:

"For so long you did one thing and a couple of years down the line, it's changed and you've done something else, and so, you just don't know: 'should we do this or should we do that?' We still don't know" (Discharge Planning Co-ordinator, FG1; p3)

There were some aspects of care highlighted by participants where guidelines are needed. Mobilisation of patients was identified as being problematic and the lack of a clear pathway for the patient's journey of care proved difficult when discussing the responsibility for decision making.

Another participant raised the question:

“...so, who makes that decision, the physio who gets the patient up or the nurse who gets ...and is that person responsible? I think that is why everybody holds back whereas as you say, you know, if [pause] sort of ...some kind of guidance to say well, local criteria” (Project Manager, FG1; p5/34)

There seemed to be a lack of knowledge around who makes the decision and co-ordinating this between the healthcare professionals. A nurse described the importance of this:

“And then on the ward there seems to be a lot of phone calls back and forth, you know, oncology are going to come and review, radiotherapy is going to start, you might get transfer, you know, doesn't seem have a clear path for patients. I'm not sure if it is a sort of thing whether you could do like a care pathway for, you know, patients with unstable cord compression?” (Nurse Practitioner 1, FG1; p4/6)

The above account suggests a care pathway may prevent delays in treatment and give some structure to the care of patients with MSCC. Most of the participants agreed that the NICE guidelines are vague and lack clarity. The situation is different in clinical practice and one of the participants said that it's open to individual interpretation:

“I think it's an evidence free zone and it's up to individual interpretation and possibly NICE guidelines...um...there's a number of areas not necessarily reflecting the consensus of clinical practice in NICE and other information where we do need to try to develop some sort of consensus even if not from evidence base” (Oncologist 3, FG2; p3/27).

This comment suggests that in the absence of evidence, it would be realistic to reach consensus on the management of MSCC as a team.

This discrepancy was also experienced by general practitioners in the community setting with regard to transferring patients to the hospital. One of the general practitioners raised this point:

“...the NICE guidelines have stated that patients with malignant cord compression should be treated as if they were...err...traumatic spinal fracture and completely immobilised on a body board and two man ambulance. And of course they are not traumatic spinal lesions, so the view of ...err... [Name of health board] is that is inappropriate” (General Practitioner 1, FG3; p9/8).

A general practitioner from another health board agreed and talked about the Glasgow guidelines:

“In fact, I think, in Glasgow, their spinal cord compression guidelines [referring to WoSCAN 2007], suggest that every case of suspected cord compression should be transported as a spinal injury. Err...but, it would be nationally the thought that...that’s unrealistic, and that the majority of people with suspicion of cord compression, I mean, do not have spinal instability and they’re perfectly safe to be transported in the most comfortable position, which is usually sitting in the car rather than lying in the ambulance” (General Practitioner 5, p8/16).

This account suggests that guidelines may not inform the transfer of patient from the community to the hospital. However, they would be cautious if the patient has symptoms of severe back pain: The general practitioner added:

“...the only symptom would probably indicate that would be severe back pain that was err...made much worse on movements which might indicate then there might be some instability” (General Practitioner 1, FG3, p9/17).

Some participants were sceptical about NICE guidelines. A neurosurgeon commented:

“...and that’s the problem, that everybody wants that didactic advice... ‘this patient is stable.’ NICE [referring to NICE guidelines 2008] has come out to say ‘you’re better off saying everybody is unstable,’ but we’ve got a variety of conditions, very different prognoses, different attitudes from patients and there isn’t a golden answer, so we have to educate ourselves to understand that first of all... [...] As neurosurgeons, are often looked to give didactic advice about ‘is this patient stable?’ and that’s very difficult cause stability is a gradation from white to black, and most people are pretty grey in the middle. And you can give various guidelines...um...but all of them will be very difficult in the situation. [...] So, if people can understand that, they can begin to understand that relationship with the patient and explain that to the patient, and we won’t be continually trying to find this holy grail that the patient is unstable or not because that doesn’t exist in most patients.” (Neurosurgeon 1, FG2; p3/41)

Given there are variations in the presentation of patients with MSCC and the unpredictability of the condition, there was a view that NICE guidelines do not adequately inform the management of MSCC. In light of controversies surrounding the inadequacies of the national guidelines, a pragmatic approach was suggested:

“It would be very helpful if we came to a decision as to what our goal’s going to be for this particular condition and stop trying to find a guideline that you can pull out of the drawer and says that’s what’s going to happen...that’s what matters” (Neurosurgeon 1, FG2; p4/28).

In recognising this, there is an emphasis on collaboration and agreement between healthcare professionals on how best to manage patients with MSCC.

However, different guidelines can also be problematic:

“Unfortunately, err...work had been done in the north, um...the west of Scotland went off and did their own thing and developed guidelines, and then the south and east came online. Now none of the work being done in the other places has been wasted, but my concern would be that we still continue to reinvent the wheel” (Head of Cancer Services, Individual interview, p1/14).

Lack of agreed guidelines can lead to inconsistent practice:

“I think it boils down to a bit of arrogance on the part, particularly, the medical staff in that they know best and everybody has an opinion and because there is a lack of evidence in the literature that anything [pause] new or different needs to be done...err...then that still leads to inconsistencies in pain relief, mobilisation, um, prompt referral for surgical opinion, is it one fraction or five fractions of radiotherapy for symptomatic relief...um...and everybody’s view is different but with the implementation of a pathway, one would hope that at least patients are captured at an early stage and it becomes embedded in practice” (Head of Cancer Services, individual interview, p4/10).

Nevertheless, a referral pathway as a strategy could assist in early diagnosis and treatment of patients with MSCC.

To summarise, these accounts showed that the need for guidelines was seen by some participants as necessary for patient care, others felt they did not meet the needs of the patients who may have different primary cancers; be at different stages of the disease; or have different prognosis and priorities towards the end of their lives. There was an emphasis that healthcare professionals should work together as a team and that decision making should be a shared process.

4.6 How can we deliver optimum care in the midst of uncertainty?

The impact of recurrent cancer on patients was described by one of the participants as a huge life changing event when there is loss of mobility and difficulties with coping. Recognising the needs of the patients, healthcare professionals discussed strategies to support patients with MSCC. A palliative care nurse described her concerns:

“Often patient and family comment on either a lack of information of what’s happening or conflicting information and the fear that goes along with, you know, [...] they may not have been particularly happy recently and they may already have quite a bit of functional impairment from their primary cancer...err...um...[Pause]. This is a huge life changing event, particularly if it is diagnosed late and the anger that can go along with finding that out...I mean...and you know, all the emotional stuff and if you’re lying flat on your back or you are getting conflicting information and all that...um...it can really help, sort of trust wise” (Palliative Care Nurse 1, FG1; p8/5).

The above account suggests a diagnosis of MSCC is a devastating event. The lack of information, or conflicting information, to the patients can evoke emotions of fear and anger. Life expectancy depends on the primary cancer and when they come in with recurrent cancer, it is described as a catastrophic event by one oncologist:

“I do think when patients come in and they have this catastrophic event and I’m not sure whether there are tools to deal well with that catastrophic event for patients to help them through that process phase” (Oncologist 3, FG2; p13/3).

Healthcare professionals recognised that recurrence of cancer posed difficulties for patients and acknowledged they needed support. In some cancers, life expectancy is short and giving bad news can be challenging.

“And quite rightly many of them are very distressed by the diagnosis, and many of them, their carers’ are very distressed by the diagnosis, and often there’s not a lot of time for them to come to terms with it” (Oncologist 6, Individual interview, p7/17).

Giving bad news in the acute setting can be challenging for healthcare professionals. Patients and carers are likely to be distressed when faced with end of life issues. An oncologist talked about patient’s psychological needs:

“So, I mean, their psychological needs tend to be met by the... you know, just the nursing staff on the ward, or us on the ward. And if they – you know, they may have – we’ve got the clinical nurse specialist who will speak to them. But in terms of ‘is someone depressed, or do you need counselling,’ often there’s no time for that because they have barely come to terms with their illness. [...] So they...they would be seen by clinical nurse specialists, there just isn’t one – because we’re all site [site –meaning in the body, like lung, bowel, brain, sort of thing] um, you know, there’s not a cord compression nurse. Maybe there should be” (Oncologist 6, Individual interview, p10/4).

In this acute situation, psychological support varies. The interpretation indicates that there was a lack of someone co-ordinating the patient’s journey and ensuring patients need are met. Thus, their psychological needs may be overlooked. Another concern of the participants was patients who are admitted with unknown cancers and having the diagnosis of MSCC at the same time.

“I think it is very difficult if they’re presenting for the first time obviously they come in a number of different routes and that is one of the things we are trying to address through the pathway...more unified approach so that they get the same care. At the minute it’s very fragmented; who they are first presented to, who they are referred to ... so that would be very different in their experience” (Oncologist 1, FG2; p11/9).

This account highlights the different pathways patients experience on admission and could have an effect on them. Another participant commented that there may be lack of support for patients:

“The unknown; certainly there is a gap for support for that group of patients when they actually come in to hospital, and it can be quite a fast, through, journey for a patient who is suspected of early spinal cord compression: in, diagnosed, treatment, and out again. Where do they get any support in the system there? And then patients who do have known cancer, there’s gaps with their support...with their CNS (Clinical Nurse Specialist) support as well, cause...just the way the service is” (Project Manager, FG 1, p3/4).

Patients with unknown cancer can also present with MSCC. The patients treated in an acute setting may be discharged very quickly. The account above indicates a lack of someone co-ordinating the patient’s journey and ensuring patients’ needs are met.

An Occupational Therapist added:

“We have had a few patients that have gone to hospice because of difficulties...um...in psychological adjustment to their condition...um...and I think what...what is very difficult for the patients as well is they’re having the five fractions radiotherapy and that unknown entity how the function is going to change post radiotherapy” (Occupational Therapist 1, FG1; p8/27).

Here the account suggests that some patients faced difficulty adjusting to their condition and needed psychological help and some had difficulty coping with the uncertainties ahead of them after treatment.

In the absence of supporting evidence on the follow up care of patients, the majority of healthcare professionals suggested a need to deal with these shortcomings and provide care according to the needs of the patients through a clear plan and a tailored care package.

A radiologist suggested a plan to start with:

“...and I think what you need...is a ...is a plan to gently start moving. Most patients will know very quickly if they’re getting neural compression” (Radiologist 1, FG1; p5/22)

To deal with this situation, a plan for early mobilisation was thought to be necessary. A palliative care nurse added:

“I think it is like any other sort of life changing events because it’s not ever one conversation you can have with people. It’s about what does this mean to me and that is gradual. So, it’s having that conversation reinforced” (Palliative Care Nurse 1, FG1; p9/20)

There was a call to have an ongoing conversation and explore the patient’s understanding of his/her condition. Along these lines, another member of the group reinforced the view:

“...and I think as long as everyone is saying the same thing when they are having all these conversations.” (Physiotherapist 1, FG1; p9/27)

This excerpt suggests that it is important that healthcare professionals provide the same information to patients and in doing so mitigate the chance of giving conflicting information.

A step-wise approach to check the patient's understanding of their condition was suggested:

"I think as well, given that the patient is going through the Cancer Centre and they hope along somewhere where it's sort of following that patient through how much they have actually understood and this sort of step approach." (Project Manager, FG1; p9/34)

Another participant considered:

"Perhaps the care pathway needs a big box on it of what patients have been told...so that they can then say the same thing again or change it if it's a new message" (Radiologist 1, FG1, p9/30)

Nevertheless, clarifying and checking for understanding was essential. Having a conversation about prognosis with patients can be challenging – from giving unrealistic expectations to managing expectations. A radiologist queried:

"Do you think we offered unfounded expectations though? You know, the evidence all points ...all the evidence said that if you got bad deficits before you start treatment your chance of improvement are very low" (Radiologist 1, FG1; p8/37)

Another member of staff thought sometimes patients could be in denial and be selective in retaining information:

"I think patients want to hear what they want to hear cause I have been there when doctors have been saying 'right...now you had your five lots of radiotherapy we don't really think there's going to be awful lot of improvement' and then they go away and you are left and the patient says 'so, when will I be up walking again?'"(Physiotherapist 1, FG1; p9/1)

Developing a coping mechanism seems to be exhibited by the patient by selective listening or blocking out the negative information or they may not understand the significance of statements about improvement and the finality of this.

However, the issue of whether patients have any information about long term or likely future symptoms and the problem of who breaks the bad news, highlights the difficulties in the conversations. The occupational therapist commented:

“I think part of that communication is not to deliver the expectation to the patients of getting...um...lots of care from lots of different people where they might not get it. So, realistic expectation of care I think is quite important” (Occupational Therapist 1, FG1; p13/20)

On one hand, healthcare professionals seem to offer hope but on the other, suggested not to deliver expectations that cannot be met. The occupational therapist explained:

“We start preparing them from the ward for where things are going to go. Quite often it is us that are sort of breaking the bad news about their functional status not improving. But quite often that’s because you are forcing them to consider leaving hospital and what the implications of that are going to be” (Occupational Therapist 1, FG1; p14/27).

The account indicates that patients may not have been informed about their future deterioration of their function and therefore unaware of its implications. Moreover, information about likely future symptoms depends on treatment outcome. One oncologist described a dilemma:

“I think it’s quite a common problem that patients and carers want- to know what lies ahead-quite specifically - and will ask you...you know, what exactly is going to happen. When we as healthcare professionals know that it’s very difficult to predict as there are a number of scenarios and is it appropriate to tell them all the different scenarios or just wait and see what happens. Sometimes people want to tie you down to be very specific as to when exactly, how many months, or what exactly will happen to me, or what exactly can I expect. I think it’s a difficult conversation to have. Not always that helpful” (Oncologist 1, FG2; p14/13).

It is likely patients want information about their future and this can be a difficult conversation to have with patients. One participant suggested:

“...and let patients and carers understand that sometimes things are uncertain and also where goals might not be, you know, set in stone...we will try to, you know, people will understand if they know the boundaries.” (Palliative Care Nurse 1, FG1; p13/32)

This account suggests being honest with patients about the uncertainty of the disease and treatment.

Continuity of care and availability of rehabilitation services is an important issue and it poses some dilemmas for allied health professionals.

“...we...um...treat patients in very acute phase and if patients need further input from a therapist, then depending on where they live, if they live in the west of the region, for example, there’s a rehab team that would pick them up and do work with them at home” (Occupational therapist 1, FG1; p1/28).

This comment suggests that rehabilitation services are variable and inequitable. There is a perception that a hospice provides rehabilitation, as voiced by another participant:

“But you know the reality is that hospices aren’t taking anybody for rehab, its palliation, you know, palliation with a short (time) span” (Nurse Practitioner 1, FG1; p2/19).

There seemed to be a lack of rehabilitation services to help patients cope when discharged home to the community.

“I think it’s part of the changing role of the hospice; the recognition of the difference in the generalist role as well specialist palliative care...but actually most of the rehab required is...it should be able to be provided for people in general with spinal cord compression, unless there are other sort of extremely unstable bits on top of them” (Palliative Care Nurse 1, FG1, p2/28).

This excerpt implies that rehabilitation should be embedded in practice. Suggestions that on-going care should be looked at and be provided on a personalised basis, and should involve family, were the views held by some of the healthcare professionals. However, the nursing staff would refer the patient to the physiotherapist for rehabilitation. A charge nurse said:

“I think you have to take each on an individual basis. We often refer them on areas like yourself, you know, for the treatment [referring to the physiotherapist]. So, it’s generally from your service that they would go to rehab” (Charge Nurse 2, FG2, p12/21).

This suggests different levels of decision making in identifying and arranging a patient’s rehabilitation needs. The physiotherapist commented:

“...I think there’s huge impact how you are going from A to B in a new way when they are dealing with everything else and then this acute environment is very challenging....got so many different services coming in giving information and you can see they are completely overwhelmed

and the ones who have family support or younger families and you know, they obviously are going to cope better than maybe somebody with one elderly spouse but they have the issues where do they go from here” (Physiotherapist 2; FG2; p12).

The above quote suggests that patients can feel overwhelmed dealing with their condition in an acute ward setting. It is thought that younger patients with support coped better than the elderly.

Another member of the focus groups said patients may not know what to expect until they have left the acute service:

“I think it’s when the patient is home that suddenly they are away from the safety bubble of the hospital that suddenly a lot of these questions come out. It’s who they then go for support in that instance. And if they’ve gone through the palliative services they have got that mechanism of support...but [pause] there are patients that don’t, they just get everything set up and discharged home” (Occupational Therapist, FG1, p9/39).

Understanding of the implications of their condition might not be apparent to those affected until they go home and they might not necessary have access to palliative care services.

Another problem in receiving rehabilitation in the community is to do with age cut off. There seems to be controversy with this aspect.

“Patients under 65 and generally, it’s the myeloma cord compressions, you’ve got a good chance to get them into the local rehabilitation. [...] So, it’s over 65s that we struggle with more” (Occupational Therapist 1, FG1; p10/36)

In contrast, a medical staff member felt otherwise:

“Over 65’s will be easier because geriatrician will take on that. Well, they may be less keen to take patients under 65 because they can’t be sent to a nursing home” (Senior House-Officer1, FG2; p12/36).

Some participants provided the view that patients over 65 have problems getting rehabilitation while others think it’s the under 65’s who have this difficulty. An oncologist did point out that in relation to the provision of rehabilitation:

“It’s a problem actually. We had two patients who I’ve mentioned already who were paraplegic. Both patients went to [name of local rehabilitation hospital] but a little bit grudgingly from the point of the view of rehabilitation physician...um...not sure whether it’s necessarily an ideal place for them. So, both patients, they did have access to rehabilitation but there is nothing very specifically for this group of patients. I don’t think there’s any...there’s no one in [name of city] with special interest in rehabilitation of spinal cord compression” (Oncologist 4, Individual interview, p8/31).

Although rehabilitation is deemed important for patients, the rehabilitation services provided may not meet the needs of patients with MSCC. A participant voiced a significant setback:

“The community rehabilitation team here don’t really categorise cancer as a condition that is going to improve, basically. There is the odd occasion if they are not busy, they will consider taking a patient on. But on the whole, that’s their ruling, for example, the group of patients that are stroke patients are going to improve” (Occupational Therapist 1, FG1; p11/16).

This comment suggests that obtaining rehabilitation support for patients with MSCC was challenging due to the nature of advanced cancer.

Likewise, in the community setting, some of the participants reported that there is no domiciliary rehabilitation service available. Patients have to travel to the nearest district hospital or local health centre for physiotherapy services. A general practitioner commented:

“...with the vast majority of people, they have to travel to a hospital, or if there is a physio department in their health centre, they would go there.” (General Practitioner 1, FG3; p18/8)

This indicates variations in the availability of rehabilitation for patients with MSCC. A palliative care nurse added:

“There’s only one sort of part-time specialist palliative physio, but, you know, her remit is sort of within the hospital and it is very unusual for her to come out and do home visits. Which means, you’re relying on generalist staff, I guess, in what might be a very complex situation at home...” (Palliative Care Nurse 2, FG3; p17/21)

This suggests that patients may not receive the appropriate rehabilitation support specific to MSCC.

Matching the level of rehabilitation was further suggested by a participant:

“...um...and the idea of seeing whether some sort of community based team could be focused on this area. [...] I think it’s an overwhelming experience for patients, doctors and the community staff, yet the patients want to get home” (Neurosurgeon 1, FG2, p17/3).

It appears that for patients who want to go home, it poses challenges for all stakeholders. A joint hospital and community based team specific to MSCC was proposed. Another consideration was put forward:

“I think to consider a pilot of as a joint hospital community based team that provided the resources for this group of patients, particularly one or two beds set aside for intensive rehabilitation where patients with cancer who we will know will have a better outcome, we should provide services to individuals who we know will benefit” (Oncologist 3, FG2; p17/25)

However, implementing a joint hospital community based team could be problematic, a hospice director pointed out:

“I don’t think it is sustainable and I don’t think you’ll get funding for it. So, I think the best support for these people is by using the existing generic services. [...] the existing model is primary care team, GPs, district nurse, community physiotherapist, occupational therapist, social work...um...or organised integrated with support from especially from palliative care if or when required. If you try to develop a small team for what is a rare condition...err...you run into issues of sustainability and um...geography, which you can’t overcome” (Hospice Medical Director, Individual interview, p8/17)

The feasibility of a community based team specific to MSCC was considered as not sustainable. Moreover, it was thought that patients would be best supported by the existing generic primary care team. Another participant added:

“I don’t think we need a separate team, I think it needs to be embedded in the current community team” (Head of Cancer Services, Individual interview, p12/1)

This comment suggested that the community team need appropriate education embedded in their core training to support the patient.

One of the members suggested early recognition pre-cord compression is important:

“We know that this is a high risk group and what kind of education do we give that group of patients in trying to prevent...um...the devastation that can happen” (Project Manager, FG1, p3/1)

Recognising and giving education to patients who are at a high risk of developing MSCC was suggested. Often a patient’s diagnosis of MSCC may be delayed in the hospital setting: An oncologist highlighted:

“I think it is also educating other healthcare professionals, for people also sit in the hospital for a long time with symptoms and it takes a long time for that to be picked up” (Oncologist 1, FG2, p11/23)

The excerpt suggests healthcare professionals out with oncology may not recognise signs and symptoms of MSCC. Therefore, education can highlight the urgency of referring patients for early treatment. Also to get early referral depended on patient presentation in the community.

A charge nurse commented:

“It also depends in the community, you know, how quickly the symptoms are picked up. Somebody lay off their legs and some sat there for three weeks being completely bed bound by the time they waited until something’s being done. Other people were picked up very quickly with just minor symptoms with back pain but presentation of getting their back pain done at that point in time is very difficult” (Charge Nurse 3, FG2, p11/16)

This suggests the difficulty in recognising the early signs and symptoms of MSCC in primary care. However, the neurosurgeon gave his view on identifying MSCC in the community:

“And I think it is ok for us to sit here and criticise someone not diagnosing someone with spinal cord compression. You know, you could have, say, ‘how they missed it?’ If you were involved in the process in a helpful way you are more likely to get them involved even if they see one or two cases you could help” (Neurosurgeon 1, FG2, p17/38)

This account suggests that instead of putting the blame on others, working together is more appropriate to address the issues of identifying MSCC early. General practitioners pointed out:

“Well, in the same period of time [similar to another GP’s 20 years career] I’ve diagnosed one and suspected possibly two which haven’t been confirmed on further investigation” (General Practitioner 3, FG3, p3/1)

General practitioners from three different health boards reported seeing few patients with MSCC in their career. They talked about seeing patients with back pain on a daily basis. General practitioners agreed that giving information to the patients before presentation was important:

“I think the other issue is, before presentation, it’s about giving information so that patients will present if they get symptoms that might indicate that if they don’t do nothing or delay but as [refer to palliative care nurse 2] says it’s getting the balance between giving them enough information to be able to do that but not frightening them as most cases with cancer will not get it” (General Practitioner 1, FG3, p14/17)

Getting the right balance can be difficult. When asked whether it was easy for them to recognise the symptoms of MSCC:

GP 1: “No! [Everyone laughs and talk at the same time].

GP 3: Technically, it should be – it’s easy in theory what the symptoms are; but we don’t see it very often and it never presents classically, does it? [Asking other colleagues]” (General Practitioner 3, FG3, p5/3)

The general practitioners accounts suggest recognising the signs and symptoms of MSCC can be challenging. Another general practitioner also conceded:

“One of the criteria for suspecting cord compression that we use is severe progressive pain, and that’s one of the ones that I personally find quite difficult because a lot of people with bony metastasis, for example, have got a lot of that pain anyway. With metastasis, they’ve got pain, they’ve got tenderness and at what point do you actually say well this is different; this has now changed such that I have to suspect cord compression and need to arrange for an MRI scan? That...that can be a tricky one, and that’s one where I prefer to err on the side of safety and phone for guidance, rather than sitting back and wait” (General Practitioner 5, Skype interview, p17/35)

It is notable that patients with bony metastases suffer pain and differentiating the new pain can be difficult. However, the patient’s safety was the main concern. This account suggests that the GPs would have to trust that their

colleagues would make the decision. One oncologist explained that sometimes identifying the symptoms of MSCC can be challenging:

“Well, if they’ve got cord compression, they can just have straightforward back pain; they can have radicular pain; they can have pain when they cough, or pain when they strain. They can have pain – shooting pains down their legs with a spinal nerve compression, so it varies. But the typical radicular pain that you get with impending cord compression isn’t always there” (Oncologist 6, Individual interview, p/8)

The general practitioners reported that their awareness on MSCC was raised from them receiving the local referral pathway by e-mail.

In one health board, education was organised through protected time- where NHS 24 and the locum took over the running of the surgery and the GPs would attend workshops. One general practitioner commented:

“So, making it easier for GPs having to decide ‘should I refer the patient to the orthopaedic surgeon’ or ‘should I refer to the oncologist’ or ‘should I refer to the urology surgeon’, or whoever, just one central point say, the patient may have spinal malignancy and it will then be dealt with” (General Practitioner 4, Individual interview, p4/19)

General Practitioners found decision making was easy with the referral pathway in each health board.

With regards to education, one of the GPs said:

“...small discussion groups I think work the best. GPs like learning with their colleagues and they also like the opportunity in a small group to be with the specialist from the hospital to discuss the issues. And also, it helps to have that personal contact because then, if you do have a problem, you know the person you’re phoning up, and that makes it easier. The discussion groups work best when they’re sort of semi-structured, so there may be a sort of small presentation but there’s also – should be plenty of time for discussion” (General Practitioner 1, FG3, p21/16)

Some general practitioners talked about the follow-up of their patients and had regular meetings with their community nurses.

“Cancer patients I would see on a regular basis, especially the palliative care set-up; we have regular meetings where we discuss every case and

we usually – very often the district nurses are involved and they're the ones who have got the day-to-day contact with the patient" (General Practitioner 5, Skype interview, p18/14)

However, there are variations on the level of funding for psychological services.

One general practitioner commented:

"...the availability of psychology services across [the local area] is patchy. And, again, one of the things NHS has been plagued with over the last few years is ...err...incentives, or initiatives –ring-fenced money, err, and so what you find is a pot of money has come in which has allowed a bit of the services to develop. Err...but you never got the money to roll that service out to the whole health area" (General Practitioner 4, Individual interview, p15/13)

This account suggests that psychological needs of the patients may be neglected due to funding issues.

In summary, participants acknowledged that MSCC is a life changing event. Patients can be admitted through different pathways. Giving bad news to patients and carers is challenging and psychological support is patchy and provision of rehabilitation is variable depending on the patient's age, diagnosis and geographical area. There are suggestions of the need to achieve consensus on the care of this group of patients as a team. Healthcare professionals are aware about the care needs of this vulnerable group of patients but faced many difficulties. Amongst them are the gaps in the support and continuity in their care. Some strategies were recommended in order to move forward in the care of patients with MSCC. Aspects of a tailored care included; a plan in commencing mobilisation, effective communication, realistic management of expectations and personalised care while at the same time not removing hope from patients. The healthcare professionals acknowledged there are different groups of patients with different needs depending on their primary cancers and prognosis. Although there was suggestion of a joint hospital community based care team specific to MSCC, it was thought this is not sustainable. However, education recognising the early signs and symptoms of MSCC is important.

4.7 Chapter summary

In conclusion, this overarching theme and four themes provide valuable insight into how healthcare professionals manage and care for patients with MSCC. MSCC is a challenging condition with uncertainties surrounding the diagnosing of spinal instability, treatment and management. There was a notion of fear in making decisions around commencing mobilisation; so there was a tendency to play safe in the care of patients. However, the healthcare professionals recognised the needs of the patients and the consequences of immobilisation and there was evidence of making trade-off decisions. There is lack of guidance in terms of surgical, medical and radiological treatment but the need for individualised care is acknowledged. Another concern was raised regarding those patients who were admitted with unknown cancers. Rehabilitation services are variable and depend on the patient's age and geographical area. Some participants suggested a community based team to cater specifically for this group of patients; however, this service is provided in the community.

Education to healthcare professionals and patients on the early signs and symptoms of MSCC was emphasised. General practitioners see very few patients in their career. Identifying the classical signs and symptoms of MSCC is not easy as general practitioners see patients with back pain on a daily basis. However, they found the local referral pathway easy to follow. The overall theme seems to revolve around negotiating for a care pathway specific to MSCC. The majority of participants suggested that it was important to consider the patient's perspectives, what are their priorities, and what is important to them and if their needs were met.

Chapter 5: **Across-case findings**

5.1 Introduction

This chapter presents my findings developed from Phase Two, the accounts of patients, carers and key healthcare professionals involved in the management of metastatic spinal cord compression (MSCC). Figure 15 provides the levels of abstractions in Phase Two findings (details of across-case analysis in Section 3.9.5). Level 1 shows the three themes and nine sub-themes: facing uncertainty in MSCC; finding a balance in the uncertainty of MSCC; and support beyond the treatment of MSCC. It became apparent from the analysis that stakeholders faced uncertainty (of the future) and enduring inconsistencies (of information, treatment and advice for the future) (Level 2 abstractions). The details on the main focus of findings can be found in Table 9.

Firstly, an example of a single case finding will be described to illuminate the multiple perspectives of a theme. Following this the across-case findings will be presented with an introduction to each theme, an analysis of the finding is discussed which incorporates sub-themes containing the participant's and my first level interpretation of the accounts.

Figure 15: Levels 1 and 2 abstractions of Phase Two findings

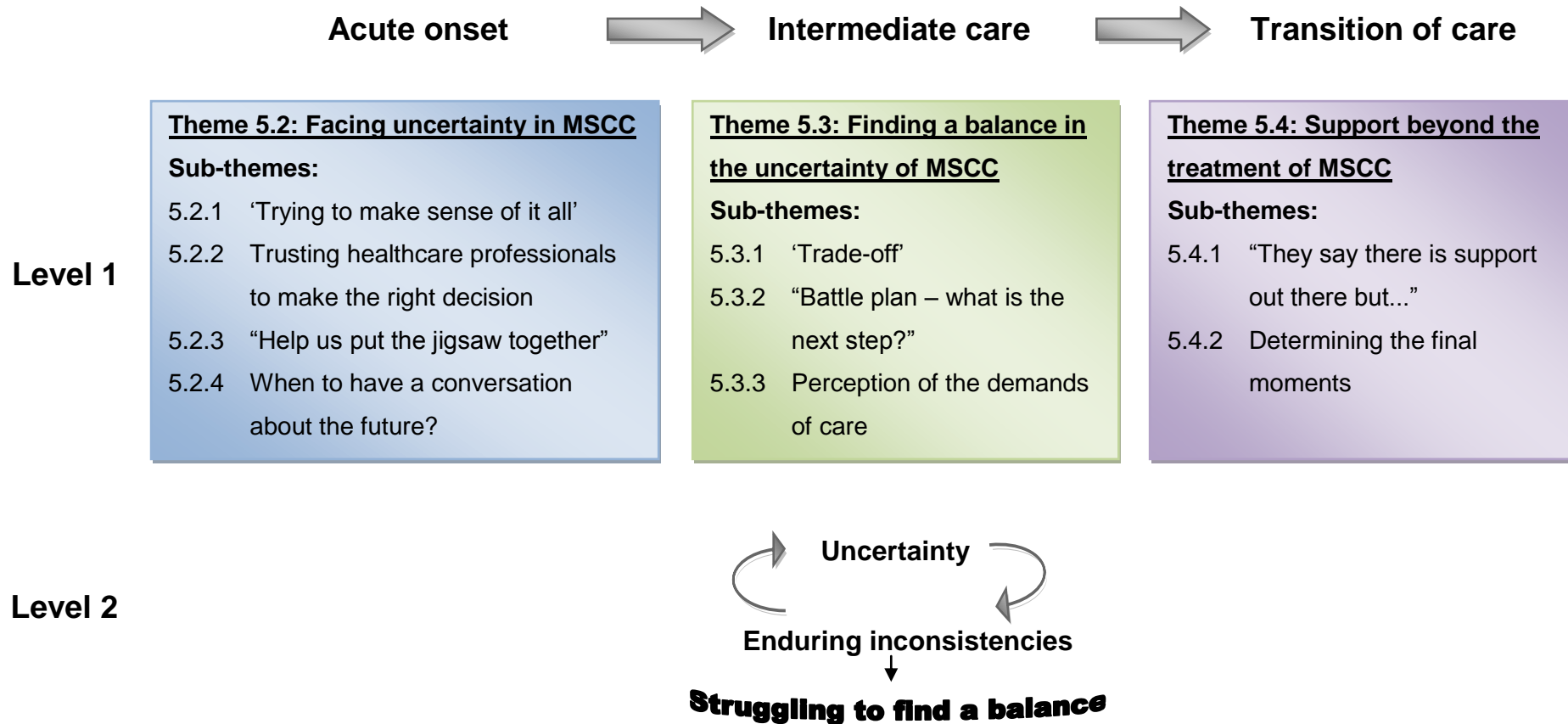


Table 9: Themes, sub-themes and main focus of findings		
Themes	Sub-themes	Main focus of findings
5.2 Facing uncertainty in MSCC	5.2.1 'Trying to make sense of it all'	<ul style="list-style-type: none"> • Recognising and interpreting signs and symptoms at the acute onset of MSCC can be complex
	5.2.2 Trusting healthcare professionals to make the right decision	<ul style="list-style-type: none"> • Emergency decision-making on treatment • To 'bed-rest' or 'not to bed-rest'
	5.2.3 "Help us put the jigsaw together"	<ul style="list-style-type: none"> • Timely information
	5.2.4 When to have a conversation about the future?	<ul style="list-style-type: none"> • Facing uncertainty of losing mobility • How long is life?
5.3 Finding a balance in uncertainty of MSCC	5.3.1 'Trade-off'	<ul style="list-style-type: none"> • Treatment options versus quality of life
	5.3.2 "Battle-plan – what is the next step?"	<ul style="list-style-type: none"> • Seeking a life line – hopes and treatment options
	5.3.3 Perception of the demands of care	<ul style="list-style-type: none"> • Reducing the demands of care
5.4 Support beyond the treatment of MSCC	5.4.1 "They say there is support out there but..."	<ul style="list-style-type: none"> • Changing priorities • Adjusting to disability • Variations in group support • Relationship dynamics
	5.4.2 Determining the final moments	<ul style="list-style-type: none"> • Monitoring of tumour • Difficulty living with cancer • Anticipating the final moments and letting go

5.1.1 A single case findings illustrating the multiple perspectives of a theme (Case Study 2)

This single case initially illustrated the theme of 'facing the unknown' and was later refined to 'facing uncertainty in MSCC'. This is a descriptive account of a single case giving a picture of the impact of MSCC and the multiple perspectives in a theme. The theme 'facing uncertainty in MSCC' was perceived by Sandra (Case Study 2) as not knowing what was going to happen next and what the immediate future held for her and her family.

This theme permeated her husband's perspective and posed a challenge for healthcare professionals when faced with the unknown. Sandra had metastatic breast cancer and had accepted that her cancer could not be cured but could be managed. Sandra had a fall in her garden and sought advice from her GP. However, it was thought the pain on her back was the result of the fall. It was during her normal follow-up appointment for her breast cancer that a routine scan showed early signs of compression. The sudden discovery that the tumour had spread to her spinal column caught her off guard. She was quickly transferred to the cancer centre about 130 kilometres away from her local hospital to receive urgent radiotherapy. Table 10 illuminates the multiple perspectives in this theme.

Table 10: A single case study illustrating the multiple perspectives of a theme – Facing uncertainty in MSCC

Patient	<i>“I am confused and concerned and the anxiety would come from not knowing what’s going to come next. You know, you don’t know what pathway the illness is going to take. You don’t understand how quickly it’s going to go, where it is going to go, how it’s going to be managed and it would...it seems that there are so many different variations in individuals that no one can actually give you a definite answer” (Sandra, 1st interview, p1/11)</i>
Husband	<i>“All this types of cancer, what is the average life expectancy? But when you get diagnosed with cancer at the moment they can’t tell you because it is a sixty million dollar question. When you get it, you say to your consultant ‘how long have I got?’ They will turn around and say we cannot tell you because your personal reaction would be different from somebody else. There must be somewhere down the line they would be able to say ‘well...’ or whatever” (John, Sandra’s husband, 1st interview, p21/22)</i>
Registrar	<i>“Um, it’s very difficult, especially with breast cancer. We’ve got ladies that are eight and ten years with bone mets. And with Sandra, it was a bone mets that was just very slightly starting to cause compression, so it’s difficult to say that things are going to be completely different from how it would be with ladies with bone mets. But then, um...if somebody’s got spinal cord compression that’s really quite severe, I think the prognosis is about six months... So, it’s difficult...it’s very difficult to give an overall figure. You’ve got to think about the patient themselves and how well they are for other treatments that might help. So, yeah, it’s sort of patient-basis” (Registrar, p15/21)</i>
Patient	<i>“I got to a point where I wanted answers, but I didn’t know what my questions were. You know, I didn’t actually know what I wanted to know” (Sandra, 1st interview, p24/30)</i>
Nurse	<i>“Any questions I would answer if I knew but if it’s to do with the kind of ins and outs of spinal cord compression, I would get the doctors to speak to her. I don’t feel I have enough knowledge on the ins and outs. I think medical staff should do that” (Nurse, p8/2)</i>

Oncologist	<p><i>“She’s symptomatically better and we talked through her experience. I’ve known her for quite a...obviously since her relapse. She has a lot of issues dealing with err...you know, the fear of the future was going to happen and the fact that living with metastatic disease and even though we have emphasised that this is low volume, good prognosis, prognosis is not prolonged but it’s not...ultimately the disease is likely to...it’s going to catch up with her” (Oncologist, p4/28)</i></p>
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The across-case analysis of the interview transcripts yielded three major themes: facing uncertainty in MSCC; finding a balance in the uncertainty of MSCC; and support beyond the treatment of MSCC. The findings are discussed across the 8 case studies below.

5.2 Facing uncertainty in MSCC

Data illuminated uncertainty as a central concept from the accounts of patients, carers and healthcare professionals when trying to interpret symptoms during the acute onset of MSCC. The accounts in the first sub-theme showed that patients felt confused and distressed in trying to make sense of the changes in their body and the impact it was having on them as a person.

Healthcare professionals described facing competing perspectives and encountered complexity and ambiguity in making a diagnosis whilst urgent treatment decisions had to be made. Due to the threatening nature of MSCC and the unpredictability of paralysis, sub-theme two showed how patients and their carers put their trust in healthcare professionals to make the right decision to relieve the symptoms at the onset of MSCC. Sometimes these decisions or a change of decision on the treatment and management were not explained to the patients. Sub-theme three demonstrated the impact of conflicting information on the patient’s immediate care. Once uncertainty was resolved at the acute stage, other uncertainties emerged and sub-theme four described patients and carers anxiety and distress at the lack of information on treatment options and future changes to their health status. What now follows are the accounts of

patients, carers and/or family members and healthcare professionals in trying to make sense of the signs and symptoms of MSCC.

5.2.1 'Trying to make sense of it all'

This sub-theme illustrates that patients were trying to make sense of their symptoms and often did not know or understand what was happening to their body. Jimmy had on-going pain from his previous thoracic surgery for lung cancer. On this occasion, Jimmy recalled his distress when experiencing mixed symptoms of pain, tingling sensations and described feelings of “*bugs creeping inside*” his sternum area. He expressed not remembering when he saw his GP but described his state of mind:

“I really don't know – maybe six weeks, two months. You can't...a lot was going on in my mind. If you meet people like that [relating to himself]...the mind is confusing, confused you know” (Jimmy, patient (CS3), Interview 1, p5/25).

This account illustrates that the symptoms experienced by the patients can be distressing and confusing to the patient and they may not recognise the significance of these. Jimmy credited his GP for his investigations, a number of radiological tests and a biopsy which detected that his lung cancer had spread to his thoracic spine causing pain.

When Sandra experienced pain in her back, she thought it was due to a fall in her garden. As it coincided with her fall, her GP was not unduly worried. On reflection, Sandra was trying to relate wobbly feelings in her legs to her hormone therapy for breast cancer:

“But I was having dizzy spells with the Arimidex and my legs sometimes felt a bit [pause] wobbly. Some days I'd feel wobbly, as though I was going to go down or I was going to faint, but I didn't faint but I felt as though I was going to faint” (Sandra, patient (CS2), p6/9).

This comment suggested Sandra was aware of changes in her body but did not suspect recurrence of cancer until her routine appointment with her consultant. In contrast to Jimmy's and Sandra's accounts of experiencing pain, Emma talked of her shock at her sudden loss of balance while doing her shopping:

“Just walking at the shops and was going back out to the car. I was starting to get a bit lethargic...err...because I have been on chemotherapy. Err, I was starting to feel a bit lethargic so I walked back to the car and that was when I lost my balance. I fell but I wasn’t dizzy or anything. It was just my legs just wouldn’t move” (Emma, patient (CS6), interview 1, p3/15).

Emma related how she got her mobility back and drove home. That night she attended her friend’s hen night but sat all night. She had movement in her legs and was walking with furniture support. Emma attributed her loss of balance to chemotherapy side-effects:

“Because I was on a trial drug, I thought it was a mixture of everything between the chemotherapy, the trial drug. I didn’t know what to expect with everything so I just thought I’ll wait till Monday and see what happens” (Emma, patient (CS6), p7/1).

Emma recalled feeling numbness from her chest area to her abdomen two weeks prior to her fall. Although she was worried at not having the sensation to go to the toilet, she was, at the same time, having small urinary accidents and reassured herself that there was urine coming out. She brought up her concerns to her doctor during her chemotherapy session:

“I had spoken to the doctor at my last chemotherapy err...who had done my medical that day. And I had mentioned it to him and he had just said ‘we’ll keep an eye on it’” (Emma, patient (CS 6), Interview 1, p9/1).

This sense of a sudden loss of control over body movement and function drew attention to the unpredictability of MSCC which was mistaken with the side-effects of chemotherapy. However, Emma’s husband Matthew persuaded Emma to seek medical advice when she had the fall. He summed up his worries:

“Ehh...I had been at her for days...nagging her for days to come in either to the hospital or go to the doctors. Erm...cause I see things happening to her that she’ll pay no attention to, she’s quite bullish at times and just gets on with things. I tend to get angry and frustrated; it can be frustrating dealing with her at times, she can be that stubborn. The fact that she had had a few falls and was, it seemed to me, she was losing the use of her left leg. It was just a kind of worry seeing that” (Matthew (CS6), interview 1, p24/21).

This comment suggested that patient’s spouse’s may be vigilant and could recognise the deterioration in their loved ones but patients, on the other hand,

may not realise the seriousness of their condition. In these excerpts there seemed to be difficulty in distinguishing the trajectories of cancer and the side-effects of chemotherapy.

Emma revealed her annoyance that she was not made aware by the trial nurse that her cancer had spread to her bones at the time of receiving chemotherapy:

“...but what I did discover in June (two months ago) I was meant to be told that I had cancer cells in my spine but I wasn’t told that. If I had known that I would have been in before” (Emma, patient (CS6), Interview 1, p14/15).

This suggested that the patient was not aware about the progression of her cancer and hence did not seek treatment early. She would have taken action if she had been made aware of what the changes in her body could mean.

Patients may have existential fears, as illustrated in Richard’s case:

“...it’s really; it’s not pain that’s what concerned me. Cause I thought ‘is it the spinal cord itself - I don’t know what’s happening to it’. ‘Am I going to be like that I got to go?’ When I am going to end up in the wheelchair cause I cannot move my back and carry on. I was very concerned and distressed and agitated at that particular time, cried quite a bit” (Richard, patient (CS5), p13/3).

Richard who had regular follow-up at his local Macmillan Centre had been informed by his Macmillan nurse to look out for symptoms of MSCC, however, he expressed not wanting to “*push things further*” as he had fears of the unknown and felt distressed.

Sandra also talked of her experience on the ward with other patients in the bay with MSCC but who were at an advanced stage of cancer. Sandra expressed her anxiety:

“...like the lady next to me that’s got it in her spine and she is saying she’s dying. I’m listening to her day in, day out, and I don’t want... The thought of being like that is really anxiety for me...umm...just being immobile...” (Sandra, patient (CS2), Interview 1, p15/24).

Here, the ward environment seemed to contribute to the Sandra’s anxiety when she encountered other patients at an advanced stage of cancer who may have

been paralysed and/or in the final stages of the illness. She confided her uncertainty about her future:

“Lost at sea. I am confused and concerned and the anxiety would come from not knowing what’s going to come next. You don’t know what pathway the illness is going to take” (Sandra, patient (CS2), p1/11).

Sandra’s account suggested she had ‘a snap shot’ of her future in front of her although she was not entirely sure what might happen which was distressing for her. Her husband considered that although there were other cancer patients, he felt that something should have been done about this matter. Healthcare professionals on the other hand were not aware of the impact of the ward dynamics on the patient’s experience. The registrar explained:

“Um, but we didn’t realise it during her stay; she didn’t mention it and the nurses didn’t mention it. So, she stayed for the whole time being worried about – essentially, she was worried that she would end up like these other ladies. But she didn’t...we didn’t pick up on that during her stay, which is unfortunate, because we could have maybe moved her to a different room or reassured her that her situation was different” (Registrar, CS2, p14/22).

These data suggest that the ward environment can have a negative impact on patients or may potentially lead to poor understanding of their own condition. The registrar was not aware that Sandra had been moved from a two-bedded room to the bay to make way for a patient who became poorly. A member of the nursing staff gave her reasons:

“...sometimes we need to change like it could be we had to bring in two men into that room...some could be poorly and they needed to be by themselves. We move patients so often here, err...so that’s why they move her to the 4 bedded room...various reasons” (Staff Nurse (CS2), p7/9).

This suggested that staff had to prioritise the needs of the patients without realising the impact it had on other patients. The patient’s ward experience led to worries and distress as Sandra related recurrent nightmares after her discharge home.

Robert had a similar pain in his back a year ago and was treated for MSCC. Robert commented on his first episode *“I thought it was killed off”* and was surprised his pain came back suddenly while travelling on the bus:

“It started off with I was coming from my son’s house, err...in a mini bus and it was one of these rounds, very fast and that was when the pain shot right up on my back” (Robert, patient (CS4), interview 1, p2/24).

Robert’s account suggested the symptoms may not be prominent until certain movements triggered off the pressure on the spinal cord. However, Robert took remedial action by taking pain killers and applied a hot water bottle to ease his pain. According to Robert’s consultant MSCC can recur:

“To have cord compression the second time at the same site, again is unusual. So, this is an unusual situation. It does happen, but it’s not a common situation” (Oncologist (CS4), p2/6).

Jane, Robert’s wife, seemed puzzled with this second episode of pain:

“I just thought it would maybe be a one-off thing, you know. I did not know it was going to...come back again, you know” (Jane, wife (CS4), p10/7).

MSCC can recur and this presented challenges for patients, carers and healthcare professionals. Patients and carers may not necessarily be aware of the possibility of recurrence and what actions to take.

Jane explained further:

“At first, I thought he had done something wrong, you know - at first. But, as time went on, that would be about two weeks – it wasn’t severe pain, it wasn’t a severe pain; it was there and then, with his medication, it wasn’t there, you know. But it was when it started to affect his legs that I had an idea then that there was something more wrong” (Jane, wife (CS4), p10/27).

Jane appeared to be trying to make sense of this second episode and, as it occurred during the weekend, consulting her GP was not possible. Her uncertainty prompted her to take action:

“I spoke to my daughter-in-law and I explained to her. I said ‘well, I don’t know what to do – whether to phone NHS24 or what to do?’” (Jane, wife (CS4), p12/6).

As illustrated, carers could be the ones who make decisions whether to seek medical help for their spouse. Jane explained that she was the decision maker as her husband was sometimes forgetful. She was hesitant in phoning NHS 24 due to past experience of having to “*explain all over again*”. She also felt her husband would not necessarily receive a medical visit, and she may just be instructed to increase her husband’s medication.

While some patients were able to voice their concerns to their doctors, some were not. Betty seemed to have difficulty articulating how her symptoms developed. Betty, who was diabetic, had difficulty convincing her doctors that something was wrong with her and had been seen by one doctor after another. Betty expressed her dilemma:

“I kept saying to them ‘I’ve got a urine infection’ because I was prone to urine infections. But we got a locum doctor in, they dismissed that and then they would give me somebody else. And the pain started travelling up the body, from the bladder up and then into the ribs and this isn’t normal. I know a doctor knows exactly how your body works, but nobody else would understand it, and if you tell her this and ‘I want to tell her this, and what do I tell her first?’ So you’re kind of in a quandary” (Betty, patient (CS1), interview 1, p2/7).

This excerpt also indicated that symptoms of MSCC can be vague and be mistaken for other conditions. In Betty’s case, she had no history of cancer and therefore it did not flag up any suspicion.

On the other hand, sometimes general practitioners found establishing history from elderly patients challenging. One general practitioner considered his dilemma:

“Obviously, you don’t want to put people to a lot of trouble, sending them all the way to the hospital if there’s nothing there. But having said that, at the back of your mind, you’re worried because you know that time is very important in this sort of situation, and somebody could end up paralysed if you don’t act quickly. [...] to a large extent you’re often operating on history because often the physical signs are not brilliant, you know. There is a degree of weakness, but we’re talking about elderly patients who have osteoarthritis, and it can be quite difficult to work out” (GP (CS4), p4/17).

This comment indicated physical signs of MSCC can be vague and that obtaining history is important but may not be easy, especially from elderly patients who may be confused or may have co-morbidities.

At times, patients may not have realised they had a problem. For example, it was Jock's general practitioner who suspected something was wrong with him during his routine appointment for flu vaccination. Jock had a good relationship with his general practitioner who had been monitoring his prostate cancer over the years. His general practitioner noticed that Jock was unduly breathless as he walked through the waiting room and decided to bring him in for further investigations.

“Well, from a clinical point of view, the issue at that point was really one hundred per cent chest. I had an x-ray that told me there was something wrong with his lungs, but it didn't give me a firm diagnosis. His breathing got worse and worse and worse. He did, at that point, start to have some pain in the left side of his chest and – that, I think, was around the nipple area. But events were dictating that he had to go to hospital, more on the account of his breathlessness than any pain at all. It was more of a localised pain, rather than a radicular one. Pain has never been a huge feature for him” (GP (CS8), p5/21).

This suggested that the general practitioner was aware something was wrong but faced symptoms which were not classical of MSCC and the general practitioner may not necessarily have the experience in recognising the symptoms. As Jock had a cardiac history, diagnosis proved challenging as the general practitioner suspected it was more likely to be a degree of heart-failure. This account highlighted that the general practitioner knew the patient well to be able to notice the physical changes in him.

However, like the general practitioner, the registrar at the referring hospital also talked about the complexity in assessing and diagnosing Jock's condition. The registrar considers:

“We were trying to find a couple of things. He was obviously breathlessness and we wondered if he had had a pulmonary embolism, so that was number one. But number two was his chest x-ray was very abnormal, it looked like metastatic deposits but the radiologist felt he [the patient] may have a mixture of cardiac failure and infection. Erm, but

certainly spinal lesions were not expected because he didn't have any symptoms at all, he didn't have back pain, he didn't have weakness in his legs, he didn't have any bowel or bladder problems, erm, so yeah, that was a surprise and also his PSA was normal" (Registrar (CS8), p3/17).

The above illustrates the problems in interpreting imaging studies to reach an accurate diagnosis. Therefore, this indicated there was discrepancy in opinions between the registrar and the radiologist and arriving at a diagnosis was challenging from different healthcare professionals' perspectives. Identifying MSCC can be an incidental finding.

There were suggestions that healthcare professionals involved in the care of patients with MSCC and those working in the other speciality, for example, surgical, urology wards and primary care general practitioners and district nurses should be educated in recognising the signs and symptoms of MSCC. A member of medical staff considered:

"We do need to get everyone a bit more up-to-speed and heighten the awareness of it (MSCC), and the MSCC pathway has done that and will do it. And the education is through that; it's through protocols, and through audit – as anything else" (Oncologist (CS4), p20/28).

However, not all general practitioners were aware of the local MSCC referral pathway or the NICE guidelines:

"I haven't used the local referral pathway, I must admit. All I did, whenever I needed to refer, was to ring up the registrar on call. I don't know whether that is the referral pathway or not, I've no idea whether it is or not. And I've never seen a written referral pathway" (GP (CS4), p11/24).

General practitioners who participated in interviews were aware of MSCC and felt that educating them on MSCC was not one of their learning needs. One of the general practitioners stressed her views when asked whether they needed education on MSCC:

"Definitely not. I mean, I think we're all very aware of that. We have our [palliative care consultant], and was very concerned about anybody that might be a missed metastatic deposit causing spinal compression, so, you know, we have been well educated on that" (GP (CS8), p16/24)

The general practitioner went on to describe a system of keeping track of cancer patients under their care and staff had regular updates about patients' condition. Here, she explained:

General practitioner: Anybody that's at that level of cancer, we would work a system called the Gold Standard. Have you heard of this?

Researcher: Can you briefly explain?

General Practitioner: It's a system whereby, in our practice, what we do is we have a register of all the patients who have a diagnosis of cancer and we actually stage them. And on every fortnight, we will get together as a multi-disciplinary team and talk about the patients. So, we do look after our cancer patients very carefully (GP (CS8), p16/11).

This implied that a mechanism was in place to monitor patients with cancer in the community to ensure that patients did not slip through the net. Most general practitioners see very few patients with MSCC in their career. One of the general practitioners emphasised this point:

"I've met, what, one case in fifteen years as a GP. If I have the need (like when a patient came along with a MSCC) I'll look it up and find out about it, when the need arises. [...] There's no point in sending me flyers and stuff about it because they'll go straight in the bin with the ones that comes in everyday for diabetes, epilepsy or chronic obstructive pulmonary disease; you name it, it's here; the information...we're just completely flooded with it" (GP (CS6), p8/27).

This comment suggested general practitioners could be overwhelmed with competing conditions and information requirements appeared to be 'on a need to know basis only'. Some healthcare professionals agreed that patients and their carers should be educated in recognising the warning signs of MSCC instead of the general practitioners:

"I think it's more the patients who need the education rather than the GPs because I think if you have patients that you know and they are at risk you give them the warning signs...say 'right you need to phone us if the following happens'. Because the NHS 24 does not have that level of support so patients end up in the wrong hospital at the wrong time. Erm...it's much more difficult if you're brand new presentation of spinal cord compression, never being known to the department) and that is

something the spinal care referral pathway is meant to be trying to address really” (Oncologist (CS5), p4/26).

Several registrars acknowledged awareness was important to doctors but how education was conveyed should be done in a tailored way:

“I think tailoring who you teach it to is important. Erm, and kind of the clinical picture is important. Just teaching people about what symptoms and signs might correlate with spinal cord compression actually can lead to a huge amount of referrals with people inappropriately being referred. Whereas, tailoring education and kind of emphasis on the whole clinical picture, err, is very important” (Registrar (CS4), p13/23).

Thus, this suggested caution in giving information and the need to prevent undue alarm to those ‘worried well’ patients. However, one of the general practitioners felt “*duty-bound*” to discuss with patients what to watch out for in relation to symptoms of MSCC once it was established that the patients had bony metastasis:

“And maybe it’s hard to know at what point you say that because, you know, it’s a very long process this, isn’t it, you know; people start with prostate cancer and they go on for several years and ...with nothing much happening, you know, and if you tell them that too soon, you know, then they’ll have forgotten it by the time they need to, and it’s just really important either to tell them and keep telling them, or when you know that they’re starting to get spine pain or bone pain, to say “look, watch out for this. If this happens, we don’t wait three weeks to go in and get your radiotherapy, we go right away, you know” (GP (CS4), p13/16).

This suggested that although keeping patients aware of symptoms of MSCC was important, the difficulty was knowing at what stage to have this discussion with the patient as the trajectory of cancer can be a long process.

In summary, the interpretations from these accounts showed that patients had varied symptoms of MSCC. Not all patients were able to recognise and associate their symptoms with the recurrence of cancer and these were attributed to other causes or pre-existing conditions. For some patients the symptoms were confusing and distressing. They were aware something was wrong with their body and it evoked a sense of facing the unknown and raised existential fears. Experience as an in-patient could be distressing for some as

the opportunity for comparison with other patients with a similar condition but at an advanced stage could cause misunderstanding. Some patients appeared able to voice their worries to their doctors but others found difficulty in articulating their concerns. However, in several cases, carers expressed heightened awareness that something was seriously wrong and appeared anxious.

Healthcare professionals on the other hand, gave accounts of facing challenges in identifying metastatic spinal cord compression when neurological symptoms were not a key feature. However, there was also a sense of uncertainty when MSCC can recur. Physical signs of MSCC can be dubious and establishing history from an elderly population can be difficult. Evidence also suggested difficulties in distinguishing natural history of cancer and of clinical trial treatment. Several healthcare professionals felt general practitioners should be made aware of symptoms of MSCC. This view was contentious as most general practitioners interviewed had an awareness of MSCC but saw very few patients with this condition in their career. Education of patients and carers was also deemed important but the risk of causing unnecessary worry should be considered.

The acute onset of MSCC as a complication of advanced cancer emerged as an uncertain problem for all participants in this study, albeit from different perspectives. Amidst this uncertainty, emergency decision making on treatment was needed to preserve patient's mobility status.

The next sub-theme describes patients heightened awareness of MSCC, its threatening diagnosis and how they put their trust in healthcare professionals to make the right treatment decision and manage their care.

5.2.2 Trusting healthcare professionals to make the right decisions

This sub-theme reflected patients' and carers' trust in healthcare professionals to make the right treatment decision at the acute onset of MSCC. To preserve a patient's neurological function or treat distressing symptoms, such as pain,

urgent decisions by healthcare professionals to treat impending cord compression had to be made, sometimes without confirming where the primary cancer was or whether further tests were required. Although the oncologist is the main decision maker, data illustrated a chain of decision making from different disciplines.

Another issue related to this sub-theme centred around decisions on how best to nurse the patient during immediate care. Although healthcare professionals seemed to make decisions on positioning and mobilisation, patients and carers were not necessarily aware of this decision.

Sandra reflected on the speed of getting her CT and MRI scan and being transferred to the Cancer Centre for treatment:

“I think they are trying to do things as quickly as possible, and as speedily as possible, to limit damage. [...] I know that they’ve given me the radiotherapy – I feel reassured because the radiotherapy and the steroids have already started to take away the pain in my back. So that I know that something’s been done. So, it is reassuring that something’s been done, and been done very, very quickly” (Sandra, patient (CS2), p32/11).

Here, it appeared that the patient accepted the reason for the treatment was to limit the damage to her spinal cord and treatment had to be quick because of the threatening nature of MSCC.

Jimmy seemed to take on board the initial treatment decision and trusted his consultant to make the best decision for his subsequent treatment:

“So, I see how well I got on in the first one [treatment] and so does the doctor. So, right Jimmy we go on [repeated what the consultant told him] – we go on. [...] So, same thing again only smaller doses of radiotherapy and then that’s it. Then the consultant will decide what’s best for me” (Jimmy (CS3), p10/14).

However, the decision arrived at by his consultant was not a straightforward one due to the nature of his cancer, which was a direct invasion of his spinal canal by a local recurrence of his primary lung cancer. The consultant had a discussion with his team members to determine the dosage of radiotherapy that

could be tolerated by Jimmy's spinal cord. In this case, decision making was challenging as a high dose could result in paralysis. Jimmy appeared happy with the decision making process despite not been fully involved as he thought the medical staff would make the best decision for him.

Richard recognised the benefits of immediate treatment and he appeared less anxious. He considered:

"I don't think I can get any better treatment than I've had, it's been very quick, very prompt. I mean it happened just so quickly but that's better for me because the quicker I'm being seen, they can treat err...the cause and the better it is for me for the pain. So, it's been fine" (Richard (CS5), p2/28).

Richard seemed pleased that his pain was resolved very quickly. In contrast, Tony had "no choice" but to trust his oncologist and neurosurgeon's decision as his mobility was compromised. He rationalised this as follows:

"Ehh...they couldn't go ahead with radiotherapy until they had confirmed with neurology. So, my consultant referred to the neurology department to review my MRI scans, to confirm if they could do anything for me, because it was impinging on my spinal cord; and one...ehh...my lower vertebrae were weak and it may break causing loss of my limbs, or function to my bladder or bowel" (Tony, patient (CS7), p15/26).

Here, his oncologist appeared to be the decision maker but treatment decisions often involved opinions and decisions from radiologists, neurosurgeons and radiotherapists. Consulting another colleague's opinion meant trusting one's colleague to make the right decision for the patient.

One of the neurosurgeons said:

"The difficulty is knowing what operation whether to resect all of the tumour during the operation or to leave it, the sort of internal scaffolding part of it we've put it in that clearly needs to be done but it is how far to take it that is difficult" (Neurosurgeon (CS7), p6/8)

Thus it appeared there was a chain decision making process but there was uncertainty about the amount of tumour to be removed and the outcome of surgery. However, the patient seemed unaware of this questioning undertaken by the healthcare professionals.

Tony's wife, Gail, became emotional as we chatted in her home, as it turned out excision of the tumour proved difficult and only the internal fixation was done.

"I think he [Tony] said something along the lines that...that they didn't want to remove the tumour erm... that would be radiotherapy would err...take care of that. And they thought radiotherapy would be the best thing" (Gail, wife (CS7), p12/3)

This account indicated that the decision on how much tumour to remove can only be made during the surgery itself so even with excellent communication, uncertainty exists. As mentioned earlier, an important issue in the immediate care of patients concerned how best to nurse the patient with MSCC.

According to the healthcare professionals, the focus here was to establish whether a patient's spine was stable or unstable in order to determine the care for the patient. One of the GPs reflected his experience dealing with patients with MSCC in the community:

"Normally we'll give the diagnosis to the ambulance crew and the ambulance crew usually know, based on that, ...um...the spinal instability...that they should, presumably, fix the spine in some way. But it's not something I'm familiar with but it's good that you're mentioning this now because I'll remember that the next time [Laugh]" (GP (CS4), p14/14).

Here, it seemed that the general practitioner relied on the emergency team to make the appropriate decision in the safe transfer of the patient to the hospital.

However, on the ward setting, getting information on the patient's spinal status varied. Commonly, oncologists were not able to identify whether the patient's spine was stable or not from the MRI images. One oncologist considers:

"I can't but, I mean, sometimes we get, err, information on that in the radiology report and sometimes we don't" (Oncologist (CS6), p4/20).

This suggests that the oncologists depended on radiologists to provide them with the information on spinal status. Radiologists, on the other hand, acknowledged they were more confident reporting spinal instability in trauma cases but not in malignancy. One radiologist explained:

“I think we’ve got a good idea about spinal instability in the context of trauma because we understand the three-column theory; where, if two columns are affected, then the spine is unstable. The trouble is that we find it very difficult to translate that into malignancy because the mechanism’s different. And so, unless something has absolutely lost height or is displaced, then we find it very difficult to be certain about instability and any amount of malignant infiltration may or may not mean that the spine is unstable and it’s not really, in a way, something that you can decide with MRI. One of the problems that we have is that we don’t see the amount of residual bone present because we don’t routinely CT these patients” (Radiologist 4, p1/8).

This excerpt suggested there was no guide to interpreting spinal instability in MSCC and scan images were static and may not reflect the true status of the patient’s spine. Capturing good images can sometimes be problematic. The radiologist pointed out Jimmy’s case as an example:

“If you look at the time at the beginning of the scan and the time at the end of the scan, we’re looking at fourteen minutes. That’s very fast and it means that they’ve been...that they know the patient’s in pain, or otherwise agitated, and they’ve done very well to get images” (Radiologist 4, p10/1).

This showed that getting a quality image of the spine can be compromised depending on the patient’s pain tolerance at that time. As there were no criteria upon which to make decisions, information about spinal instability seemed vague.

“So, um, no-one has ever shown me a convincing algorithm, if you like, or any mechanism by which we can accurately judge, on imaging, the stability of metastatic disease. Think a lot of it goes on clinical grounds. And, certainly, if you’re mobilising a patient with it, you have to be quite careful. If they start showing any signs of neurological compression on movement (and that’s a sudden change in their neurological status, or shooting pains, or, you know, extreme pain on movement) then, you know, you want to be very careful about moving them” (Radiologist 1, p3/20).

Another oncologist talked about consulting the neurosurgeon if she suspected a patient had spinal instability:

“But if I had someone that I was concerned that they were unstable, very symptomatic, then I would speak to neurosurgeon or physio about that and take it from there” (Oncologist (CS2), p4/14).

The above account suggested that a patient's spinal status can be unpredictable and 'pain' seemed to be an indicator of spinal instability. The interpretation above suggested that decision making on spinal instability involved neurosurgeons. One of the medical staff rationalised his decision on mobilisation:

"Um, my policy is that we mobilise everybody unless there's obvious instability. Um and that usually manifests itself as incident pain, and the pain itself, that usually stops people mobilising. So, I put no restrictions at all on what people do. I think that – I don't think there's any evidence that people are more at risk of transection if you mobilise them, and I'm sure they are more at risk of thrombo-embolic complications if you don't mobilise them" (Oncologist, CS1, p2/19).

Although medical staff advocated the advantages of mobilisation, others did not necessarily give specific instructions and believed there were protocols on the ward for nurses to follow. The oncologist, however, stated that instructions would be given if the patient was going for surgery:

"Ah, I'm afraid, err, I don't see any logical reason why their risk of further insult to their spinal cord is diminished by finishing their radiotherapy, yet their radiotherapy is not going to have any immediate impact on spinal stability. And so, err, I think if patients who are going for surgery, nursing them flat until they have surgical stabilisation, just from a common sense point of view, just seems the right thing to do. [...] so for patients who are going for surgery, I don't give any specific instruction" (Oncologist (CS6), p3/3).

Others left the physiotherapists to make the assessment and decisions about whether to mobilise the patient or not and the intensity of exercise:

"I see patients obviously on the ward rounds regularly, I would say 'do what you can and the idea is to mobilise as soon as possible' but largely it's the physiotherapist err...assessment that determines how much exercise they should get...yeah" (Oncologist (CS5), p3/6).

However, the physiotherapists expressed that the doctors need to be specific in their instructions as they may not be aware of 'the ins and outs of the MRI' or whether a patient was at risk of neurological problem:

"Then I think it would be nice if the doctors could give us some kind of guidelines cause often time is the case if they came in walking then they continue walking but it gets a bit more vague if somebody is just

transferring from bed to chair but does that mean that they want us to see them, do they want us to, erm...to mobilise them further than that or should they only be bed to chair” (Physiotherapist (CS5), p1/30).

This account showed that the physiotherapist was unable to ascertain the level of exercise the patients required or when there was further risk of deterioration. However, one of the oncologists cautioned treating MSCC as “one entity”:

“It’s just like everything, nothing is black and white. So, you get collapse of the vertebra bodies, the management would be very different, it would be bed-rest, you know. If it’s unstable you worry you’ll make it worse. If it’s the soft tissue mass and the patients...well mobilisation is absolutely fine. And also it will be different with different disease because of the natural history of disease will be different and also how well you know that patient sometimes” (Oncologist (CS5), p5/9).

This excerpt suggested that the management of spinal instability depended on whether there was involvement of the vertebra or soft tissue mass and the natural history of different cancers. Individual assessment seemed to be the basis on which to make decisions in the management of MSCC.

Similarly, a medical staff member talked about involving the surgical team to make decision:

“Even though we don’t always get a direct answer from them...eh...but we make it a point to speak to them. We don’t make the decision ourselves. I think number one is: we stick to uhh...the patient’s own sort of assessment how they are feeling. If it’s uncomfortable for them to mobilise, then yes, obviously we wouldn’t do that, but if they are comfortable – without sort of significant evidence of neurological dysfunction – then we could use that as a guide. Obviously, we would want to see the MRI and see the actual anatomy there before we decide on anything. So, I think, err...most of the time we try to play it safe. Before we do the MRI, we asked them to sort of play it safe’ til we’ve got the MRI” (Registrar (CS7), p4/20).

The interpretation suggested that information on spinal instability can be uncertain and the patient’s safety is at risk if allowed to mobilise. Some of the nurses and allied healthcare participants identified their difficulties and anxieties due to different opinions given or even the absence of guidance. One of the nursing staff explained the use of a care plan but pointed out that it was not specific to MSCC:

“It’s not a specific protocol and that’s what I found lacking considering how many people come in with it. It’s really weird, you know, because there’s a protocol for everything else” (Staff Nurse (CS3), p2/20).

However, medical staff felt that the NICE guideline was not helpful.

“Total immobilisation...er...and ...really very much at odds with what most people are doing. [...] So really they ...it was a consensus document which, um...did not represent a lot of peoples’ practice, you know, and I was not convinced that you needed, for example, to log roll patients and all the other things. So I was a bit critical of some of the NICE guidance” (Oncologist (CS4), p4/16).

The account suggested that the present guideline may not be appropriate to clinical practice as patients may be mobile on admission. Therefore, this lack of guidance or protocols prompted nursing staff to ‘play safe’ in caring for their patients. A member of nursing staff gave her views:

“The way that we manage patients, is that there is a risk that they can perhaps do damage and they can, erm... you know, become paralysed, or whatever. So, that’s kind of what I think: ‘well, if you’re on bed-rest, you’re not doing anything that can aggravate your situation,’ until they’ve had treatment and then the physiotherapists get involved once they’ve finished their treatment. So, that’s kind of my rationale. It’s the safest way to manage them” (S/N (CS8), p5/15).

The unpredictability of MSCC resulted in nurses being concerned for the patient’s safety and there was little evidence that patients were fully informed about the pros and cons of mobilisation so they could contribute to decision making. One of the nurses reflected her views when caring for one of her patients:

“I think safety, the safety side from mobilising from getting the patient up. I think that was probably the most challenging you had to do. Although the physios were assessing daily, they do that in the morning and towards the end of the day is probably when the safety is a bit more compromised because of tiredness” (S/N (CS6), p13/23).

The nurses concerns reflected apprehension of things going wrong and this resulted in a level of indecision which contributed to mixed instructions for patients. This impacted on one patient’s care and she reported her anxieties and confusion:

“One’s telling you one thing, one’s telling you to do another thing: one’s telling me ‘you’ve to rest’, ‘you’ve not to get up and walk or you could be’

...you could be like what I am now [paralysed]" (Betty, patient (CS1), p12/2).

Another patient expressed that he had difficulties maintaining strict bed-rest before his surgery:

"The main thing, I think, was just routine washing and going to the toilet. I found it very difficult to use a bedpan. I did actually, I admit now, did stand up slightly and go to the toilet at the edge of my bed, because it was just ...on one, really difficult to do. I started to get sore elbows, because you're shuffling about in your bed with your elbows, if you want to move over and get a drink or move over, like maybe slide bedsores" (Tony, patient (CS7), p21/18).

From the above account, it seemed paramount that patients should be on strict bed-rest if spinal instability was suspected. However, patients may find difficulty in maintaining that position for a length of time. There were issues around maintaining dignity, soreness on prominent parts of the body and discomfort using a bedpan.

A staff nurse recounted her experience when she cared for Tony:

"No, erm...but contrary to that I never heard 'don't let him walk', you know, 'he's on bed-rest' so that wasn't passed to us. He was getting up and walking and... from my point of view I thought that's, you know, just what was happening. It wasn't till after maybe it was the day after that I think the doctor came and said 'he's meant to be on strict bed-rest' and apparently this already had been passed on but wasn't communicated in our notes or our paper work. And, the patient wasn't compliant either, so, I don't know how clear that instruction was made from the start or is it just non compliant" (S/N, CS7, p6/15).

Instructions on mobilisation could easily be missed or not communicated.

However, the patient may not be aware of the importance of strict bed-rest or did not participate in the decision making process. One of the physiotherapists highlighted the problem of having separate documentation:

"That raises the whole communication issues and the fact that we're all working for the same patient that we should all be on the same page and if we were all documenting in the same medical record that we would have access to everybody's information erm...from all the different teams which I think is ideal"(Physiotherapist (CS5), p8/8).

The documentation of patients care kept by different team members means that information may not be easily available to all the members of staff and plans for rehabilitation could be delayed or overlooked. The above accounts suggested the issues around communication could be improved with a '*unitary patient record*'.

To summarise, this sub-theme emphasises that given the nature of the condition and the sudden onset of symptoms, prompt decision making in MSCC is vital. Consequently, patients had expectations and trusted that their consultant/healthcare professionals would make the right treatment decisions. Healthcare professionals on the other hand based their trust in their colleagues in making the right decisions for the patients under their care. However, treatment decisions can be challenging and the outcomes remain uncertain.

It was apparent that there were no easy answers in decisions around positioning and mobilisation. Healthcare professionals' views on guidelines differed, with some needing protocols and guidelines for MSCC whilst others took into account the patient's priorities and their short life expectancy. When discussing this issue, there was a sense that healthcare professionals had to consider many complex aspects when seeking a satisfactory solution to the problem of mobilisation. It remains one of the challenges of caring for patients with MSCC.

Initially, patients welcomed the urgent treatment which often was needed to give them relief from pain, but when the acute onset of pain had resolved, patients began to ask questions and had doubts about their future treatment decision making. The presentation of MSCC is complex, patients often present with varied symptoms. Upon presentation healthcare professionals need to discuss and interpret these symptoms based on history and then make complex decisions regarding treatment. Patients are trying to make sense of their condition and healthcare professionals are trying to make sense of the presenting symptoms.

5.2.3 “Help us put the jigsaw together”

This ‘in-vivo’ code was identified by one of the carers. It seemed appropriate as it reflected the patients’ and carers’ frustrations when the initial uncertainties were resolved but other uncertainties emerged about the lack of information and sometimes not receiving timely information on diagnosis, treatment options and discharge plans. Some patients and carers expressed the view that information could be vague or they may not understand the information given to them.

Betty talked about the vagueness of her cancer diagnosis:

“...they said that...umm...I did have cancer, and that they couldnae (could not) operate. That they needed to take...they were actually going to do another scan, but that...to get a biopsy, they thought it might be in the pancreas. So, after that they said they werenae (were not) doing any more” (Betty, patient (CS1), Interview 1, p15/26).

Betty’s daughter, Mary, expressed her frustrations when there was any discrepancy on the diagnosis and she was informed initially that her mum was going for an emergency operation but nobody then informed her when it transpired the operation was not an option. Subsequently, Betty was transferred to the Cancer Centre for radiotherapy. Mary expressed not understanding her mum’s condition:

Mary: The bone at the back of her lung, is that her rib, or is it the spine or...?

Researcher: Did they tell you?

Mary: No, I didnae (did not) ask. That’s something I need to speak to somebody about. This is all too vague, and we sort of...as I was explaining, we’re not stupid people, eh. You need a certain amount of information to go and ask questions. So, whether we’re getting told and saying ‘you got to go and look after her’ and you’ve not got a clue and you’re told... There’s so much you need to know, eh; ignorance doesnae (does not) help you” (Mary, daughter (CS 1), Interview 1, p16/14).

Patients and carers may not understand medical information on spinal cord compression and may not know what to ask or have the courage to ask healthcare professionals. Then there was conflicting information about her mum’s discharge plans. Mary voiced her confusion:

“My mum phoned me this morning telling me she has to go to the hospice to be assessed before coming home. The day before, prior to that, she’s not getting home at all. We didn’t know whether we’re coming or going...we need to talk to someone that knows. We need somebody to do that so that we can then ‘put the jigsaw together and say, okay, here’s what we have’” (Mary, Carer (CS1), p15/22).

Medical staff talked about juggling giving bad news and at the same time preparing the patient for emergency treatment:

“For most patients it’s very difficult because they... the classic, um, presentation is a Friday afternoon, in a patient who doesn’t previously know they’ve got cancer, who arrives paraplegic. And so you have at the same time to tell them (and often not their family because their family are often still in the referring hospital and haven’t gone with them)...um, that A: they have cancer, that B: that they, er, are not walking and they may not walk again, and C: ‘this is the treatment we are going to try’ and that tends to be rushed in a way that would never be dreamt of in somebody who is coming for an out-patient appointment with cancer” (Oncologist (CS1), p7/18).

The process of giving information on diagnosis and the planning of urgent treatment simultaneously can be challenging for the healthcare professionals.

Tony gave his reaction when he was informed of his diagnosis:

“So, it was a complete...complete shock really, because obviously, I’d come in for my...to find out the results of my other tumour, and found out there...that this is a new one which hadn’t been picked up before my chemotherapy, which, obviously...I wondered, because the other ones had been stable... [...] Second time when I found out I had a tumour, I was just in myself because I was just in the ward on my own. But it was explained that they had to go in with the surgery” (Tony, patient (CS7), Interview 1, p18/14).

This highlights that some patients’ immediate emotional needs could be overlooked as he/she might not have family present for support during this distressing time. Similarly, Robert had no idea what the doctor meant about ‘a spot’ on his back:

“I don’t know what they mean by this - this spot. It’s just a spot in the spine causing trouble. I don’t know what they mean by ‘the spot – is a hard spot’; where does it come from; what does the spot...what does it do? I don’t know” (Robert, patient (CS4), Interview 1, p5/7).

Or why there was a change in his treatment plan:

“They have decided to step up and give me nine instead of five. I don’t know. I don’t know whether the spots are bad or whether they have seen something. I don’t know. I was never X-ray again” (Robert, patient (CS4), Interview 1, p12/13).

Changes in treatment and discharge plans added to the patients and the carers confusion and they may not necessarily have known the reasons for the changed in decisions. This sometimes meant that patients and carers were not fully aware of what was happening and the reasons why they were not involved in aspects of the decision making process.

Although Sandra was pleased initially with the speed of her treatment, later in our conversation she confided a lack of understanding on the progression of her cancer:

“It all happened very quickly which is great but it’s difficult to get your head around it when it’s going at that speed. Although you do want speed but you do not actually understand what it is” (Sandra, patient (CS2), Interview 1, p2/17).

She added:

I can say it’s on T10, whatever...whatever they tell me, but the actual cancer itself and the way it grows and what’s happening with it...umm...I don’t have that kind of intellect and I have to trust these people to do their best for me” (Sandra, patient (CS2), Interview 1, p23/15).

Sandra gave an example of wanting in-depth information about her condition:

“I don’t know, some people maybe don’t want it, but I quite like more a theoretical type of explanation as well as...not just a general, you know, ‘you may feel dizziness,’ but actually what it’s physically doing to me. That...I would like to know that kind – I mean, I wanted to see my scans today, that’s how nosy I am. I want to see what they look like. [...] But I sometimes think that should be made available to you” (Sandra, patient (CS2), Interview 1, p34/7).

Sandra talked at length about her years of living with breast cancer and how her confidence in the health system had “chipped away” when the spread of cancer to her lymph nodes was not detected. Therefore, she wanted to have details such as:

“Umm, the pathway that the disease can take. And...what treatments; all the treatments that are available to me and why certain ones would be selected. And I’d rather know that well in advance” (Sandra, patient (CS2), Interview 1, p30/6).

This account indicated that the patient wanted to have detailed information to be able to anticipate and participate in decision making. Although she felt reassured with her present consultant, she found conflicting information on the internet about treatment options. She was told her tumour was inoperable but was not given a say:

“I am still very mobile, I can still move about; I can feel the niggling. I don’t know how long it can be controlled for; I don’t know what the other options are. I have been told it’s inoperable but I have gone on to the internet and read in Australian and American places they can actually take the disc out and put a plate in, and you wonder well, why? What’s available to me that I am allowed to go for and at what point would that kick in?” (Sandra, patient (CS2), p2/1)

There was a sense that Sandra wanted to empower herself to participate in decision making and be involved in treatment plans. She obtained information from the internet, which reported positive outcomes from surgery and to her this was at odds with the information she was being given.

This suggested that patients do want follow-up information or clarification during the course of treatment and healthcare professionals may need to ask patients whether they have any concerns to discuss during their stay in the hospital. Sandra’s husband, however, had anxiety about her emergency admission:

“Err...basically speaking ‘is she coming out, what’s happening?’ They don’t...I mean it’s like everything else, you just get told and then you sort of panic and it goes to your head. [...] You know what I mean...experience like that...err...I mean you could be very depressed. You can say it is a scary sort of feeling...” (John, husband (CS2), Interview 1, p10/11).

Carers may live far from the hospital and may not have full information which may cause anxiety and uncertainty about the immediate future. Patients attributed the lack of communication to staff working under pressure. Some patients commented that information given by staff seemed rushed or

sometimes inadequate. Patients expressed wanting information because they were uncertain of what to expect.

For example, Richard talked about lots of information being available on the websites, and in leaflets and books that mentioned side-effects of treatment. There was a sense that patients were trying to relate what they had read to their own experience. However, general information may not be relevant to the patients, as Richard pointed out he wanted information pertaining to *'him as an individual'* and *'not so much textbook'*.

He added:

"...one doesn't get time often to speak to people about what's going on in your body, what the disease actually is and what it's going to do to you and things like that. So, I do think being able to speak to people individually with the time, for me is quite a big factor, you know, even just being able to speak to your doctor for an extended length of time rather than just, you know, the few minutes that you often get with a GP; you need to have extended period of time" (Richard, patient (CS5), Interview 1, p28/18).

Although Richard said he wanted information, he was also wary of getting too much information:

"...too much information isn't good. Cause it starts to put things into your mind, I mean if I sat and read a bit of paper – erm...wheelchair. Is that going to ...oh... automatically you think I'm going to end up on the wheelchair?" (Richard, Patient (CS 5), Interview 1, p26/14)

Similarly Tony found lots of information on the internet:

"You know, I went on the internet, finding out, phoning up, going to Macmillan sites, cancer research sites; there's so much information there. And I think the big thing is...ehh...you can get a lot of information from them, but it's maybe not all relevant to you. I believe they are consultants, they are specialists, and all that information is out there is for you to use. [...]But certainly, they've always been open in giving me information and, you know, being honest" (Tony, patient (CS7), Interview 1, p33/21).

The above accounts showed that patients seek out information on the internet but identifying what was relevant to them as individuals can be difficult and can

potentially misinform them. Therefore, they trusted their consultant to give them information that is pertinent to them. One patient said he left this information giving in the hands of his consultant:

“Only what they think is suitable for me, not what I think because I don’t have the intelligence” (Jimmy, patient (CS 3), 1st interview, p17, L23).

Even though Jimmy said he left the information giving to his consultant, as the conversation continued he revealed that he had bought a new laptop and looked up information on the side effects of steroids. This account suggested that patients may not know what to expect and therefore may not know what questions to ask.

In contrast, Jock said he had received *“plenty of information”* but he could not remember and *“was not really interested”* but in hindsight, he commented:

“I would’ve been listening, but taking it...only taking half of it in” (Jock, patient (CS8), p17/9)

It appeared here that Jock was given information about his condition but he may not have understood it or been able to take in all the information at that time. However, his oncologist explained the unknown cause of his metastasis together with the need for investigations to identify the cause of progression which made information giving difficult.

Some healthcare professionals highlighted that the referring doctor from the district hospitals should have given some explanation to patients as some had no idea why they were being transferred to the cancer centre. In this particular case, Jock’s attending doctor was unable to establish whether he understood his condition or whether he did not want to worry his wife. He requested his doctor not to inform his wife of his condition. The registrar commented:

“I certainly picked up the second time that I’m not sure that he’d taken everything onboard, he didn’t entirely understand what was going on. He certainly wasn’t confused and he didn’t have a background history of confusion, but he certainly didn’t seem to be accepting or understanding of all the information, erm, regarding that. Erm, but as he didn’t want me to let his wife know, I, I couldn’t tell her anything” (Registrar (CS 8), p17/14).

Healthcare professionals faced an ethical dilemma when a patient wished to withhold information from their family. This added to their difficulties in not knowing whether the patients understood their condition, were in denial or were exercising their right to keep their information confidential.

The lack of information caused Jock's wife anxieties as reported by his general practitioner during the interview:

"What happened was his wife phoned me because she felt that perhaps communications hadn't been that good. I did get a phone call one afternoon asking me could I find out exactly what was happening" (GP, (CS 8) p7/7).

Here, it seemed GPs could be approached and found themselves in a role as the patient's or carer's advocate in chasing for information from the hospital. Carers felt they did not always have the opportunity to discuss their concerns with the oncologist as they were usually in the presence of their spouse and did not want to upset their loved ones. Carers felt they got second hand information from their spouse, sometimes information seemed vague or their spouse may not have been able to explain to them. Their concerns were about how to manage when cancer progressed and balancing their own needs with those of their loved one. Linda felt she knew very little:

"Well, very little because nobody actually said anything to me. [Husband] His understanding not being a medical person, he's not really very clear about what I asked him" (Linda (CS5), Interview 1, p7/21).

The above account suggested a lack of acknowledgement of the carer's role in the care of patients. Healthcare professionals seemed more focused on the patient's needs and were not necessarily aware of the carer's needs. There seemed to be a lack of someone co-ordinating or being instrumental in identifying patient's and carer's needs to provide this support. A nurse suggested:

"Erm...I don't know, it would be quite nice to know if there are people who could like say, you know, a link nurse or something that could come in provide more emotional support with the patient and explain things a bit more in-depth with the patients" (SN (CS7), p12/2).

Nurses felt they lacked the knowledge on different cancers to provide the information and to address this problem.

“I think the problem is within the training, you kind of deal with something as you come upon it. And if you don’t come upon it...I mean as I say I’ve learnt a lot more since looking after patients. [...] you know you’re getting flung at the task at the minute. Err...the actual cancer side and all the different cancers and different things like that are kind of sitting in the back burner” (S/N (CS6), p3/8).

The account suggests nurses learn and gain their skills in clinical practice. One nurse talked about her conversation with the project manager working on the MSCC project:

“Erm...I did say to her (the project manager) should there be training. She said she had offered but was told there wasn’t a need. I was like I think there’s a need because especially for myself, there’s a couple of newly trained you just think they probably need it as well you know. Maybe the older ones don’t need that as they have been here a while. From my point of view I needed that” (S/N (CS6), p5/11).

The nurse appears to recognise her learning needs, especially as she was new to the speciality. Another nurse said that she was not confident in giving information to patients and their relatives and gave her reasons why:

“We had quite a big complaint recently where a nurse had told them a scan was negative. It was negative to something from memory but it wasn’t. I think it was negative to spinal cord compression on that occasion for that patient but they did still have metastasis and it wasn’t negative. So in that respect I wouldn’t tell something like you’ve got SCC. I would be there but I would never be the one cause the patient would have questions I would not be able to answer I think as well. And I think it should come from the doctors who have reviewed the scan” (S/N (CS2), p8/11).

This account suggests the challenges faced by nurses in acknowledging their lack of understanding on MSCC. There seemed to be a notion of fear of giving the wrong information.

The nurses felt that the doctors are best placed to give explanation to the patients about their condition. However, nurses know the importance of emotional support and felt providing this aspect of care can be challenging because of the pressure of routine work. Some suggested that the patient’s

specialist nurse or a link nurse would be in the best position to attend to patients with MSCC. When asked whether the patient's primary site (tumour-specific) nurses would see their patients, one nurse commented:

“Not that I know of. Because, some of the nurses you see them, they're quite active round the wards but some of the other ones you never see at all. They maybe stick more in the clinics than in the wards. I suppose it depends how they divide their day up really. But it would be good if there's somebody that we could call if...if we felt that, you know, patient or family would benefit from a bit more information” (SN (CS7), p12/13).

However, many specialist nurse roles are focused around primary treatment at diagnosis and follow-up of patients with metastatic disease may not be part of the remit. If patients have palliative care needs then the palliative care nurse specialist may become involved but, because MSCC has acute onset, patients are dealt with in an acute setting so navigating the journey is complex. A hospital palliative care nurse said she saw Richard when he was referred to her for pain management:

“He (Richard) actually had regular contact with his local palliative care team. [...] I think, probably, the referral originally came through them to alert us to the fact that he'd been admitted...erm...for radiotherapy. If I remember, I could be wrong in that but certainly that's the impression that... It's a case of waiting until he's actually referred to us. So, it's not necessary on admission that we would be alerted” (PCN (CS5), p1/30).

Here it appeared that patients may not necessarily see a palliative care nurse unless they are referred for pain control issues. In addition, some patients gave their views on what mattered to them:

“I think for me as a patient, the greatest things would be that you have to see people as a holistic thing. You know, you don't come in the door... and they try, I see the doctors trying to be very human and very approachable, but there's a restriction on their time. And I do think they need more support to help them assist... likes of the psychologist, great idea but they pulled the funding” (Sandra, patient (CS2), Interview 1, p35/23).

Though the patient highlighted that the psychologist helped guide her, she felt there was a need for back-up information:

“So, back up with information sheets, or back it up with breast care nurse having the time, or an appointment with someone else who can take the

information the consultant...and explain what the consultant is saying to you” (Sandra, patient (CS2), Interview 1, p33/10).

This account suggests there is a need to clarify and enhance understanding of the information given by healthcare professionals. Patients would welcome an information leaflet to be read later on. There seemed to be a need for someone to go through information with the patient.

To summarise, when explanations were not readily available, patients felt frustrated as some of them did not have the courage to ask, could not formulate their questions, or were waiting for the healthcare professionals to provide them with answers. These accounts demonstrate that healthcare professionals may not be aware of the need to ask patients how much information they would like or the need to reinforce information given at the time of diagnosis regarding long-term management beyond the acute onset phase. Data also highlighted that patients need emotional support when receiving bad news as their family may not be there to provide this support. Most of the patients wanted information on what was happening to their body rather than general information. However, not all patients wanted the full information. This indicated that information needs vary between patients and carers.

Carers felt they were not involved or consulted in their loved one’s care. Carers also felt they could not address their concerns in the presence of their spouse but would like the opportunity to have their concerns heard in order to make plans and to balance their needs.

Patients and carers want the healthcare professionals to help ‘*put the jigsaw together*’, and that means evaluating individual needs and discussing what is important for the patients and their carers’. Nurses felt they lacked sufficient knowledge of different cancers to provide in-depth information and suggested a link nurse or a specialist nurse to meet these needs. This is discussed further in the next sub-theme which illuminates the complexities of deciding what information to give and when.

5.2.4 When to have a conversation about the future?

This sub-theme demonstrated the varied opinions of patients, carers and healthcare professionals on when to have a discussion about the future, in terms of; symptoms, mobility, progression of cancer and life expectancy. Some healthcare professionals felt that patients and their carers should be prepared to face the reality but others expressed having that conversation too early was not appropriate. Some of the patients and carers accounts showed they did not anticipate these changes and hence such conversations caused them distress. Overall, this situation highlighted how healthcare professionals struggled with giving realistic information and planning the timing of conversations so they did not take hope away from patients and carers.

Betty talked about losing the power in her legs and how she fell on the floor when trying to go to the toilet immediately after completion of her five fractions of radiotherapy. Her daughter, Mary was visibly keen to know whether her mum would regain her mobility after her treatment or what she was capable of doing:

“Err...the fact yes, my mum will die but right now my mum is living and this is her living for the family or for my mum, so really, what was to be decided I think is...erm...we need to speak to somebody today, just to let them know that erm...we really like to find out what is my mum is going to be finally capable of” (Mary, daughter, Interview 1, p3/18).

This excerpt suggests a sense of not knowing what was going to happen. Mary seemed to accept the fact that her mum would die but also expressed a sense of wanting to be prepared for the eventuality. Healthcare professionals on the other hand stressed that treatment is palliative; in some cancers treatment may not work and the outcome remains uncertain:

“The dose of radiation that we use is not the dose which is going to eradicate cancer; it’s a dose which, in people with – certainly people with lung cancer – usually provides at best a few weeks of palliation. And we know that a significant number of cancers are not radio-responsive, so some people progress, I think” (Oncologist (CS1), p4/7).

Emma talked about her lack of mobility but she was still hopeful that the steroids and radiotherapy would work for her:

"I have not felt the benefit of it but I don't know what to expect of it. Erm, I know that it's obviously relieving the tumour but I don't know how quickly the symptoms are to be relieved what have you" (Emma, patient (CS6), p11/7).

However, some medical staff explained that the full effects of treatment may take time in some instances.

"Erm...we would say six weeks to see the full effect of radiotherapy, although you should see some effects in the first two weeks" (Registrar (CS5), p12/19).

This account indicated there was a sense of not knowing whether the treatment would work. However, the physiotherapist explained that a full neurological assessment daily and the actual *'getting up on the feet'* would indicate the capability of the patient. The physiotherapist talked about the extent of deterioration in Emma:

"Unless they do a full assessment every day, neurologically –that they might not really - sometimes they (the medical staff) don't realise the extent of the deterioration, and I think that was what happened on that Thursday-Friday. Until you actually get her (Emma) up on her feet, you might not realise just how much. So, I had to keep on relaying back to...to the medical staff, 'she's deteriorated further, she's deteriorated further'" (Physiotherapist (CS6), p16/22).

Neurological assessment may not be sufficient to assess the patient's mobility but the actual effort of movement would indicate the patient's capability or deterioration in mobility. This suggested that getting a realistic view of the outcome of treatment was difficult to predict. There were also difficulties in predicting when mobility would diminish.

Richard reported his legs felt weak after treatment and because he experienced two falls on the ward, he was conscious of his walking. Richard talked about his frustrations in his diminishing capabilities; for example, he had to get somebody to cut his grass in his garden and the maintenance man to do maintenance on the house. Richard voiced his concerns for the future:

"I still have the wheelchair at home but don't need it. Well, not at this present time, I don't know what it will be like when I get home" (Richard, patient (CS5), Interview 1, p21/24).

This indicated the uncertainty he faced about how long he would maintain his capabilities. Sandra felt that she needed to know how long she would be well enough to function as she taught physical education. Sandra confided her anxiety:

"I have always been independent. So, there's uncertainty that way because I don't want to be...stop, here I don't mean that [became emotional], I don't want to be miserable and worried about money as well as being sick...you know. And I enjoy my job and I don't want to give up my job that way. Umm...I feel as though I am going to lose my identity" (Sandra, patient, Interview 1, p15/7).

Sandra faced the uncertainty of losing function and the significant impact that this would have on her physically, financially and emotionally. Sandra was also worried how her two children would cope if her mobility deteriorated:

"Well, my eldest son was ten when I had to tell him I had cancer the first time – because I was advised to let the boys know. So, Denis was eight and Simon was ten, so they've lived with this through their whole teenage years. And I've always been quite positive and been, you know, on the go. But every time, something like me getting brought in here, you can see it in their faces, you know" (Sandra, patient (CS2), p16/11).

This account suggested that Sandra and her family had faced uncertainty of cancer recurring over the years and it had impacted on the quality of their family life.

Some healthcare professionals felt that patients should be informed of their future symptoms but not all agreed:

"Well, I think it's best discussed after they've had their radiotherapy and you see the effect of the radiotherapy. Some people, it takes longer for them to get an effect, and if you start talking about all sorts of different things it can be quite distressing" (Registrar (CS4), p19/24).

However, for Emma, it came as a shock and adjusting to her disability caused ongoing frustrations. She talked of her determination to get her strength back:

"I know my left leg isn't moving as it should be but because of my determination I will get that moving [laughs] so, err...and with the steroids it does make me confident to be able to get that" (Emma, patient (CS6), p11/1).

Here, the patient wanted to be positive and not lose hope. Medical staff described conversations around diagnosis and prognosis as difficult. Some of the patients expressed a need to know the prognosis to allow them boundaries to work with and to help them make short or long term plans. Sandra, for example, gave her reasons for wanting to know:

“Basically, how long you’re going to live. How long you’re going to be well enough to function? [...]It’s like your whole life is on hold because they don’t give you...um...parameters to work within. And I can understand they don’t want to because of the new advances in drugs and things, they don’t want to tell you too much. But – as a patient it makes me feel... [Big sigh] I can’t focus on anything because my life’s always on hold. I got to a point with depression” (Sandra, patient (CS2), p17/1).

This account demonstrates that the patient found it hard to cope with not knowing what her future held and it stopped her from moving forward. However, Sandra’s consultant was aware that she had not been coping and the issue around prognosis was brought up during her follow-up appointment. The oncologist reflected her conversation with Sandra:

“We haven’t been any more specific than that because I don’t think you can be really apart than talk about it you know. She’s already kind of exceeded the statistics and done better than the statistic would have said she would do at this stage. And so I pointed that out to her and I hope that is reassuring to her. So, we had had some conversations about her prognosis” (Oncologist, p6, L14).

This illustrated that healthcare professionals faced difficulty in discussing issues around prognosis when the patient’s survival had exceeded the expected life span in statistical predictions. There was the uncertainty whether she would continue to respond to further treatment.

Sandra’s husband believed getting information on prognosis was going to help them make plans. John considered:

“I mean most people want to know whether it’s good or bad or indifferent and if you get told that’s the best way. And then you can cope with it or make plans whatever you know what I mean. Put it this way, say if somebody were to come and tell me ‘hi John, you’ve got four years to live’ or ‘John, you have only a year to live’. If I have four years, I would do ‘x, y and z’ right, but if I have only a year to live I won’t be going to work tomorrow, I would be going somewhere else cause there’s

something in this world I want to do before I die” (John, husband (CS2), Interview 1, p23/17).

The above quote illustrates John wanted to know his wife’s prognosis in a qualitative way rather than in statistical terms. For John and Sandra, knowing the prognosis would provide some form of ‘control’ to be able to make plans.

Not all patients, however, wanted to know their prognosis and this posed challenges for healthcare professionals in determining whether to have that conversation with patients and their carers’. Richard talked about how he reconciled with the issue around prognosis:

“They are not going to fix me, you know, but extend and give me quality of life, and that’s all, really, I can expect at the present time. For how long, I don’t know. There’s nobody who can tell me that, obviously, either. It could be next week; it could be next year. I’ve been diagnosed for coming up to two years or whatever it may be. So, no, no, I don’t want to know, no. So...I don’t think so, no. I’d rather just err...pass away peacefully, if you know what I mean” (Richard, patient (CS5), Interview 2, p17/22).

Here, it seemed Richard was being realistic about his condition and would rather not know how long he was going to live. His wife, Linda expressed not wanting to be weighed down by that information too:

“You don’t really want to know what someone’s opinion is of your life expectancy, you know, because I’m not very much in favour of that because I think that is a horrible burden to have. I think I’d rather not know something like that” (Linda, wife (CS5), interview 1, p12/17).

Some of the healthcare professionals felt it was not appropriate to discuss prognosis when patients were on active treatment or if they had other treatment options still available. The oncologist made his point:

“But I actually disagree with the idea that you have to tell everybody this is how many months you have until it is appropriate when you can’t do anymore. Then that’s the right time to do it” (Oncologist (CS5), p4/4).

Other healthcare professionals had to listen for cues from their patients as not all patients wanted to talk about end of life issues. The oncologist reflected his discussion with Emma and her husband:

“I mean she was immensely disappointed but she accepted and didn’t challenge, err, the information that she was given. And in fact she had very little in the way of follow-on questions. So, err, that’s really why prognosis, in terms of survival, was not discussed. Because she, effectively, stopped the conversation” (Oncologist (CS6), p7/17)

The oncologist seemed to give the control to the patient as a means of opening a discussion on prognosis and took the cue that she did not want to have that discussion. In contrast to what the oncologist perceived, both Emma and her husband, Matthew seemed to want to know the prognosis but at the same time described it as a “mixed bag”.

“Err...time scales – err...in some ways you don’t want to know type, but I have to – I’m a stickler for those kinds of things; I need to... Yeah. It’s a mixed bag” (Emma and Matthew (CS6), Interview 1, p30/25).

There was a sense that the patient and carer oscillated between the desire for more information and avoidance of information on prognosis. Matthew added his reasons for wanting information on prognosis:

“It’s more upsetting not knowing what’s ahead. Cause your mind starts to go into overdrive, and you think ‘what are they keeping from you?’ or ‘are they not telling you everything?’ They never are [Emma: they always do tell.] Yeah, they do tell, but it’s your mind that starts to kind of go that way, so I’d rather just know everything and deal with it at that point” (Matthew, husband (CS6), Interview 1, p31/10).

Matthew expressed that he needed time to think through the information given to him. However, healthcare professionals sometimes may not interpret this cue accurately. The consultant commented on his observation at the time of breaking bad news and knowing the couple over the years:

“Err, she expressed disappointment, rather than fear. Err, he said very little. Err, which is quite normal for him. Because I’ve met him many times over four years, and he tends to say very little” (Oncologist (CS6), p8/11).

In contrast to the above accounts, Betty seemed to accept that she was going to die but left her fate to a higher power. According to her consultant, Betty ‘was extraordinarily sanguine’ about her paralysis and her imminent death:

“...she didn’t really accept the prognosis that we were suggesting because, from her point of view, God was going to look after her and it –

whatever happened was up to Him, not up to her or us anyway, so it really didn't matter" (Oncologist (CS1), p7/14).

Patients and carers also discussed about having existential fears of progression of cancer. Jimmy described his concerns:

"The first thing I thought I had fear when I was told 'how long I've got to live?' That's the first thing that comes in my mind 'How long?' But then I say before I had the cancer, I only have so long to live anyway and I wasn't frightened then. I might be frightened if I am going to die screaming with pain and salivating about, cannot talk and all that" (Jimmy, patient (CS3), Interview 1, p14/7).

Jimmy and Sandra feared they could end their lives suffering in pain. However, when probed further, they seemed to get this information from the internet.

Sandra said:

"You know...it could go to my brain; it's this...I'm going to be in agony, the pain... And all the internet says, when it is in the bones, it's...the pain is horrendous. You just imagine this torturing death that you're going to suffer, and that's just the way...you know, when you read – and I read [Laughs]" (Sandra, patient (CS2), Interview 1, p20/31).

These interpretations indicated patients have existential fears of suffering in pain at their end of life. Healthcare professionals may not be aware of this issue and a discussion around pain control may be reassuring to the patients. Similarly, carers Matthew and Linda had worries about their loved ones suffering in pain and breathing problems. Linda confided her concerns:

"Umm...I'd have liked to talk to somebody about the disease and the umm...progression of the disease and you know, what is...I mean I know everybody is a unique individual and everyone would be slightly different and how the disease progresses. I would just like some general information and you know progression and halting that progression and generally what kind of things helped" (Linda, wife (CS5), Interview 1, p12/11).

Carers have concerns of not knowing how to recognise and cope with deterioration in their loved one's when the time was near. Carers seemed to need someone to explain and provide the information to be able to anticipate and support their loved one's needs.

In contrast to the above accounts, Jock did not seem worried about his prognosis. He reasoned:

“I don't want to live till I'm over eighty (I'm seventy-six), it's no use living to that age if you can't get about and be active” (Jock, patient (CS8), Interview 1, p10/18).

Here, it seemed that the patient was more concerned with quality of life rather than longevity.

In conclusion, patients and carers experienced uncertainty in not knowing what the future held and wanted answers for some of their concerns. For example, patients had questions about how long they were going to remain mobile, issues around how long they had left and about progression of cancer. Patients showed extreme fear of suffering and dying in pain and being helpless. Carers also have fears of not recognising and coping with the deterioration in their loved ones condition. Healthcare professionals, on the other hand, found that diagnosing MSCC was challenging; treatment in metastatic disease is mainly palliative; response to treatment is uncertain and, therefore, conversations around maintaining mobility and life expectancy can be difficult. These findings suggested there is a chain of decision making from healthcare professionals and there are some areas of concerns that healthcare professionals can help to clarify or to provide an explanation for patients and carers. However, they may not necessarily know, identify correctly or anticipate when to have a conversation with the patient and/or carer regarding the patient's future.

5.2.5 Summary

This theme reflected patients' and carers' difficulties in judging the significance of the signs and symptoms of MSCC whilst healthcare professionals faced challenges in recognising and identifying the patients presenting symptoms. There was evidence that patients trusted the healthcare professionals in making the right decisions and welcomed the immediate treatment and care. Some patients later questioned whether the healthcare professionals had made a balanced decision when the treatment they received was different from those they had read about via the internet.

Not all primary care professionals were aware of the local referral pathway or the NICE guidelines on MSCC and other healthcare professionals were sceptical about the NICE guidelines (2008) in clinical practice. Contradictory instructions on mobilisation added to the patients' distress and uncertainty. Other uncertainties emerged after the initial treatment and some patients and their carers felt information was not forthcoming. However, patients' and carers' needs for information varied where prognosis and end of life issues are concerned. Healthcare professionals' perspectives in giving patients information on prognosis and future symptoms were debatable due to the uncertainty of the disease pathway and outcome of treatment. There seemed to be uncertainty from the accounts of the patients', carers' and healthcare professionals' perspectives but evidence also illuminated their strategies in balancing and managing these uncertainties which will be discussed in the next theme.

5.3 Finding a balance in the uncertainty of MSCC

In this second theme, I give examples from the accounts of patients, their carers and healthcare professionals to demonstrate a range of ways to find a balance to deal with the uncertainty of MSCC. Sub-theme 5.3.1 shows healthcare professionals sought to make 'trade-off' decisions about treatment versus the quality of life of the patients. Patients and carers appeared to feel the progression of cancer was beyond their control, however, sub-theme 5.3.2 demonstrated their *'battle plan - what is the next step'* highlighting their priorities and hopes for the future. Healthcare professionals faced challenges as treatment was palliative and there were difficulties anticipating the progression of cancer. Sub-theme 5.3.3 reflects different perspectives of the demands of care. Accounts from the patients illustrated they did not want their families to be burdened with their care; however, carers felt decisions of care made by healthcare professionals might be disparate from their needs. The following sub-themes are the interpretations of patients, carers and healthcare professionals in finding a balance in the uncertainty of MSCC.

5.3.1 'Trade-off'

This sub-theme demonstrated healthcare professionals' decision making in the context of impending cord compression treatment. There was a notion of trying to find a balance where healthcare professionals sought to make trade-off decisions in treating advanced cancer versus the patient's quality of life. However, treating metastatic disease was challenging as the treatment was palliative and medical staff found it difficult to determine the patient's response to treatment. Patients and carers, on the other hand felt dis-empowered with the recurrence of cancer but data showed their coping strategies in dealing with uncertainty of MSCC.

Healthcare professionals talked about making difficult treatment decisions. In the account below, the oncologist got his team involved in Jimmy's treatment plans. Jimmy was mobile and quite pain free at that time. The team had to consider the dosage of radiotherapy to give Jimmy:

"So, if you assume that the cancer has a 100% chance of causing paralysis in due course, then the question is; do you give a radiation dose that gives a one per cent risk, or a 10% risk, or a 20% risk, or a 50% risk of causing that same problem in due course? Er, and in the end he had a dose which probably runs about a five per cent risk of causing him radiation injury. Erm, I suppose it might've been possible to give a higher dose with a higher risk, but in the end we didn't go that far. Just compromised somewhat" (Oncologist (CS3), p12/8).

Here, it appeared that the oncologist made a trade-off decision with the dosage of radiotherapy versus maintaining the physical outcome. The focus in this case was on the physical condition of the patient which informed decisions around treatment. The account here seemed to be shared decision making. However, this team discussion was confined to a specific discipline only and did not involve the patient or carer as part of the team.

Healthcare professionals discussed making decisions based on evidence. One oncologist referred to the NICE guidelines (2008):

"There is very little comment there about non-surgical intervention. There was one radiotherapist on the group, but very little about

radiotherapy and at one stage there was virtually nothing about radiotherapy, it was all about surgical nursing intervention. The other thing was, of course, there was no evidence base at all to make those recommendations on” (Oncologist (CS4), p4/10).

This interpretation suggested that evidence on radiotherapy treatment was limited and therefore there is uncertainty in the outcome. Another medical staff member commented on the evidence of surgery outcomes:

“Well, there’s American randomised trials saying that surgery plus radiotherapy, um, is better than radiotherapy alone, in terms of how long people walk for, and the various outcomes. It’s a very highly selected sub-group...and how many people it actually applies to is a difficult question. And there are severe limitations over that in terms of, erm, theatre access and putting the two people together (neurosurgeon and thoracic surgeon), about the patient’s fitness for the procedure” (Oncologist (CS1), p5/1).

Although there was some evidence on surgery, it is a complex procedure involving the collaboration of different disciplines and patients may not necessarily meet the criteria and have other co-morbidities. However, patients may not have this information or understand the levels of decisions made by healthcare professionals.

Robert compared his condition to another patient in the same bay. He said:

“A chap, he’s in the room...and he’s got the same as me ‘a spot’ but his is actually curled around the spine and they don’t know what to do with it. He’s going to have operation to get rid of that before he gets err...chemotherapy or anything. They never told me mine is...err...but they are giving me...I am getting radiotherapy. So, it must be alright, not having any worries about me ‘crippled man’” (Robert, patient (CS4), Interview 1, p9/15).

It was not clear whether the patient understood his condition; it appeared that his consultant made a trade-off decision:

“Re-treatment is always difficult. We would have considered surgical intervention. I presume it’s because...er...of the extent of the disease, which was...um...extensive (just looking at the MRI scan report) and the fact that he’s got multiple areas of bone disease, which would make surgery more difficult. But, certainly, you need to consider – both the first time and the second time – surgical intervention. That was excluded...ah...and, therefore, we re-treated him with radiotherapy” (Oncologist (CS4), p2/14).

Some oncologists made decisions based on the age and the general health of the patient:

“Err, and I think for young, fit patients, there may be a role for surgery, err, so the role of surgery was discussed with the on call neurosurgical team and felt not to be appropriate” (Oncologist (CS6), p1/23).

The oncologist was trying to make a trade-off decision based on the patient being young and fit and the potential that surgery could prolong life. One member of medical staff expressed that most challenging thing for him was to inform the patient whether surgery was possible or not:

“So, sometimes we might feel a bit inadequate in answering the patient’s questions about these things, but then we say that neurosurgeons are the best people to answer these questions. And, in our minds, sometimes it is difficult because...err...the decision of whether to go ahead with operative treatment or not can be different, depending on the surgeons involved. So, I think there’s probably...it needs a bit of consistency in that...in...in the decision on whether to operate or not – because we need to tell the patient”(Registrar (CS7), p12/20).

The accounts suggested decision-making on surgery depended on the neurosurgeon but this could differ between neurosurgeons and this could delay the treatment for the patients. As he indicated, Tony’s operation was delayed. On the other, he also pointed out that the surgeons may have their own priorities, time factor and availability of resources such as theatre. In addition, the doctor was uncertain how decisions were made for Tony and Emma:

Registrar: Err...I’m not sure, to be honest, in the sense that...err... Because we had a similar patient but...who had a slightly...err...she had some evidence of neurological involvement before, and she was not offered an operation. (Registrar (CS7), p13/14)

Researcher: Are you talking about Emma?

Registrar: Yeah. So, the thing is she had a bit more neurology and she was in a similar situation as Tony: she had a mixed response to chemotherapy, she was on a trial...similar sort of situation. She’s a young patient as well. But she had some neurology at presentation, so I don’t know if that was the decision...that was the reason why they decided not to operate on her” (Registrar (CS7), p13/20).

The above showed the decision making process can be complicated and no two cases are the same and the neurosurgeons criteria for surgery may differ. Conveying this uncertainty to patients can be awkward. The neurosurgeon gave his reasons on Emma's condition:

"If the spine is unstable and you can put metal-ware in, you stabilise the spine, yes. But in her case, we had nothing to fix the metal-ware to – with the multiple secondaries up and down the spine" (Neurosurgeon (CS6), p7/3).

However, the neurosurgeon prioritised patient's survival to benefit from surgery:

"Whether or not we operate? Yeah. Um...basically, it comes down to how long does the patient have to survive? If the oncologists say 'well, they've got several years of life - you know, predicted life –ahead of them'; that's fine, we will do large operations. If, however, they say 'well, there's only three to six months of life, we expect,' then it really isn't appropriate that we have...undertaken massive operations. They are not going to recover. They are not going to live long enough to recover or get any benefit from it" (Neurosurgeon (CS6), p5/1).

The neurosurgeon made a 'trade-off' decision based on patient's life expectancy and quality of life. However, he depended on the oncologist to predict the patient's life expectancy before any decision on surgery could be made. Sometimes this movement of decision making between the oncologist and neurosurgeons could cause some confusion for the patient who may have been given the impression that surgery could 'fix' them and then it turned out that surgery was not possible. The neurosurgeon explained:

"The major problem, from my point of view, is getting them (patients and carers) to understand why you've made the decision, you know, whatever you've arrived at, trying to explain to them. Because, they usually know people that have had an operation and trying to explain that no two are the same and there are various things you have to think about... That can be very difficult for them to get hold of, especially if they've spoken to someone...um...say outwith oncology, or out with neurosurgery, who has already given them an idea. Um...which we meet quite commonly: 'oh, you'll go to the neurosurgeons and they'll fix you'" (Neurosurgeon (CS6), p7/13).

This account suggested that the patient's expectations may be raised but conveying the decision can be complicated when the patient was given 'false hope' and the neurosurgeon needs to balance the perceived benefits of certain

treatments with the realities of the trajectory of the condition. When surgery is not an option, some patients would ask for more information about other treatment. The neurosurgeon said:

“Usually, if there’s no surgery: “what is the treatment?” “Will the treatment make them any better?” If the answer is “no,” I have difficulty answering that. I don’t know what the outcome is from radiotherapy, so I tell them to ask the radiotherapist that. Um... “how long will it be before they’re completely unable to walk?” Again, it’s impossible to say that. Usually, they ask questions to which we don’t have answers: they want us to look into the future and cross bridges we don’t even see. Um...it’s very difficult to answer the questions” (Neurosurgeon, CS6, p8/14).

The exchange in conversation illustrates the difficulty the neurosurgeon faced in conveying the decision to the patient when surgery was not possible and the outcome of radiotherapy uncertain. In addition, this account demonstrates the patient had to approach several people to get answers to their queries.

Another neurosurgeon gave his views on his decision about Tony who had metastatic colon cancer:

“What is the prognosis and how good are they at the moment, if they are bad to begin with and they are unlikely to walk again, well, they can but they are much less likely to...so that’s my view of them, that’s the two difficult things; one is easy to sort out, walking or not, the histology and the implications of it but the prognosis is the harder thing” (Neurosurgeon (CS7, p7/11).

This suggested that patient’s mobility status and prognosis was an important guide. However, when asked what other criteria he would consider in his decision making to operate on the patient; the neurosurgeon considered:

“No, just looking at him and talking to him, what is his expectation, what he wants to do and all those sorts of thing, that’s what guides me most” (Neurosurgeon (CS7), p7/21).

Here it appeared the neurosurgeon used a person-centred approach to his decision making, taking into account the patient’s wishes.

Accounts from patients and carers also illuminated their strategies for coping with uncertainty when there were limited treatment options. Richard talked of his prostate cancer which had spread to his bones and moving from one clinical

trial to another which failed to bring down his PSA (Prostate-Specific Antigen). He summed up his lack of choice treatment-wise:

“I know it’s not curable which I think is the main thing. I know all the treatment I’m getting is to give me relief and to keep cancer at bay but each time they do it, it’s likely that’s going to show itself in another place and I know they can only do so much” (Richard, patient (CS5), Interview 1, p25/18).

This showed the patient knew progression of cancer was beyond his control and there was a sense of disempowerment. The following account revealed that Richard wanted quality time with his wife but found it frustrating:

“So, I want to cram as much into what time I’ve got ... is now to do as much as I can. And that can be a little bit frustrating ‘cause there’s lot of things stand in your way like going on holidays and things like that. Like booking and suddenly find you’ve got treatment, so you got to cancel your holidays, all stuff like that” (Richard, patient (CS5), Interview 1, p23/7).

Recurrence of cancer presented challenges and brought sudden changes to the plans of Richard and his wife. As identified above, Richard had to make a ‘trade-off’ decision on receiving treatment versus spending quality time with his wife.

In some instances, decisions could be made by the registrar or on call oncologist to transfer the patient to the cancer centre for treatment. The patient is then referred to the cancer-specific oncologist for subsequent care. One oncologist gave Jock’s case as an example:

“But this guy had hypercalcaemia, which is a poor prognostic factor for malignancy. He had metastatic disease in his lungs, which is a poor prognostic factor...erm, and what we seemed to have succeeded in doing erm...was to make him spend twelve of his last 34 days in the cancer centre, rather than in his district hospital. So, our attempt to prevent his spinal cord compression progressing had the effect of separating him from his family and friends for one-third of his remaining lifetime. Erm...whether, if we hadn’t treated him, he would’ve become paraplegic in the meantime, I don’t know... [...] But I don’t think that discussion would have been held with him before he came up” (Oncologist (CS8), p2/14).

This excerpt suggests that decisions to accept patients could be made by a doctor on call without exploring this with the patient. The decision about

treatment may or may not have been discussed as to whether to trade-off treatment against quality of life considering the patient's poor prognosis. There seemed to be a chain of decision making at various levels with patients coming through the system from different pathways. There is the likelihood of delayed diagnosis and treatment and the impact it would have on patients and their carers was great.

One neurosurgeon commented on the local MSCC referral pathway:

Neurosurgeon: [Pause] It's fine. They should come to neurosurgery first because the big decision is going to be: 'can we do an operation to improve the patient?' If we can't, we know where the patient's going. Um...referral to somewhere else – to oncology, for example – sometimes doesn't result in the neurosurgeons being involved until it's too late" (Neurosurgeon (CS6), p9/28).

Researcher: You mean to say...would you see the patient first, or...?

Neurosurgeon: I don't think it matters who sees the patient first in a good system, as long as the neurosurgeon gets involved in this decision – 'will there be an op?' – at the beginning. What we sometimes see is the patients come to us with a...say, two collapsed vertebrae, but these metastases have been known about for six months. You know, we may have considered resection six months earlier, when the neurological...the neurological state is much better, whereas, now if they have collapsed...compressed the cord, there's no guarantee we can produce improvement. We sometimes feel we should've got some patients sooner, but there's more than one pathway. [Laugh]" (Neurosurgeon (CS6), p10/5).

This account suggests that the likelihood of prolonging patient's life expectancy is better if the patient was referred early before vertebrae involvement.

Importantly, the neurosurgeon should be consulted in the decision making about the feasibility of surgery. However, co-ordination was required to achieve this. The neurosurgeon considers:

"...but, certainly, a hospital based team (the same as they have the MDT for inter-cranial tumours) would be very useful, in that we could meet... well, the MDT meet once a week; we could meet once a week/once a fortnight (they're not as common) and discuss the best way forward for patients, but er...I think that would be a good move: to have a team that meets – sort of, surgeons, oncologists or whatever description, and radiologists meet and discuss the case" (Neurosurgeon (CS6), p12/14).

A multidisciplinary team (MDT) for MSCC would allow an understanding of the decision making process and avoid delaying diagnosis and treatment. However, there was no mention of including the patient as part of the team and identifying what the patient's preference or needs are.

Data showed healthcare professionals made their decisions by taking into consideration the available evidence, consulting with other colleagues and the patient's life expectancy. Some healthcare professionals seemed to focus on the neurological condition and prognosis of the patients to plan decisions around treatment, whilst others involved patients in a person-centred approach by identifying what patients wanted. The complexity appears to be the different pathway patients undertake and this can delay the diagnosis and treatment. To reduce the decision making process chain, a co-ordinated MDT was seen as a possible solution to the management of MSCC. However, including the patient as part of the MDT team would identify what the patient's preferences and their needs are. In the next sub-theme, some patients and carers give accounts of how they recognised they needed to move forward and described their battle plans in facing the uncertainty of MSCC.

5.3.2 “Battle plan – what is the next step”

This sub-theme “*battle plan – what is the next step*” was described by one of the carers which reflected the patients and carers accounts in trying to find a balance by seeking out other treatment options and quality time with their family. There was a sense that patients and carers wanted to move on, however, some of them found difficulty doing this with the uncertainty of MSCC. Healthcare professionals on the other hand were often uncertain about a patient's response to treatment and whether they were suitable and fit for further treatment. This sub-theme describes this mismatch between the two requirements.

For example, Emma and Matthew described wanting to know what the healthcare professionals had for them which they referred to as a “*battle plan – what is the next step*”. Matthew was keen to know:

"I mean, once I know what's happening, I can get a battle plan, as it were, eh. [...] Eh...just how positive Emma is and how much she keeps fighting on. We try to look into err...to different treatments, err...or all different options, diet eh and everything like that eh. Just to keep fighting away; you cannot...they always say you cannot lie down eh to these things. If Emma keeps fighting, I will keep fighting" (Matthew, husband (CS6), Interview 1, p27/12).

The excerpt suggested the patient and carer look for other perspectives and described their determination to find alternative treatment. The use of 'battle' language seemed to illustrate having control of the situation. The occupational therapist thought Emma may not have been realistic but gave an explanation of the patient's positive mind-set:

"But what's hard with this lady is that um, four years ago she had cancer [bowel] and she was told she only had six months to live. And she's still here. But when we told her that 'we don't expect the power in your legs to come back', it may be hard for her to accept that". (Occupational Therapist (CS6), p12/27).

The patient's experience of defying the odds seemed to add uncertainty to the trajectory of cancer and could potentially make planning for end-of-life care difficult.

Jane also used "battle" language to illustrate her point as her husband previously had an episode of MSCC:

"We were devastated when he was diagnosed with it, you know, we just said 'well, we'll fight it together' you know. And then, when we knew that it was into the bones... my doctor at that time said 'look, it's very slow, very slow growing in the bones. You could die of old age before that, you know'. He would have the bad pain because of that in the bones, and then we had quite a long period in between that he was well and you push it to the back of your mind" (Jane, wife (CS4), Interview 1, p2/19).

The account suggested a fighting spirit, a sense of having control of the situation. There was also a sense that trajectory of cancer was a long process full of uncertainty of when recurrence could occur. This illustrated patients and their carers coped by compartmentalising cancer in their mind.

Richard, for example, knew that his treatment was palliative but there was uncertainty about further funding:

“But I’ve still got the radiotherapy to go through, I’ve got the chemotherapy if they get the funding and I’ve still got the strontium, so I’ve still got, you know, like three, not options, but three things I can get which is going to be of help at the end of the day so that kind of gets my life line” (Richard, patient (CS5), Interview 1, p25/2).

There was a sense of this patient wanting to have the reassurance that there were further treatment options available. However, his consultant was uncertain whether Richard would respond to his radiotherapy treatment and whether he was fit for further treatment. The oncologist talked about his concerns:

“Err...I mean he did well, he got his radiotherapy, he’s still walking, actually walked home. And it’s just that he’s a very unfortunate man and his disease progressed unfortunately. Hopefully he might be well for the second line treatment but he might not be” (Oncologist (CS5), p3/34).

Although there was uncertainty on the treatment outcome, the advances in cancer treatment could raise the patient’s hopes and expectations and this added to the uncertainty of prolonged survival. Furthermore, the availability or appropriateness of treatment complicated the perceptions of patients and carers. For example, both Sandra and her husband, John, took a political view on the availability of treatment. Sandra was uncertain of her treatment plan:

“Um...I don’t know what kind of treatment plan they are going to offer me. And I don’t know how much say I’ll have in that. And then you wonder, well, if it is NHS, if it is private, if I was in different county, is there different things that I would get? ...what I was told was that the operation could be more dangerous towards me than the tumour is itself at this stage. And that I suppose I can accept. But then you think, is it money? Is it politics? Is it just that that’s the way the NHS is?” (Sandra, patient (CS2), Interview 1, p22/8)

This account suggested the patient questioned whether she was at a disadvantage in terms of treatment being offered to her. Sandra had difficulty coping with this uncertainty:

“But I just don’t know what the future holds, and this living in fear, I suppose, is hard to cope with most of the time [patient became emotional]” (Sandra, patient (CS2), Interview 1, p22/26).

This account reflected the anxiety Sandra experienced not knowing her future treatment. John, however, identified the inequality between the resources given to the treatment for cancer.

“You always got the doubt- is the drug that is being dispensed the right one for you? Because I mean I recalled a few years ago, we actually knew somebody in the north east, his wife was diagnosed with breast cancer. And at that time she was on a drug which we couldn’t get up here but the drug Sandra was getting at that time was a better one than what she first got. At the end of the day, it’s the postcode lottery whether you’re staying in the right place and all the rest of it” (John, husband (CS2), Interview 1, p6/25).

Here there was a doubt about the right drug being given and whether the treatment given might be subject to the geographical area the patient is from. Healthcare professionals stressed the importance of telling patients the aims of the treatment, however, that can be challenging:

“Um, for the patient, they should be...should be aware of the aims of treatment, um... and I think it’s quite a difficult thing when patients come in with very poor mobility because of spinal cord compression. It’s, em, I don’t know, really know how we’re meant to say to them ‘this might not get much better’. I don’t know how... it’s...it’s very difficult to say that to a patient you’re trying to treat. And it’s, you know, you want to leave them with some hope that they might get their mobility back, um... but that maybe brings unrealistic expectations for the patients and relatives” (Registrar (CS2), p9/12).

Healthcare professionals want to be realistic yet they do not want to take hope away from the patient. Getting that balanced was challenging. There seemed to be tensions within their experience of balancing hope and reality.

Some patients seemed to try to find a balance by coping with their treatment in stages. In Jimmy’s case, further treatment depended on how well he responded to his treatment:

“What really is going to happen, I’ll only do that as it comes along. I told you it’s the five treatments of radiotherapy. No, it should finish but they are extending it so I am doing another two – just two and that’s another back part and they are going to check that. Then hopefully, I have agreed to do the other four and a half or five weeks – that’s another session” (Jimmy, patient (CS3), p11/3).

This account showed the uncertainty in the treatment outcome and there was a sense of coping with the here and now. Despite saying he was going to take it “a step at a time”, Tony appeared anxious on the plans after his discharge from the hospital:

“But I’m sure the neurosurgeon has been in touch with oncology ward, so I’m imagining they will tell me, before they release me, what the next step is, but I don’t know, as yet” (Tony, patient (CS7), Interview 1, p32/27).

This indicates that the discharge plan had not been discussed with the patient which placed undue worry on him. When Betty was informed that there was nothing the doctors could do, she described her future as ‘a journey’ and how she was coping:

“And, as I said, they couldn’t do anything more for me, but I said ‘we’ll take it from there’ I just take one day at a time and make the most of what I’ve got there in my family and... I’m quite...I’m not even stressing myself out about it because I know that this is another part of a journey I’m going on” (Betty, patient (CS1), p21/13).

There was a sense of helplessness at the same time trying to have positive thinking by focusing on “here and now” instead of worrying about the future.

Some participants felt disempowered when there was no treatment option available; however, this varied and as demonstrated below, Betty seemed to accept her illness:

“And I depend on Him (God) for everything. And my faith keeps me strong. And that helps me to keep my calm in the storm” (Betty, patient (CS1), p18/23).

Here, Betty seemed to try to take control and find meaning in her life by turning to her faith for comfort. The patient adopted a positive outlook which was seen as a strength that provided a sense of meaning and coping.

Jock voiced his anxiety about his immediate future when he got back to his local hospital:

“I don’t know what they’re going to do to me next. And I’ll probably go to [name of local hospital] tomorrow or the next day. Well, as soon as they can get transport I think” (Jock, patient (CS8), Interview 1, p1/5).

Jock was also uncertain of his future living circumstances:

Jock: Looking away ahead, the only thing that worries me is if I ever needed to be taken into care where...I do not want that. That's a worry.

Researcher: What do you mean by that?

Jock: Well, a care home or something. Well, you'd have to pay for it, for a start. Selling your house and all this nonsense.

This quote illustrated the patient's worries about his future living and financial circumstances and implications for his family.

This sub-theme illustrated the notion of finding a balance where patients were seeking other perspectives in the midst of MSCC. Some patients and their carers looked for alternative treatment, others were uncertain about future funding for their treatment and some participants were accepting of their condition and future. Some of the patients and carers expressed their doubts about the efficacy of the drugs provided, realising the potential futility of continuing treatments whilst others felt that the provision of treatment could be politically influenced. However, there were also tensions in balancing hope and non-curative treatment, which added a layer of uncertainty to the pathway of cancer.

Data illustrated some patients tried to move on by coping on a day to day basis whilst others seek a '*battle plan*' to deal with the unknown. Healthcare professionals wanted to give a realistic picture, however, they did not want to take hope away from the patients. When there was no treatment available, some patients accepted their illness by turning to their faith for comfort. Others were worried about the demands of care on their family. These data demonstrate that all participants, lay and professional had a number of decisions and preferences to balance, as they dealt with the uncertainty of MSCC.

5.3.3 Perception of the demands of care

The accounts in sub-theme 5.3.3 illustrate patients' concerns about the lack of support for their carers. Some patients were worried about imposing demands of care on their carers and families. As a result some patients revealed little information about their condition to their families. Carers, however felt healthcare professionals did not involve them enough in the care of their spouse or parent.

Healthcare professionals thought that as the majority of elderly patients had an elderly partner they might be too frail themselves to care for the patient. The following are examples of the different perspectives that patients, carers and healthcare professions took in trying to reduce the demands of care.

Some patients were concerned there was no support for their carers. Richard commented:

"I think a lot...more emphasis maybe put on the people that care as in if it's the daughter looking, err...someone or a wife looking after the husband because they at the end of the day, are the carer, not someone that comes in from outside to either clean the house or to do whatever they do, you know, it's that individual who is attached to the person" (Richard, patient (CS5), p29/7).

The above account indicates the patient thought his wife needed some support. Jimmy was resigned to giving as little information as possible to his wife and family. He described his wife as a 'worrier'. He considered:

"How the consultant is taking it, he'll not say 'see you in December you'll not be walking'. He's not telling me that, because he doesn't know. So if he doesn't know, how do I know? So, if I don't know, I don't tell my family. So, why give them extra worries, concerns, if it is not necessary. And that's the way I am looking and that's the way I want it. My wife, she got upset and crying and the rest of it, you know" (Jimmy, patient (CS3), Interview1, p10/24).

This excerpt reflected the uncertainty of the trajectory of cancer and it appeared that the patient was trying to protect his family from unnecessary worries. It demonstrates the patient taking control of the situation and making his own decisions based on knowing his wife and protecting her.

Likewise, carers were trying to protect their loved ones. Jane talked of her “*built up*” stress from the time John’s prostate cancer had spread to his bones. Jane became emotional as she revealed her state of mind:

“You learn to live with it. And I keep up for his sake, you know, I’m on anti-depression tablets which he doesn’t know” (Jane, wife (CS4), Interview 1, p1/31).

This interpretation indicated that carers faced challenges in caring for their loved ones over time and the illness often had an unpredictable trajectory. Although Jane said she could turn to her children for help, she was reluctant to make demands on them as they had their own families. Jane confided that it was her GP who detected that she needed something to calm her nerves:

“Ehh, I think the doctor saw that I was needing...needing just something” (Jane, wife (CS4), Interview 1, p20/18).

The carer’s ongoing concern had an impact on her quality of life, however, GPs often develop a close relationship with patients and their families and it appeared that Jane’s GP was able to recognise her needs.

Mary looked at caring for her mum as her ‘*responsibility*’ rather than a burden and was disappointed the healthcare professionals did not involve her in planning her mum’s care. Mary stressed her point:

“...whoever makes the decision doesnae (does not) know what sort of family... one shoe doesnae fit a dozen people, you know what I mean. Basically, it should be discussed with whoever it is that cares for you, whether that is going to be possible” (Mary, daughter (CS1), Interview 1, p17/14).

The point the carer was making was that family support differs and here she wanted to be actively involved in her mother’s care.

Data revealed that often the carer was unaware of what was being planned and felt that healthcare professionals made assumptions of their needs. The family circumstances and life stage of patients and carers was instrumental in how they coped with MSCC and the support they needed. However, it appeared

that healthcare professionals had to consider various factors in protecting the family. The oncologist gave his views on the reality of circumstances:

“The people who are paraplegic will very often go to hospice, rather than home. Um, on the grounds that in, err, an elderly population needing full care, there is rarely a carer who can do that, because the carer is usually as old and not much less frailer than the patient you want to look after in the first place. Um, and you always have concerns about having one seventy-five year-old looking after another seventy-five year-old at three o’clock in the morning: what happens when that goes wrong?”
(Oncologist (CS1), p16/25).

Here, the patient and her daughter may be oblivious to the intention of the healthcare professionals to protect the family. These interpretations suggested that getting a balance was complex and the medical management and treatment was not always a priority for patients and carers, particularly once pain and symptom management was achieved. There existed a mismatch in many respects between the meaning of balance for healthcare professionals and patients and their carers. This second theme has drawn on patients’, carers’ and healthcare professionals’ accounts to provide a picture of the processes of decision making and strategies in finding a balance in the uncertainty of MSCC.

5.3.4 Summary

Data illuminated trade-offs between treatment versus quality of life and how patients and their carers talked of ‘*battle plans*’. Some patients seemed to have strategies to move forward whilst others had difficulty living with the progression of their cancer. There was evidence of different views on the demands of care from all perspectives. Some patients were concerned with the lack of support for their carers. There were, however, some patients who did not want to worry their families. Carers, on the other hand, felt left out of the discussion about the care of their loved ones. Contrary to this, patients and carers were unaware of the healthcare professionals’ intentions of reducing the demands of care when planning what they thought was appropriate for the patients and carers needs.

5.4 Support beyond the treatment of MSCC

This last theme demonstrated patients' and carers' transitional needs from hospital to home or district hospital/hospice, after the initial treatment of MSCC. The long-term implications became more obvious as patients, carers and healthcare professionals participated in a range of decisions and negotiations around how care should be managed. Sub-theme 5.4.1 "*They say there is support out there but...*" showed differences emerged between groups of participants. Examples were given where healthcare professionals were providing for what they perceived were the support needs of the patients in the community. This did not necessarily match with what the patients and their carers wanted. In addition patients and carers sometimes felt excluded from the decision making. Furthermore, some patients faced challenges living with the progression of cancer and sub-theme 5.4.2 illustrated patients and carers inherent anxieties around 'determining the final moments'.

Healthcare professionals may not be aware of how to facilitate these changed priorities or the needs of the patients and their carers. Below are the accounts of patients and carers as their priorities changed and how manoeuvring the healthcare system was challenging from all perspectives.

5.4.1 "They say there is support out there but..."

Given the nature of MSCC as a condition and the limited life expectancy of many patients, issues around going home could be contentious and different views could prevail. This 'in-vivo' code "*They say there is support out there but...*" indicated patients and their carers had various needs at different stages of their cancer journey. However, healthcare professionals provided support they thought matched the needs of the patients in the community. Some carers, on the other hand were not consulted about what was needed. Furthermore, patients and carers priorities and needs changed and healthcare professionals were not always aware of this, so did not anticipate and facilitate these changed priorities.

For some patients, their physical capabilities meant they could not carry out their daily activities. During her time on the ward Sandra was assessed and identified by a member of staff that she needed some equipment to help her at home. However, the staff said:

“We have another pro-forma here...that tells us kinds’ of what kind of house, there’s any problems. She might have needed a bed rail to help her get in and out of bed. We have a social meeting every Tuesday to discuss this kind of things. But she’s probably been and gone. And it has been decided no” (Staff Nurse (CS2), p4/5).

This account suggested the patient was discharged home very quickly and this precluded addressing these issues. It appears there was a lack of follow up. Sandra also found getting practical help was difficult:

“They say there is support out there. I did speak to the financial guy, who said there was nothing they could do for me. I did ask about a disability pass because if I’m trying to carry messages or...or walking... but because I can walk 50 metres, I’m not entitled to a pass” (Sandra, patient (CS2), Interview 1, p27/19).

Here, it appears the patient had difficulty obtaining help from social services agencies. Besides facing physical challenges, some patients and their carers had financial worries.

Sandra’s husband, John considers:

“You don’t seem to get an allowance for having cancer. No, well, the thing is we have a wage packet we don’t get any help, right, because we earn too much money. It’s people who don’t earn money at all who seems to get it which I think is quite wrong because at the end of the day I’ve paid my tax and national insurance and I feel as if why should people in the lower income just get help with...you know, I mean we’ve got a lifestyle we still should get help” (John, husband (CS2), Interview 1, p19/19).

In contrast, Jimmy got help with claiming his benefits:

“I have something from the doctor I have to send away for. Letters...aha...benefits. She (clinical nurse specialist) said ‘you definitely got to get that’. I get it for my legs and arthritis in my back – a small one. She said no, she says you have to get a lot of benefits because you need to jump in taxis and all the rest, you need to move about and you take that” (Jimmy, patient (CS3), Interview 1, p15/20).

These accounts suggest some patients needed disability or financial support but they may not necessarily know how to access the appropriate social services.

In Jimmy's case, he felt supported by his nurse specialist in helping him with this information. However, many patients were unaware of this assistance from the hospital social services department or the Macmillan, or Maggie's Centre.

For patients who were mobile, going home was straightforward, however, if the patient was paralysed, this was more challenging. For example, Betty wanted to go home but her daughter, Mary, described getting her mum home had been "a fight and red tape the whole way". Mary stressed her point on both interviews:

"I think what is important for medical staff erm...that are dealing with people with...spinal cord compression or any sort of cancer or illness that erm...patients have a right when they do want to go home. They have a right. And family have a right to make the choice whether they want to care for family [Patient: at home] and they shouldn't have been dismissed without actually speaking to the family" (Mary, daughter (CS1), Interview2, p23/23).

This account suggests the patient's daughter wanted to participate in decision making in her mother's care and was prepared to care for her. However, the registrar who was assigned to see to Betty's discharge anticipated the risk of Betty going home:

"And because she lived alone, um...it would be medical negligence to send her back home, where she can't cook, eat, or go to the toilet, or anything like that. So, the hospice was the only viable option in her case, because she's big – totally immobile. If she lived with somebody, that person alone can't take care of her needs" (Registrar (CS1), p18/9).

This account suggests that healthcare professionals make decisions they perceive to be in the best interest of the patient.

However, the patient and carer may not have been involved in discussions and/or the availability of support in the community investigated. Mary was able, through her friends working in their local hospital, to arrange for her mum to be

transferred there instead. Four weeks later, during my second interview with Betty and Mary at their local hospital, they were still waiting for her discharge home. Two community nurses talked of their experiences of arranging for Betty's package of care:

"Because this lady had been risk assessed by the hospital to say she needed four people at all times for moving and handling. This was a big problem for us. But they also said that she needed 24 hour care. We do not provide 24 hour care. But you've got the legal aspect of then putting your staff at risk, - lift, moving and handling with people who aren't properly trained (meaning the carer). We had to get legal advice before she came home, you know, where we stood legally if family wanted to be involved" (Community Nurse 2 (CS1), p5/34).

This interpretation suggests that although the patient's family wanted to participate in the patient's care, there were legal implications involved. Moreover, arranging a care package also involved approval from other agencies. The community nurse continued:

"So, you're always waiting on people getting back to you. So, it's just getting the puzzle to fit. [...] but this is with every discharge: you get limited information and it's like a fishing trip; you have to get...you're gathering information from everybody you meet until you build up a better picture" (Community Nurse 2 (CS1), p20/6).

It was notable that getting resources involved a range of agencies and it was evident that getting coherent information and transition in care from hospital to home could be challenging for the community nurses.

One of the community nurses talked about the assessment done by the hospital team:

"I think it was the multi-disciplinary team within the ward that said that was what was needed. And if that hadn't been documented, we could have then gone and done our own and decided, because the lady was easier to move than initially we were told. Once she was at home, things were different. You know, with the right – we didn't put a hoist in because it did hurt her and because of her oedema, etcetera – but with the right sliding sheets, the right bed, etcetera, she was easier to move, and I think two could've probably done it" (Community Nurse1 (CS1), p8/12).

These accounts highlight the prescriptive pathway followed when arranging for this patient's care package and delayed the patient's discharge home. This

proved challenging for the healthcare professionals in the community as they needed to look beyond the task and take into account the other aspects of the patient's needs, home environment and priorities for continuity of care to be effective. In contrast, Emma's going home was a different experience. The occupational therapist considered:

"The options have been discussed with her. You know, whether its home or hospice or somewhere else. Um, we discuss with her and her husband and they both were super keen to get her home" (Occupational Therapist (CS6), p12/13).

Here, Emma had an accelerated discharge home with all help put in place. The occupational therapist commented on the swift community arrangement:

"They're all working really efficiently actually. Because initially we were saying that maybe the end of next week, but we gave the district nurse a phone and she says that 'we can maybe try and get services in by Tuesday'" (Occupational Therapist (CS6), p17/27).

There seemed to be variations in getting support from different geographical areas. In some regions, support was arranged and put in place at short notice, whereas in other areas, support services were not readily available.

Furthermore, it was apparent that some patients were given a choice in their place of care whilst others did not have a say. A senior nurse described that discharge planning can be challenging:

"Erm...I guess for us, it's...it's really the ongoing (care). Cause, I mean we're quite an acute side of things. And it's the uncertainty of how long it's going to take for that patient erm...to find the appropriate placement for them. And for us that's...even in the acute area, that is a problem" (Charge Nurse (CS1), p6/22).

There was a sense that trajectory of cancer was a long process and considered a chronic condition and when an acute episode occurred this needed immediate attention. However, arranging subsequent care was challenging and patients needs could be overlooked.

Although Jimmy was still mobile, his consultant gave his reasons for referring Jimmy to the palliative care team. He said:

“And we usually...we try for most patients, if they will accept the idea, to get them to make contact with Marie Curie.... Macmillan at diagnosis, if they are incurable. Because it means that, when they do need somebody, they know where to go straight away, and they know who the person is, rather than otherwise” (Oncologist (CS3), p16/6)

This account indicates the oncologist was anticipating the patient’s future needs and addressing the transition from hospital to the palliative care team in the community.

In Jimmy’s case, he was happy for his consultant to make the decisions for him:

“I think it’s the Marie Curie or something this way or another. The other support to get me for here: my own doctor, the nurse who sees me – excellent. Even...even my family says she helps me in every way, helps me in every way: ‘Jimmy take this’, ‘Jimmy do that way’, ‘that’s the way’. She will work out for me” (Jimmy, patient (CS3), Interview 2, p10/34).

Here, it appears Jimmy accepted his follow-up care unequivocally. This excerpt also highlights that his specialist nurse was his source of professional support and that there was a sense of staying connected and supported. Some patients and their carers seemed to get into a routine by the time of the follow-up interview. For example, Matthew laughed when we talked about using the hoist *“I think I’m better at that than most of the nurses that come in!”* He added with the nurses help:

“Yep, gets her up in the morning, gets her all ready to go, and then at night just putting her to bed. They were here three times a day, but we were finding they weren’t needed, so we just put them off. It gives us our day” (Matthew, husband (CS6), Interview 2, p2/5).

This excerpt indicates that the patient and her husband had priorities and needs which changed over time and they wanted privacy and quality time together.

Richard was discharged home but experienced difficulty controlling his pain. A week later he was admitted to the hospice for pain management. When Richard’s condition deteriorated, Linda, felt the healthcare professionals at the hospice did not give him an opportunity to stand on his feet but treated him like *“an invalid”*:

“It’s like I’m out of control, that they...that the people who are looking after him now have the control and, you know, they’re, they’re kind of managing him in a way which I am not in a total agreement with. Um, I mean I wouldn’t mind...you know, cause I understand they’ve got to protect their own staff, but what I would like in addition is perhaps using the hoist is giving him a chance to stand and to get practice in that” (Linda, wife (CS5), Interview 2, p23/18).

Linda, also a nurse herself said she understood that the staff would be blamed if they knew about Richard being at risk and did not take notice. However, she expressed that healthcare professionals may assume *“the risk was high”* although she thought it was a *“probability”*.

“So, I do know all that, but at the same time I think there’s a balance between risk and I don’t, I don’t know quite how to put it, um, because like we all fly and we all go in cars and we know there’s a risk. It’s not...life isn’t free from risk, and it’s that balance of trying to not take away unnecessarily someone’s independence without trying to maintain what they have” (Linda, wife (CS5), Interview 2, p25/8).

The account above suggests that sometimes carers were willing to take risks. The interpretation also highlighted this sudden disruption could be challenging for carers to cope and they wanted some control in managing their daily routine. It also appeared that the carer may not have been involved in discussions about the patient’s deterioration or about the use of the hoist. Linda added:

“I’d imagined we’d use a wheelchair of course but I didn’t realise we’d be using a hoist or we’d be waiting on people coming to do that and all that kind of thing and, you know, having people come four times a day. I mean your life’s not really your life anymore” (Linda, wife (CS5), Interview 2, p29/19).

This account demonstrates that the level of support and the nature of the interventions required came as shock to the carer. Although Linda was grateful for the care and attention, she felt that healthcare professionals were *“a bit prescriptive”* and did not understand why using the hoist could not co-exist with giving her husband some opportunities to stand. Moreover, there was a sense of apprehension of losing their control and privacy with the frequent care that was planned. In addition, carers expressed that they faced a dilemma when discussing their concerns with the patient’s consultant. Linda considers:

“I think because he’s under the hospice then the doctor [consultant’s name] obviously isn’t going to interfere with that, so all we’re gonna do is go back and see, um, the consultant at the end of the month I think” (Linda, wife (CS5), Interview 2, p4/11).

This account suggests that patients and carers have to deal with different care providers and getting their concerns across was not easy. The lack of opportunity to discuss their concerns resulted in continued anxiety and uncertainty in the carers. In some instances, patients reported there were issues around communication between the hospital and their GPs. Sandra commented that her GP was not in “*the loop*” and was “*not up to speed*” with her recent admission to the hospital:

“And two weeks after I was out [of hospital] my doctor still well...two weeks after the consultant had prescribed me this drug, two weeks after that she still hadn’t had the letter telling her what drug I was on. I had to spelled it out to her and take the packet with me to show her what it was so that she could get the prescription ordered” (Sandra, patient (CS2), Interview 2, p45/18).

Continuity of care could be a problem when communication was delayed. This may result in treatment delays, increased stress and a loss of confidence in the health service. Some GPs felt communication with the hospital was adequate; however, one of them felt that a personal call could clarify patient’s subsequent needs. One GP said:

“...they were absolutely insistent: oh, the hospital says that the nurse has to do this, you know. And so, our district sister was going in every day for two weeks to check blood sugar that there was nothing wrong with, you know. [...] it might have been better if someone had phoned up and spoken to one of the doctors in the practice – because that was kind of complex – and explain what was happening, rather than just send this home with a message to the patient which was very clear but probably unnecessary – I mean, there was really no need for that man to check his blood sugar twice a day, there really wasn’t” (GP (CS4), p6/32).

This excerpt suggests the hospital was prescribing ‘hospital type care’ instead of discussing with the patient’s GP. As the GP knew his patient was diabetic, his wife would not have the problem of monitoring her husband’s blood sugar. This also suggested that resources could have been better placed in other areas. Similar communication issues were also encountered between

hospitals. The registrar at the Cancer Centre commented about receiving Jock from the district hospital:

“Um, in Jock’s case, when he was transferred up, um, he had very little information sent with him about his, um, his background and certainly he had a transfer letter but he had had previous follow-up for his prostate cancer and none of those letters were copied, um, and sent up to us, we had to organise that after he was admitted” (Registrar (CS8), p16, 18).

This showed the need to gather information from different aspects of the patient’s medical history. The registrar at the district hospital had difficulty making out Jock’s discharge information and commented Jock needed further investigation and explained why it was delayed:

“Erm, I had spoken to them on the phone before I went on holiday to basically say ‘yes’ to his transfer coming back, and they had mentioned a possibility of a biopsy erm, and they said they would put it in the letter which they sort of did, but it was, as I say it was difficult to read. [...] there was a delay because the staff who received him back couldn’t read the letter clearly, erm, and there were concerns about trying to get him home, trying to get care arranged and equipment arranged for home, and it kind of got overlooked. So, I came back from holiday and arranged the biopsy fairly quickly” (Registrar (CS8), p27/19).

These accounts suggest a chain of communication at different levels between hospitals, general practitioners and the different support agencies. This increased the possibility of patient’s needs and their continuity of care being overlooked or falling through the net. The discharge letters can vary from structured discharge forms to a fax letter with minimal information.

Jock had further investigation after his transfer back to his district hospital. Although Jock had a history of meningioma and prostate tumour, his PSA was low enough to be suspicious. His skin lesion biopsy confirmed the primary site of spread. According to the registrar, Jock was very anxious to go home by that time and they had to rush to get his investigation done:

“His final diagnosis was a little bit odd. I’ve got it here. [Shuffling of papers] Erm, metastatic small cell neuroendocrine carcinoma, erm... the pathologist has reported that the most likely site being prostate. Erm, so it’s just a slightly atypical type of prostate carcinoma. It was a little metastatic deposit that was in his skin, so they did it with ultrasound

guidance...because you couldn't actually really feel it" (Registrar (CS8), p19/2).

Patients may continue to have further investigations after radiotherapy to determine the primary site of spread. This could cause anxiety and uncertainty for the patient and his family. However, not all medical staff felt the need to do further investigation if the patient had a short life expectancy especially in lung cancers. Betty was an unknown primary case and after several investigations; it was futile to continue once her mobility deteriorated.

Accounts from patients and carers also illuminated the disruption and in some instances difficulty in coping with side-effects from steroids and radiotherapy once they were home. Richard, however, was admitted to the hospice a week later for his pain management. His palliative doctor was not sure whether Richard's change in mobility was due to the sudden drop in the steroid dose and restarted him on steroids, which improved initially. However, when planning his discharge, the difficulty was getting the steroids dose right:

"The steroids made the leg oedema worse, which made his mobility poorer, but when we dropped the steroids, then his mobility got worse again, so it was just there were lots of factors going on with him and so it...it took a long time to get things set up to get him home" (Palliative Care Doctor (CS5), p4/26).

The situation for Sandra seemed to have affected her greatly. She described not being aware of the effects of treatment and that extreme fatigue had led to difficulties performing her daily tasks. Sandra expressed her frustrations:

"Erm...I would wake up and I was absolutely soaked in sweat from head to toe. I come out in a rash on my back but the doctor said sometime coming down from the steroids, you know, when you've been on a high dose of steroids and as you come down you can go through quite a few different experiences. I just don't think I took in or understood just how [Pause] badly they can affect you or they seemed to affect me. Erm...and I don't think I realised...I didn't think with only 5 doses of radiotherapy I would feel as tired as I do" (Sandra, patient (Case Study 2), Interview 2, p6/12).

Sandra was used to leading a busy life in which she was in control, however, her extreme fatigue and her rash had resulted in several visits to her GPs. Sandra talked about being depressed:

“I felt quite bad and what is the point of going on and looking back now, I felt as though I could end it now and it was the steroids that were doing it and I felt really down. I also felt really drunk all the time when I came home as though I had about 6 bottles of wine” (Sandra, patient (Case Study 2), Interview 2, p9/1).

Patients also talked about difficulty coping with their pain. During our second interview, Jimmy talked about his continued pain despite receiving radiotherapy treatment and that adjusting to a comfortable level, with morphine was difficult. He talked about his frustrations during meal times:

“Aye...sitting is sore. I sit there I get sore but...what I do is I stand up...no, I’ll do that for a while and then another thing is...I stand up [illustrating by standing up] and I have been walking straight and that eases it off. Even I eat standing up. I eat standing up and then I can enjoy my food” (Jimmy, patient (CS3), Interview 2, p5/23).

By coincidence, after our second interview, I saw Jimmy on the ward. He related that he had been admitted twice, once to the hospice and then to the cancer centre because he had overdosed with his pain killers. He, however, was mobile but sometimes needed the aid of a walking stick.

Whilst some patients had difficulty coping with the side-effects of treatment and pain, some patients expressed difficulties in adjusting to their disability. For example, Emma’s mobility rapidly deteriorated but it was when she was home the reality sank in:

“I think it was just the realisation that I was in the chair and I had lost the use of my legs and...erm... I was having to depend on everybody and I think that’s basically what it was” (Emma, patient (CS6), Interview 2, p14/19).

Although Emma said she was coping fine and consoled herself that she could at least move around in her wheelchair, she found it frustrating and said she had “lost her confidence”:

“I don’t know. Just going out and people seeing me in the wheelchair, and that’s just never been me, so...so, it’s that...it’s just something that I need to get used to” (Emma, patient (CS6), Interview 2, p11/8).

This excerpt suggests Emma was apprehensive about the stigmatisation of her disability, resulting in a loss of self-esteem. She realised she had to adjust to

her changed circumstances. However, she was not keen about attending support groups activities:

“I just don’t want to go along to that kind of thing and it be constant talk about cancer and what have you. It’s not that I’m trying to bury my head; it’s just I don’t feel I need it at this moment in time” (Emma, patient (CS6), Interview 2, p16/2).

In contrast, Robert and Richard had previously been attending the Macmillan Centres for managing their pain before this episode of MSCC. They were enthusiastic about the support they received from their local centres. Richard could not fault the support he received thus far:

“...it’s a terrific place to go to get different views, to see people who are in a similar...who got cancer in the prostate what have you, so it’s a good place to go to. It’s kind of relaxed...” (Richard, patient (CS5), Interview 1, p16/9).

Here, it appears the Macmillan Centre seems to have provided emotional support and symptom control. Richard’s wife, Linda, on the other hand, felt that she had to deal with it herself:

“...I find it is of limited benefit because at the end of the day what can anybody say to me, you know. It’s something that you have to work through in your own head. And of course, again I pray about it and then you have to just ...it’s accepting it and then also thinking well at least he’s not dead” (Linda, wife (CS5), Interview 2, p37/6).

Although patients and their carers had varied views about support groups, most of them talked of good support from their spouses, families and friends.

“My mum’s in every day, my dad’s in every second day, if not every day” (Emma, patient (CS6), Interview 2, p16/14).

Some carers turned to spirituality for comfort. Others preferred a personal contact or a phone call from a healthcare professional. Sandra felt her previous sessions with a psychologist had helped her:

“You get lots and lots of support at the beginning or when you got problems and you spoke to the doctor. And I had the psychologist to talk to, she has moved away now. Erm...I got no one...and you know, my husband, I feel guilty because I feel as I talk something to do with me

every day and it must wear him down” (Sandra, patient (CS2), Interview 2, p14/24).

However, her sessions with the psychologist were discontinued as her consultant felt that she no longer needed that service. Sandra talked about experiencing extreme fatigue and her reaction to her bone-strengthening medication. All these compounded on her rollercoaster of emotions:

“I have good days where I feel quite positive. Today I don’t feel bad. There are other days where I feel really, really low, really down. And I can’t pick myself up for anything...and on those days...I love...there was somebody I could speak to when I needed them. It’s not frequent and not regular basis” (Sandra, patient (CS2), Interview 2, p17/12).

Sandra described her experience as an *“isolated feeling of dealing with it on your own”*. Sandra considers:

“Erm, I just think you don’t have a district nurse coming in anymore just to check on you although I don’t have anything physical but nobody will phone you up and say ‘how are you doing today?’; ‘how are you keeping?’ you know. For three months you’re on your own and then you got a five minutes slot, 10 minutes slot to get out all your worries, any symptoms, get that sorted and out the door you go and you’re another three months on your own. So, for the majority of time I feel I deal with this cancer by myself” (Sandra, patient (CS2), Interview 2, p41/27).

Sandra felt a sense of being abandoned and ‘journeying alone’ in her cancer journey. Although she said her husband was supportive, she felt he was not able to handle the emotional aspect and may not understand what she was going through. John too, had his worries and was uncertain how his teenage sons were coping:

“That I can’t honestly say because I think it affected them in different ways. Erm, one is at uni obviously affected because he was not concentrating right obviously. My other son, well, he’s [signs] he’s trying to block it out. He’s trying to ignore it. So, I say he is dealing in his own way” (John, husband (CS2), p15/12).

Carers sometimes did not reveal their worries or concerns to their loved ones and this may be interpreted as not emotionally engaged. Patients sometimes may not have family support or live in a remote area and this can have an emotional impact on them. According to Sandra, her mum and sister were not supportive and her nearest neighbour lives far away. Healthcare professionals

may need to explore patients support networks and consider alternative support.

Similarly Tony found difficulty dealing with his emotions:

“I suppose I keep a lot of things inside myself. I have my own particular moments, but, as I said, I find it difficult to talk to family members about things – how...exactly how I’m feeling – sometimes, because...eh...because it gets...it just gets too emotional, and I..and then I don’t get the support that I need at that time. Not through any of that person’s fault; it’s just because it’s too strong an emotional contact for talking like that, because it breaks down to... But if you talk to someone that is not emotional, then they can stay fixed on what you’re trying to say” (Tony, patient (CS7), Interview 1, p28/13).

The above accounts suggest patients felt lonely and talking to someone as and when needed would have been beneficial. It also suggests that patients talking to family members may be difficult as they too were emotionally involved.

Therefore, this suggests not all patients turn to their family for emotional support. Healthcare professionals may need to recognise that individuals cope differently and may not necessarily ask for help.

Illness and the recurrence of cancer had a profound effect on all the family and home is where many of the challenges were faced and needed to be met. However, healthcare professionals may not be aware of patients’ needs as not all patients were able to articulate their worries and as in Sandra’s case, did not want to bother the healthcare professionals.

Some carers expressed frustration in their attempts to resume normal family life. Gail and Tony had two young girls age three and five. Gail kept Tony’s Zimmer frame out of sight: Gail gave the reasons for her action:

“And he’s got a Zimmer frame which I didn’t like him using it at all. Erm...we put it in the garden...erm...I didn’t like it in the house. I think it’s an old person’s ...I just didn’t like seeing him using it” (Gail, wife (CS7), Interview 1, p23/8).

This account suggests that the carer had difficulty adjusting to her husband’s changed needs and it affected their family dynamics. There was sadness in

Tony's voice when he confided about his difficulties participating in his children's care due to his condition. He acknowledged the increased demands on his wife, looking after him and their children:

"It's hard for me because I feel as though I'm not doing my bit, I'm not doing my share, I'm not helping out and I'm not...eh...well...held my children as much. This is frustrating and a bit err...hard, a bit hard for me, you know what I mean" (Tony, patient (CS7), Interview 2, p26/5).

These interpretations suggest that for patients and carers, the development of MSCC and their attempts to move forward is difficult and impacted on family dynamics.

Matthew confided about his living circumstances:

"Eh, I think I adjusted quicker and easier than I thought I would with the change. It's obviously a – I don't think its ideal having Emma down here [referring to the living room]. It's ideal for the situation, but not ideal for me; I want her back upstairs, eh..." (Matthew, husband (CS6), Interview 2, p9/11).

Here, it indicates that physical changes to home and living space had an impact on getting back to normality for the patient and carer. In addition relationships could be affected with the role change. Patients and their carers reported the shifting of roles from wife or husband to carer. Gail took over responsibility for dealing with her family's practical needs; for example, driving her children to school, attending to Tony's hospital appointments and at the same time working part-time.

Linda talked about having to reduce her working hours which meant less income, however, she had been poorly lately:

"I'm not sleeping very well at the moment because of that and worrying about Richard and, you know, all these things, so I don't feel brilliant at the moment" (Linda, wife (CS5), Interview 2, p41/6).

This account suggests that she had to cut down on her working hours to look after her husband and this had affected her health and perhaps their financial security.

The main issue from these interpretations is that for patients and carers, after the initial treatment was over, the impact and the long term implication of what

was happening became more obvious. Some of the professionals' decision making was grounded in the acute phase of the patient's condition and the transitional needs from hospital to home were not always identified and met. For patients who remained mobile, their support varied depending on their life expectancy. However, if the patient was paraplegic, the rapidity of organising support services appeared to vary depending on their geographical areas. Some patients had a choice in their place of care, while for others decisions were made for them. Moreover, there appeared to be a chain of communication from different agencies and the patient's needs could be overlooked. Some of the patients were unaware of the impact of coming off steroids and the side-effects after completion of radiotherapy.

Patients talked about experiencing extreme fatigue, some had difficulty managing their pain and in some cases felt depressed and found difficulty in coping with their daily activities. They were uncertain of their health status and their capacity to continue working. When the patient's physical capabilities deteriorated, support in terms of equipment and financial aid could be challenging for patients and their carers to access.

Healthcare professionals may not be aware of their changed priorities and the support they provided may not necessarily meet the needs of the patients and their carers'. Patients and carers views towards support groups were mixed. Some patients were offered psychological help while others were not. Some patients expressed difficulty turning to their family for emotional support as the carers and family members themselves were emotionally involved. However, they expressed that support can be in the form of a telephone call from a healthcare professional.

Some patients and carers expressed frustration in their attempts to return back to their normal family life. The next sub-theme illustrates that patients continued to face uncertainty as their physical functions deteriorated and this raised fears around dying. Carers found themselves struggling with uncertainty and trying to determine the patient's final moments.

5.4.2 Determining the final moments

This last sub-theme indicates that the patients' and carers' cancer journeys were still fraught with uncertainty and that there were movements between waiting for continued treatment and palliation of symptoms and death. Others expressed the fear and anxiety of not knowing how to determine the final moments.

Tony had radiotherapy following surgery but in interview 2, he talked about his concerns regarding continued treatment:

“Eh...now my concern is...I suppose my big concern, because I have this problem, I've stopped the chemo now my initial tumours the longer the time extends out that these might get bigger. So, that's my concern, my worry at the moment and so that's why I wanted everything really to go quickly so that they can go back on course for my original treatment” (Tony, patient (CS7), Interview 2, p11/22).

On a similar note, patients also talked about waiting for MRI scans to be taken on their spinal cord. Richard was admitted to the hospice after experiencing falls and had pain issues. Richard expressed his continued worry during my second interview with him:

“I mean, I don't know whether they can do the chemo, I don't know whether they can do the strontium; and I don't know whether...um...the radiotherapy's working. I don't know. I mean, I really don't know. And I don't know how they actually tell without going to get MRI scans, or whatever it may be. This is what I'm hoping to discuss on Monday with the doctor” (Richard, patient (CS5), Interview 2, p11/5).

The above accounts show the patient's constant oscillation between palliative and curative treatment demonstrating the link to the uncertainty of the illness pathway. In my field notes, I recorded my conversation with one radiologist:

Researcher: “Do you do scans to check whether the tumour has shrunk?”

Radiologist: “Not necessarily, unless they are going to treat the patients” (Field notes R1).

However, patients did not have the information that scans may not be routinely done unless there was further treatment planned. The 'waiting for a scan'

caused some patients to have continued worry. Moreover, over the years of follow-up, patients had expectations of surveillance scans, and when this did not happen, they experienced continued uncertainty.

Patients also raised the issue of the follow-up being too long apart, notably as they assumed the urgency in getting treatment at the acute stage also meant they would be followed up closely. Sandra highlighted the need to monitor her tumour which would provide her with peace of mind:

“I think it would put my mind at rest if I did get a scan and they said the tumour has shrunk” (Sandra, patient (Case Study 2), Interview 2, p33/26).

The above accounts suggest patients need to be reassured in knowing that there were no problems detected and this seemed important to assist them to cope with their cancer. In interview 2, Sandra said she had several episodes of nightmares after her discharge from the hospital. She described her indeterminate state as *“waiting for the inevitable”*. Sandra added:

“But it was scary, it was all about being immobile, being tied to something, not being able to do things for myself get about and ...umm...that I was going to die” (Sandra, patient (CS2), Interview 2, p1/16).

The accounts demonstrated an oscillation between wanting treatment and monitoring against the understanding this could be terminal. For example, the palliative doctor talked about Richard’s reaction after his appointment with his oncologist:

“So, when Richard came back from that appointment, he was feeling very optimistic. I think just the fact that [name of consultant] had given him an appointment after Christmas had made him feel ‘oh, gosh! so, I’ll make it past Christmas then!’” (Palliative Care Doctor (CS5), p17/9).

This evidence suggests that patients perceived follow-up appointments as an indicator to their life expectancy. Emma’s GP talked about how she tried to determine Emma’s understanding of her terminal stage:

“I said to her, you know, ‘have you any questions?’ and I said things like ‘sometimes people are worried about what happens at the end,’ and I said ‘is that something you want to ask me any questions about?’ and

she said 'no,' and she said 'I might do nearer the time,' and I said 'yeah, that's fine; I'll just keep dropping hints and you can let me know if you want anything.'" (GP (CS6), p4/23).

Emma expressed her fear when confronted:

"I'm scared. She asked me...erm...about my issues about dying and what have you, and how I'm always sort of cheery and what have you. But I am...scared of dying...erm...and that's what I was saying to her. And she was asking if I wanted to be resuscitated, and...erm...I said 'yes'" (Emma, patient (CS6), Interview 2, p20/13).

This indicates that a discussion around end-of-life issues was a sensitive area but the GP had to explore the patient's wishes in her final moments. Emma's GP encouraged Emma to contact her priest:

"She was a member of the...Catholic Church and I encouraged her to get in contact with her priest, but I don't think she ever did. I think she thought she would live longer and I don't think she wanted to cause any trouble to anybody. That was very 'Emma'. [...] I would have liked Emma to have sought support from her priest and that would have, um...been a comfort to me; not on a spiritual level, but I would have felt that I had...that all those areas had been covered" (GP (CS6), p6/19).

This suggests that the GP tried to provide what she viewed as holistic care, however, not all patients were ready or wanted spiritual care. Carers on the other hand expressed their ongoing anxiety about end-of-life issues. Matthew expressed his worries about his uncertainty on how to establish Emma's final moments:

"Well, things like pain. If it starts to come back, with any tumour growing, if they're putting any pressure, like on the bone or things like that again. The tumours in her lymph nodes are near her air pipe – wind pipe, whether it starts putting pressure on that causing breathing problem. It's all 'what ifs,' really. You try not to dwell on it too much, but it's those type of fears and it's those kind of symptoms that may present, that type of thing" (Matthew, carer (CS6), Interview 2, p11/9).

Here, the carer's uncertainty was in respect of trying to establish and anticipate what signs and symptoms to look out for to determine their loved one's final moments. Linda also talked about facing and *"not fighting the inevitable"* when Richard became poorly. She talked about making an appointment to discuss this issue with Richard's consultant:

"I think I'll do that and then Richard is not there, you see and the last thing I want for Richard to have is a horrible prognosis, you know, cause that's discouraging... and I think he's better just not having all the details and I...yeah. Whereas, um, it would be better if I had them so I can be realistic, cause the last thing I want to be is in denial that this is happening and, you know, and fighting against the inevitable instead of you know, just accepting all the help I can get and just going with it, if you see what I mean" (Linda, wife (CS5), Interview 2, p19/18).

Here, the carer thought she should shield her husband from the worst news. It was notable that the carer's needs for information on prognosis changed when the patient's condition deteriorated. This account suggests that the carer felt helpless; however, she had to accept and prioritise what was important at this final moment. Linda was not keen to know her husband's prognosis during the acute stage of MSCC; however, the above account showed her needs were more pressing at the terminal stage. This may also indicate she wanted control in anticipating grieving.

Richard, however, talked about his emotions:

"Well, you're emotional all the time. I mean, I think most people would go through maybe a day/a couple of days without feeling particularly emotional, and then it suddenly hits you again that, you know, it might not be long, and you get a bit tearful and that. And it just comes and goes, you know. It might be in the middle of the night, it might be you're sitting getting your dinner and you feel a bit of flush of tears and what have you, because you know you're not seeing your grand-bairns (grand children), or whatever it may be. But again, what do you do, you know? You just have to accept the fact that's going to be there; there's nothing much you can do about that" (Richard, patient (CS5), Interview 2, p18/25).

It appears the patient had difficulty coping emotionally and experienced fears of dying and was also worried on issues beyond death. These fears can occur at anytime, as Richard said he could be crying at mealtimes. There was a sense of helplessness and the patient talked about accepting the roller coaster emotions. Richard turned to his chaplain for spiritual comfort:

"...there's a better place to go to, not to be frightened, that Linda's going to be looked after, my family will be...so, I'm quite comfortable with that. Quite comfortable" (Richard, patient (CS5), p20/17).

There was a sense that both the patient and his wife knew what was going to happen and appeared to be protecting each other. Richard confided that his mainstay was to go home and be with his family. Sadly, Richard died before Christmas at the hospice.

Betty's daughter gave the researcher a lift to the train station. On the way she expressed not knowing when her mum's final moments were. She talked about her uncertainty during the journey to the train station:

"You know, they have removed her catheter because it kept getting blocked. She was passing large clots of blood, I am not sure whether this is her coming to the end" (Field note C2).

Carers face difficulty when seeing their loved ones slipping away:

"Tony not being here...hmm...hmm...thinking that yeah...I think about it every day. I don't tell him that but yeah I think about it every day of him not being here" (Gail, wife (CS7), Interview 1, p17/14).

Here, it appears the carer was grieving and was anticipating life without her husband. Tony was readmitted to the hospital for jaundice but his condition deteriorated rapidly; his consultant encouraged him to spend his last Christmas at home with his family. Sadly Tony died before the researcher had the second interview with Gail. However, Gail was keen to continue with the second interview and agreed to meet two months later to allow her to grieve. During the second interview Gail said it was hard to accept the bad news but felt supported by his consultant:

"She did ask me if I had any questions, and at that point I thought 'no I won't ask her how long,' and then, luckily, she phoned me a couple of days later and I did ask her"(Gail, wife (CS7), Interview 2, p13/27).

This implies the carer wanted to determine her husband's final moments, however, she did not want to cause her husband emotional distress. A telephone call from Tony's consultant showed support and gave Gail an opportunity to voice her concerns and ask questions. This information gave the carer some anticipation that death was near. Gail talked about her decision and her conversation to her husband:

"He didn't know how long, but I got that from [name of oncologist], but then I couldn't keep that from Tony because we...we always shared things; we never kept anything from each other. So I went up, once the

girls were in their bed that night, and I did tell him that 'I can't keep it from you: [name of oncologist] said you've got about two to three weeks,' and he said 'well, I kind of like knew that'" (Gail, wife (CS7), Interview 2, p6/22).

The goal is then shifted from 'cure' to providing her husband with comfort and an opportunity to say goodbye.

"Well, you know, we kind of like cried and just did the...the normal emotional things, eh. And, erm...you know, he just wanted to make sure that the girls and me were well looked after. His mum and dad came down for a weekend, before Christmas – and he sat with his mum for a good four/five hours and they sat and chatted and his mum found a lot from Tony what he wanted, you know, about the future and things like that" (Gail, wife (CS7), Interview 2, p14/5).

Defining the final moments allowed patient and parents an opportunity to express the patient's last wishes and to say goodbye. The final moment also allowed patient's spouse to express her wishes. Gail brought up their conversation about Tony's ashes:

"Well, he was...he said to...erm...unbeknownst to me at the time (and I felt ...I did say to him that I felt quite hurt about it, but we sorted it out) that he was...his ashes he was going to give to his mum and dad, so they could...emm...once the mum and dad had died, Tony's ashes would be spread with them" (Gail, wife (CS7), p47/26).

Tony's parents were anxious about Gail coping on her own. Gail, however, made the decision to have her husband die at home knowing that it was what he would have wanted. Gail felt supported by his GP's constant visits to ensure she got the help she wanted.

Although Gail thought she could cope with her husband's care, she was emotionally not prepared to cope with Tony's requiring constant personal care. Gail related that Tony was still very much concerned about his dignity till the very end of his dying days. She continued:

"And he said 'I don't want you remembering me like this'. Which was pretty horrendous, because he'd lost a lot of weight; his...his bottom was just like flesh hanging, and you know that wasn't Tony" (Gail, wife (CS7), Interview 2, p3/16).

Maintaining a husband and wife relationship was difficult as the wife's role changed to a carer and witnessing a dying patient can be distressing. Gail,

although she was happy with the help of the district nurses, felt there were some who were insensitive when having a conversation about her husband in front of their young children:

“...that nurse came down and she was talking about things that I thought hold on, my five year-old daughter’s here, do you know? I can’t remember what it was. When she left, I just went into floods of tears because I thought she was un- I just thought you were the last person, district nurse-wise, to handle my husband, and I wasn’t happy with that, because I didn’t like her...her attitude. It was kind of like matter of fact...em” (Gail, wife (CS7), Interview 2, p4/23).

The above account suggests the carer was already distressed dealing with her husband’s final moments and was also trying to shield her children from the crisis. However, the attending nurse in that situation may not have been tactful in managing the issues where young children were concerned.

This section reflects patients and carers accounts of their experience when the end was near. Some patients were still oscillating between curative treatment and palliative symptom control. Some patients look to their appointments with their consultants as an indicator of their life expectancy and reassurance. Carers on the other hand, were concerned about not knowing how to determine the final moments of their loved ones.

Medical staff faced the challenge of when to broach the issues of patients dying and how to provide holistic care that included spirituality. Some patients and their carers turned to spirituality for emotional support, others to their family members and their doctors. It was also noted that patients wanted to die at home but they were worried that their spouse could not cope. The interpretations also illustrate that patients’ and carers’ needs change at different stages of the cancer trajectory. It was also unclear how children were supported in facing the uncertainty when of one of their parents was dying of MSCC. Patients were concerned and wanted to have the comfort of knowing their spouses were taken care of. However, carers talked about anticipating the inevitable and they were grieving in anticipation of the death of their loved ones.

5.4.3 Summary

This theme showed that patients' and their carers' in their journeys beyond the treatment of MSCC experienced changed priorities, continued uncertainty and un-met needs. There was a lack of follow-up in terms of practical aids and securing help from disability and social services proved difficult for some patients. However, those patients who were guided felt supported. Some patients and carers talked about anticipating a loss of income whilst others did not seem to have financial worries.

Patients were not aware of the side-effects of steroids and radiotherapy and experienced extreme fatigue, depression and skin rashes. Others continued to have problems with their pain control. Some patients had the choice of going home whilst others had decisions made for them which meant they ended up in somewhere which would not have been their choice. Patients, carers and healthcare professionals in the community found decisions on support care made by the hospital staff were prescriptive and dealing with different agencies was challenging. Patients found communicating with different health providers difficult and this affected their continuity of care.

Patients who were mobile talked of the uncertainty of their future and expressed difficulty in living with cancer. However, those who were paralysed came to terms with their disability, but found frustration in adjusting. Most patients experienced good emotional support from their spouse and family but some had difficulty expressing their emotions to their spouses or family. There were variations on patients' and carers' views on group support; with some finding conversation around cancer, depressing. The unpredictability of MSCC led to changed relationship and family dynamics, as patients and carers struggled to find a balance.

The boundaries between curative and palliative intent were blurred as patients oscillated between continuing treatment, palliation of symptoms and death. Patients gauged their life expectancy on their appointment with their consultant. When patients' mobility deteriorated, carers were unprepared for the level of support and found it distressing and felt out of control. Both patients and carers

found defining the final moments challenging. Discussing end of life issues was sensitive and patients expressed a fear of dying. There was a sense of patients and carers protecting each other from receiving bad news. Patients wanted to die at home but felt their spouses or family might not cope. Carers were grieving, but wanted to be in control and expressed a desire for some indication to help them anticipate the final moments and giving them the opportunity to say goodbye.

5.5 Chapter Summary

This chapter with the themes and sub-themes provides the accounts of patients', carers' and healthcare professionals' experiences at different stages of the patient's journey with MSCC. The patients' and their carers' narratives illustrated the difficulties in trying to make sense of the symptoms of MSCC. Patients experienced emotions such as anxiety, distress, confusion, uncertainty which raised existential fears. Healthcare professionals, on the other hand, experienced difficulty recognising and identifying the patient's presenting symptoms. It is evident that patients' and their carers' information needs in recognising the symptoms of MSCC have not been addressed. Although it was debatable whether GPs needed education in MSCC, it was apparent that the signs and symptoms of MSCC were not readily differentiated by healthcare professionals in all settings.

The patient's risk of losing mobility influenced the need for urgent treatment. This suggests the scope for decision making was limited and patients put their trust in healthcare professionals to make the best decisions for them. However, some patients later had doubts whether they had made a balanced decision based on the treatment options that were available.

The apparent lack of timely information on diagnosis, treatment decisions and how the progression of cancer was going to affect the patients, contributed to patients' and their carers' uncertainty of their immediate and long term future. The acute ward setting with patients at different stages of their cancer trajectory

could potentially cause misunderstanding and anxiety. Although patients and carers looked up the internet for information, this appeared to cause distress for some. These interpretations suggested that patients' and carers' concerns and their need for information were not readily met. There were variations in the need for information on prognosis and future symptoms of MSCC, however, patients and their carers wanted some indication of their immediate future to make short and long term plans.

The accounts from patients, carers and healthcare professionals described the trade-off decisions in balancing the treatment versus quality of life. Evidence suggests patients wanted to participate in decision making; however, they may not be aware of the levels of decision making involving different disciplines. It was notable that the patients, carers and healthcare professionals showed strategies to find a balance in the face of ambiguity and uncertainty. Some patients and carers talked about dealing with the present and spending quality time with their families, some had difficulty living with cancer, and others talked about alternative treatment. However, patients and carers were trying to reduce the demands on each other and might not be aware of the plans healthcare professionals had for them.

Patients and their carers gave accounts of challenges in the transition from the acute setting to their home or to another healthcare setting. Evidence suggests that some patients and carers may not be involved in the decision making process and therefore, some of the support provided a mismatch to what they anticipated. Moreover, patients and their carers priorities changed and therefore some of their needs were unmet. Patients and carers faced uncertainty defining the final moments and looked for reassurance from their follow-up appointment with their consultant. The three themes illustrate that patients, their carers and healthcare professionals faced uncertainty which is multifaceted at different levels in MSCC. There is alternation in the interface between curative and palliative care in the patient's trajectory of the cancer journey. Several key issues from these findings will be discussed in Chapter 6.

Chapter 6: Discussion

6.1 Introduction

In Chapter 6, I outline how I have addressed my research questions and explain how they were exemplified in this study. I then present my synthesis using three key themes identified from both phases of this study in relation to relevant literature and policies, focusing on the new knowledge that has been generated from this study. The three key themes are: uncertainty in MSCC; finding a balance in MSCC; and support beyond the treatment of MSCC (Figure 16). From these themes important concepts emerged which contributed to the theory of collaborative decision making in MSCC. The assumptions of this proposed theory are illustrated in Figure 17. Further explanation on the development of this theory is found in Appendix 21.

In addition, the strengths and limitations of this study will be discussed. I conclude with my reflections on the research process, what I have gained from undertaking this study and how this is going help me in the future.

6.2 Answering the research questions

This study set out to explore four research questions prior to data gathering. Having discussed the findings, I will summarise that I have addressed the research questions.

What are the patients' perspectives and experience when diagnosed with MSCC?

The patients' experience of MSCC was confusion, distress, uncertainty, anxiety and not knowing what was happening to their body. They expressed fear of becoming paralysed, fear of dying in pain and suffering, and a sense of helplessness. Patients felt lonely and abandoned even though they had good family support, therefore, their emotional needs were often not met. They continued to endure uncertainty, inconsistencies and struggled to find a balance.

How do carers and/or family members perceive support when coping with the patient with MSCC?

Carers' experiences were of being left in the dark and not being involved and consulted by healthcare professionals in providing support to the patient, although they had been providing the bulk of the care and support prior to the hospital admission of the patient. They felt distress, a sense of helplessness and not knowing how to cope with the transition towards end of life.

What are the healthcare professionals' perspectives and experiences in the management of patients with MSCC?

Healthcare professionals' experiences were of uncertainty around treatment outcomes and the unpredictability of the patient's functional outcome and prognosis. They felt a sense of helplessness when treatment was no longer curative.

What are the similarities and differences in the perspectives and experiences of key stakeholders?

The case studies have revealed that patients, carers and healthcare professionals all make decisions. The current study indicates that all stakeholders were looking for a structure to guide them in decision making although their goals varied. Most patients wanted to take control of their situation and lives. However, sometimes decisions made, or a change of plans were not explained to them which affected their ability to make decisions about their job, their finances, spending time with their family, and to prioritise what was important to them. There were examples of patients who put their trust in and handed over responsibility to health care professionals to determine their care and management of MSCC. This emphasises the challenges for health care professionals in determining what an individual patient and/or carer may want.

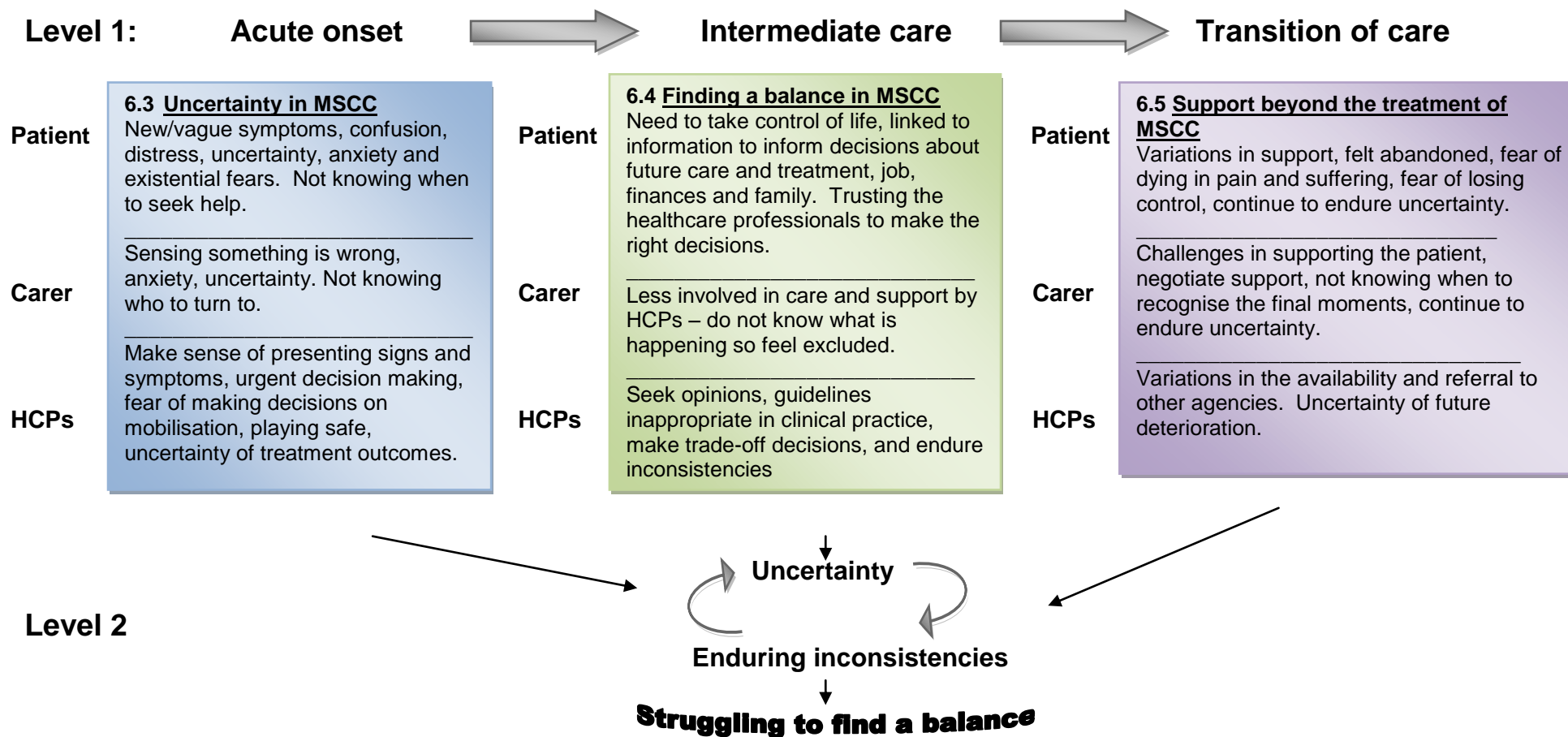
The carers' experience was that decisions made were often prescriptive and they were not consulted, despite their role in supporting the patient. They also had to make decisions about their job, how to recognise deterioration in the patient, and recognise they themselves were going through a period of transition and were grieving in anticipation of their pending loss. Although they

appreciated support, this requires negotiation and respect for their privacy and allowing them to spend quality time as a family.

The healthcare professionals' experiences illuminate the many variations which could exist in the management and care of patients with MSCC. Guidelines on mobilisation were not appropriate in clinical practice, and there was a feeling of apprehension and a notion of fear in mobilising a patient when the spinal status was not known. Therefore, healthcare professionals tended to play safe' at all levels and tended to discourage mobilisation in most cases. This is further compounded by the outcome uncertainty of treatment. Decision making involved other disciplines and some of the healthcare professionals felt less supported. As a result of a lack of evidence, the healthcare professionals endured the inconsistencies and prescribed care they thought would be in the best interest of the patients. Healthcare professionals felt that rehabilitation would benefit patients, however, there was limited access to services specific to patients with MSCC. The support for patients on discharge was perceived by healthcare professionals in primary care as too prescriptive as patient needs may not be intense and moreover those needs changed overtime.

My synthesis of the findings and the wider literature has resulted in the development of a theory on collaborative decision making. Figure 15 illustrates my level 1 and level 2 abstraction of concepts in the patient's journey in MSCC which was explained in three stages. The acute onset, at the left hand corner, relates to uncertainty in MSCC; the intermediate care relates to finding a balance in MSCC and finally the transition care, at the right hand corner, is about support beyond the initial treatment of MSCC. Each stage is represented in a box identifying the factors that influenced or impacted upon the patient's, carer's and healthcare professionals' experiences in MSCC. Having discussed all three stages, there was a sense of consistent themes which culminate in another, higher level of abstraction (level 2 of abstraction), where all stakeholders experienced constant movement between uncertainty and enduring inconsistencies, resulting in struggling to find a balance in MSCC.

Figure 16: Levels 1 and 2 abstraction of Phases One and Two findings



6.3 Uncertainty in MSCC

One of the main findings from this study was that MSCC is a complex condition plagued by uncertainty within the trajectory of the illness. As the onset of MSCC is often sudden, unexpected and severe, patients are normally admitted to and treated in the acute setting. A focus on acute management is often at odds with the palliative nature of the condition and this contributes to the complexity for patients, carers and healthcare professionals. The findings from this study demonstrate the intricacies of uncertainty which affect all the key stakeholders when MSCC presents.

Awareness of the signs and symptoms of MSCC was seen as integral in initiating action in getting medical help (Sections 4.6 and 5.2.1). This supports guidelines and previous studies (NICE 2008; Levack *et al.* 2001; Mitera and Loblaw 2010; Hutchison *et al.* 2012). However, evidence from the current study demonstrated that only one patient of the eight who participated was informed by his Macmillan nurse about the signs and symptoms of MSCC. One patient had recurrent MSCC but he thought he was cured the first time (Section 5.2.1). Often patients and carers' were unable to make sense of their symptoms. The patients gave accounts of new and vague symptoms from severe back pain, shooting pain, pain in the sternum, feelings described as 'bugs' creeping, numbness from chest to abdomen, urinary retention and sudden loss of mobility (Section 5.2.1). The patients' and carers' accounts displayed a level of confusion leading to distress, fears and uncertainty for both patients and carers. This proved challenging for patients as they sometimes found it difficult to verbalise their concerns. This reinforces the suggestions made through the study by Levack *et al.* (2002), to listen to the patient's symptoms.

Although all eight patients in the current study were mobile on admission, two patient's mobility deteriorated rapidly after treatment. The unpredictable nature of MSCC indicates the limitations in the use of health-related quality of life assessments to assess the patient's quality of life (Section 2.5.2). Some

patients attributed their symptoms to concomitant chemotherapy and hormone therapy (Section 5.2.1).

One of the patients felt let down when she was not informed that her cancer had spread to her lungs and bones, whilst another said he did not understand why there was recurrence when he was still undergoing treatment. Both patients indicated they would have sought treatment early if they had information about early signs and symptoms of MSCC. This issue was reflected in a recent study by Hutchison *et al.* (2012), who found that the majority of patients want prophylactic information about MSCC. Wilkins and Woodgate (2012), also reported cancer survivors want healthcare professionals to provide information about a second cancer risk in order for them to make decisions about how to take care of that risk.

Mitera and Loblaw (2010), reported that 69% ($n=27$) of patients delayed seeking medical attention for their symptoms despite 95% of patients ($n=38$ out of 40 patients) previously having been informed by their physician about the suspicion of MSCC. However, the common reasons given were patients in their study did not associate their symptoms with MSCC. As mentioned above, one patient in the current study had an awareness of the signs and symptoms of MSCC (Section 5.2.1). However, the patient confessed he had fear of the unknown, experienced existential fears, confusion and distress, and only sought medical attention when his pain worsened. Eadie and MacAskill (2008), offered an explanation that people who fear cancer can respond irrationally to symptoms and consequently delay treatment, especially men. Although this study was about cancer screening, this can be taken on board for MSCC as patients need to have an understanding of what might indicate MSCC in order to differentiate from “normal” changes. So although patients may have the information about possible signs of MSCC they may not act on this. To overcome this, Manson and O’Neill (2007), suggest that giving information alone is not enough, but strengthening the level of understanding is required in order to empower patients.

Mitera and Loblaw (2010), found that patients with only one neurological symptom, such as back pain, had an interval median delay of 19 days compared to those who had more than one symptom (a median delay of 14 days). During this interval, 50% of patients deteriorated neurologically; a critical time window for treatment to reduce the likelihood of irreversible neurological damage (Husband 1998; Mitera and Loblaw 2010). Audits have reported that some patient's symptoms had been present for more than four weeks before treatment (Levack *et al.* 2001; Sui, Fleming and Kehoe 2012; Whigham 2012).

NICE guidelines (2008), and Hutchison *et al.* (2012), do not recommend giving the information about signs and symptoms of MSCC to carers. Findings from this study suggest that carers and the patient's significant others do have an influential role in persuading and making the decision to seek medical help on behalf of their spouse or parents (Section 5.2.1). For example, one carer (Case Study 4) recalled her husband had back pain for 2 weeks and the pain got worse while on a bumpy bus ride but it was only when the patient's legs felt weak, that she suspected something was wrong. This concurs with other studies on advanced cancers, where carers were able to 'sense the changes' in their spouse/family members and get help (Mellon, Northouse and Freeman-Gibb 2006; Penrod *et al.*, 2012).

The benefits of family involvement have been highlighted by Gilbar (2012). The current study also revealed that although the carers sensed something was wrong, they did not know who to turn to or what actions to take. Carers were hesitant as to whether to get help during weekend from NHS 24 or the hospital (Section 5.2.1). In cases where MSCC was an incidental finding, sometimes the delay occurred when patients were seen by locum doctors who did not necessarily know the patients or were not aware of the signs and symptoms of MSCC. The findings of this study reveal potential for gaps in the care pathway and guidelines, and patients and carers should be advised to contact the oncology centre directly.

Hutchison *et al.* (2012), found disparity in healthcare professionals' views in initiating awareness in patients at high risk of developing MSCC. Within the findings of this study, there were suggestions that general practitioners, district nurses and medical staff out with oncology should be educated in recognising signs and symptoms of MSCC, while others said patients and carers should be made aware of MSCC (Section 4.6 and 5.2.1). There remain uncertainties about who is responsible and when the right time is to give this information.

In this study, general practitioners expressed that where there is evidence of metastatic disease, giving patients information before presentation was important. However, getting the balance right and not frightening patients was challenging (Section 4.6 and 5.2.1). Some general practitioners talked of the follow up of their patients and had regular meetings with their community nurses. One general practitioner explained they already had a mechanism in place called 'the Gold Standards Framework (GSF 2004)' and held regular meetings with staff to discuss their cancer patients (Section 5.2.1).

The Gold Standards Framework (2004), is a model that ensures good practice is available to all people nearing their life's end, irrespective of their diagnosis. Through this framework, better co ordination and collaboration between healthcare professionals can provide care in consultation with the patient and family. However, several studies have evaluated the implementation of GSF and reported variations in the process in inter-professional communications, and the impact on patients and carers is not known (Munday *et al.* 2007; Thomas and Noble 2007; Walshe *et al.* 2008; Dale *et al.* 2009; Shaw *et al.* 2010). An important point in the current study is that patients were often being followed up by their tumour-specific doctors during their cancer treatment and their contact with their general practitioner could be minimal (Section 5.4.1). Thus general practitioners might not be actively involved in the patient's follow-up. This finding has not been reported in the literature. Therefore, to make any difference, giving information about signs and symptoms of MSCC should be embedded within a patient's tumour-specific doctor's consultation with reminders by the patient's general practitioners.

Contrary to perceptions that general practitioners need education on the signs and symptoms of MSCC, in this study, general practitioners indicate they are already aware of signs and symptoms (Section 4.6 and 5.2.1). They reported seeing very few patients with MSCC in their career. They also expressed that assessing and establishing the symptoms of impending MSCC was challenging in reality, especially in elderly patients who may be confused or have co-morbidities, such as osteoarthritis.

Although some of the general practitioners acknowledged they were not aware of the local referral pathway and the NICE guidelines (2008), they felt their need for information was 'on a need to know basis only'. Some other general practitioners and medical staff felt that tailored education with an emphasis on the 'whole clinical picture' was important. Some general practitioners indicated that education sessions in the format of discussion groups with colleagues from the hospital would be helpful (Section 4.6). Therefore, the findings in this study underline the important role of tailored education in supporting healthcare professionals.

This thesis identified that it is not easy to detect impending or cord compression in metastatic disease. A Cochrane review highlighted that very few studies were carried out in primary care to identify what "red flags" could be potentially helpful (Henschke *et al.* 2011). The general practitioners in the current study mentioned that identifying signs and symptoms of MSCC as straightforward in theory, but challenging in reality. One significant symptom they would look out for was severe progressive pain in patients with a history of cancer (Sections 4.6 and 5.2.1). However, most patients with metastasis have pain and identifying when the pain had changed in nature was challenging to detect. In those circumstances, the patient's safety was the first priority of the general practitioners and they would seek guidance from hospital specialists.

Similarly, medical staff outwith the oncology department often found patient's presentations were not classical of MSCC, for example, as pain may not be as significant in some patients, or it could be subtle (Section 5.2.1). For example,

one patient (case study 8) with prostate cancer experienced breathlessness, localised pain at his nipple area and his PSA test was normal. Accounts from the patient's general practitioner and the referring hospital medical staff found that pain was not a significant feature at that time but breathlessness was a new problem for the patient (Section 5.2.1). This reflects the variations in the presentation of symptoms. Baley *et al.* (2001), reported that 41% of patients ($n=9$ of 22) in their prospective study with MSCC were pain free. Furthermore, the authors highlighted that the duration of continuous hormone therapy in metastatic prostate carcinoma can be a risk factor for the presence of occult spinal cord compression (Baley *et al.* 2001). Tensions and conflicting opinions in establishing a diagnosis between medical staff and the radiological staff can be challenging and delay treatment (Section 5.2.1).

This study identified that patients felt vulnerable and may be preoccupied with their pain and trusted the healthcare professionals to make the right decisions at the acute onset of MSCC (Section 5.2.2). However, some patients later questioned their treatment decisions once their pain was resolved. For example, one patient questioned why surgery was not offered when there was evidence of good outcomes from reading information on the internet. One carer questioned why a plan for surgery was changed to radiotherapy with no explanation.

Patients expressed a desire to be involved and have an understanding in the treatment decision as they want some control over their lives (Section 5.2.2). Another study parallel to these findings was reported by Nakano, Mainz and Lomborg (2008), on emergency admissions of patients with acute cardiac conditions. They reported that patients do not necessarily participate in decision making - they simply need direction and action. In the current study, some patients did leave the decisions on treatment to their consultants. This posed challenges for the medical staff (Section 5.2.1). For this reason, communication about treatment is an on-going discussion and medical staff need to review this with the patients from time to time.

Establishing spinal instability is an important basis for making decisions about treatment and mobilisation, but accounts from radiologists indicated there is no agreed criteria for determining spinal status in malignancy and it was difficult to assess the functional status based on MRI static images (Sections 4.4 and 5.2.2). This concurs with the literature on the lack of consensus evidence in assessing spinal instability (Dirksmeier and Kang 2001; Loblaw *et al.* 2005; Kilbride *et al.* 2010; Lee *et al.* 2012). In the current study, views on having a guideline or protocol to help in decision making on commencement of mobilisation vary with some wanting a guide and others citing that care should be individualised. Interestingly, the current study indicates healthcare professionals found the NICE guidelines on MSCC (2008) on total immobilisation unhelpful and at odds with clinical practice (Sections 4.3 and 5.2.2).

NICE guidelines (2008: 7), recommend: “Patients with severe mechanical pain suggestive of spinal instability, or any neurological symptoms or signs suggestive of MSCC, should be nursed flat with neutral spine alignment (including ‘log rolling’ or turning beds, with use of a slipper pan for toilet) until bony and neurological stability are ensured and cautious remobilisation may begin”. Similar findings were also noted during my scoping exercises with healthcare professionals in West Scotland; they also doubted the recommendations, in their own regional guidelines, of total immobilisation (WoSCAN 2007). This is useful knowledge and there remains a clinical problem. NICE guidelines (2008) need further review and to take healthcare professionals’ and patients’ views into consideration for it to be meaningful.

Several audits have reported a lack of a clear plan or guidance for patients on positioning and mobilisation (Warnock *et al.* 2008; Sui, Fleming and Kehoe 2012, Whigham 2012). Moreover, there is risk of chest infection and of deep vein thrombosis (DVT) if immobilised (Pease, Harris and Finlay 2004). However, this study identified that the threatening nature and unpredictability of MSCC reflected the anxiety in staffs’ decisions regarding the provision of care to patients. A common notion that threaded through the views here was a

feeling of fear and a lack of role and responsibility in who should make the decision with respect to the patient mobilising (Sections 4.4, Section 5.2.3). These findings have not been reported in the literature. Although the oncologist was the decision maker, the role seemed less defined. Within the findings, medical staff said they advocate early mobilisation but the decision to commence mobilisation was sometimes left to the discretion of the physiotherapist and nurses. There was a lack of evidence to suggest a patient's spine is at risk should the patient mobilises, so, extreme pain on mobilisation seemed to be the indicator for spinal instability (Mercadante 1997; Coleman 2006; Izzo *et al.* 2012).

The range of opinions and the lack of guidance and protocols caused anxieties for the nurses in this study who often decided to 'play safe' in caring for their patients (Section 4.3 and 5.2.2). Nurses rationalised that the patients would not hurt themselves if they were on bed rest, thus safeguarding the patient safety aspect of care. Similarly, some registrars 'played safe' when information about spinal instability was not confirmed. Physiotherapists, on the other hand expressed that they needed information from the medical staff about the patient's spinal status before initiating mobilisation, as the unpredictability of paralysis was a great concern. Again, these findings are new knowledge on how healthcare professionals make decisions at different levels when there is a lack of evidence on the process of care.

In this study, there were inconsistencies in communicating and documenting care for patients. As a result, patients reported conflicting information on mobilisation, resulting in distress and uncertainty about when paralysis could occur (Section 5.2.2). Evidence in the current study indicated that patients were not included in discussions and decisions about mobilisation. For example, one patient felt that strict bed rest meant his personal needs were met by nursing staff and he perceived this as undignified. This finding adds to the body of knowledge in MSCC as previous audits have reported this anecdotally (Pease, Harris and Finlay 2004).

Documentation was identified as a problem in the current study, as each discipline had different documentation which may not be easily accessible to other members of the team (Section 5.2.2). For example, a weekly nursing care plan was introduced to the ward, however, some nurses said this was too general and depended on whether someone would record and pass on crucial information. The evidence from these data indicates that the patient's care should be viewed as a process with a range of issues and ongoing decision making. However, this information needs to be transparent so that 'who does what and when' is easily accessible to healthcare professionals. The problem is that as the health system is designed to deliver episodes of care, often patients have multiple problems and integrated documentation is an issue management need to address.

Analysis of these data revealed that uncertainty about one's physical body changes and existential fear could be influenced by seeing other patients with a similar condition but in an advanced stage of their cancer trajectory. In Section 5.2.1, I highlighted how witnessing other patients' distress caused anxiety in one patient who went on to have recurrent nightmares after her discharge from hospital. Likewise, one patient compared his condition with another who was going for surgery and was not sure why he received radiotherapy. This suggested that a poor understanding of one's condition could have an ongoing psychological impact. Healthcare professionals seemed to be focused on the management of treatment. However, they may not have recognised the need to explore a patient's concerns or understanding during the course of receiving treatment.

6.4 Finding a balance in MSCC

Finding a balance between treatment interventions, communication and patient preferences in the acute stage of MSCC was threaded through the views of all the participants. The fact that MSCC is an acute condition, sometimes with impending cord compression, requiring emergency treatment, meant that quick decisions had to be made to maintain the patient's functional status. The uncertainty of treatment response could be challenging and healthcare

professionals made trade-off decisions based on treating the advanced cancer versus the patient's short life expectancy. Patient and carers tried to establish ways of achieving a balance between treatments versus quality of life for the family (Sections 5.3.1 and 5.3.2).

After the initial acute symptoms were resolved, patients and carers found other difficulties emerging around accessing timely information; being aware of what was happening and the reasons why; lacking understanding of how cancer was affecting them; knowing how the treatment was going to affect them; how long they would remain mobile; and issues around prognosis (Sections 5.2.3 and 5.2.4). This concurs with other studies of patients with advanced cancer where their information needs have been underestimated (Fallowfield, Jenkins and Beveridge 2002; Gaston and Mitchell 2005).

Within this study, information was identified as difficult to obtain by patients and carers, citing healthcare professionals' lack of time explaining to them about their condition as the main cause. This made it difficult for them to feel informed about their condition and therefore identify their priorities for care as they tried to keep some balance in their lives. They expressed strongly that this was about their life and a 15 minute consultation was not sufficient to address their concerns. Nanton *et al.* (2009), highlight that in prostate cancer patients, men viewed information on the process of care as important. However, the current study findings suggest patients want information about care and also to understand the process of decision making. For example, they wanted to know why surgery was not an option when studies indicated positive outcomes. They wanted information about them as an 'individual'. It is also apparent within this study that patients were used to getting lots of information about their treatment for their primary cancer, but this was a new event. Therefore, there was a sense of no structure to help make immediate or long term plans (Section 5.2.3). This is also evident in acute cardiac conditions, where patients' attitude towards participation in their care changed over time (Nakano, Mainz and Lomborg 2008).

Wilson (1997), described this information-seeking behaviour as a coping strategy. Patients suggested it was important that a designated healthcare professional should go through with them the information their consultant had given them as back-up information while some patients wanted both reinforced in a leaflet format (Section 5.2.3). Van der Molen (1999), said this activity gives one a sense of cognitive control through active participation.

Literature indicates that patient navigators may improve the care of patients with cancer (Wells *et al.* 2008). Patient navigators has been widely used in the care of patients with head and neck cancers (Rogers, El-Sheikha and Lowe 2009; Ghazali *et al.* 2012). According to Paskett, Harrop and Wells (2011), patient navigators are more effective for interventions for cancer screening outcomes. Less is known about their impact on advanced cancer patients' experience.

In the UK, the clinical nurse specialist's (CNS) roles in specific cancer groups and palliative care are effective in collaborating patient and organisation needs (Poole 1996; Tarrant *et al.* 2008; Ream *et al.* 2009). The findings in the current study indicate the CNS may not be involved once the patient was diagnosed with MSCC. However, one patient (Case Study 3), expressed he continued to received good support from his tumour specific CNS and district nurse (Section 5.4.1). Within this study, the patient's referral to a palliative nurse varies in the acute stage. As well as the need for a CNS, another mechanism to identify patient needs is through the use of a patient's concerns inventory (PCI). Delivering for Health (Scottish Executive 2005), has set out that we must recognise and develop the services to meet the changing health needs, and that the care of patients with MSCC should be a priority.

Most of the patients and carers in this study looked for information on the internet including cancer websites, but felt that information might not be relevant to them. Thus most of their trust was in their consultants (Section 5.2.2). Ziebland, Evans and McPherson (2006), reported that cancer patients used the internet for a wide range of information, often for support needs, many of which were not met by conventional health care.

In the current study, not all patients are computer literate or know how to source information and leave the decisions on treatment to their consultants. Although Mishel *et al.* (1988; 1990), suggest that it is important healthcare professionals provide information to the patient to initiate a positive response and cope with uncertainty, the current study indicates that healthcare professionals themselves faced uncertainty. Healthcare professionals were aware that treatment is palliative and the difficulty is to determine the patient's response to treatment. However, patients may not be aware of this decision making process and may not have an explanation about why there was a change in their radiotherapy dosage. The treatment dose of radiotherapy may compromise the patient's mobility, causing paralysis. For example, in Section 1.4.3, the treatment impact on the spinal column is not known. This illustrates that the treating oncologist had to find a balance in treatment where the outcomes could be uncertain.

This study also revealed that healthcare professionals themselves were also looking for evidence (Sections 1.3.2, 4.5, 5.2.2 and 5.3.1). Oncologists talked about evidence of a 'good' surgical outcome for patients as reported in the NICE guidelines (2008). However, some medical staff expressed less support was received from the neurosurgical team when they referred their patients for surgical opinion. They were unsure how decisions were made and whether neurosurgeons used any tools to guide their decisions to consider patients for surgery (Sections 4.4 and 5.3.1).

As I had identified in Sections 1.4.3 and 2.7, several studies proposed prognostic scoring systems to help clinicians make treatment decisions (Tomita *et al.* 2001; Tokahasi *et al.* revised version 2005; Bilsky and Azeem 2007; Tokuhashi, Ajiro and Umezawa 2009). However, their use is not evident in the current study (Section 5.2.2). Neurosurgeons assert that decisions for surgery should be made on a team basis. They need information from the oncologist about the patient's life expectancy in order to determine the potential benefits of surgery. In addition, one neurosurgeon talked about respecting the patients' preferences. Decisions about treatment are complex, as current guidelines lack

an evidence base so have limited use in clinical decision making (Kilbride *et al.* 2010; Lee *et al.* 2012). There is a lack of research to provide the evidence and despite all this, patients were not offered a choice and might not fully understand the intricacies of medical decision making. This indicates that all stakeholders want evidence to make trade-off decisions and it was important to know the process of decision making. For these reasons, there seemed to be a lack of clarity in the local referral pathway and guidelines.

An issue in the current study is about who should see the patient first. Some oncologists felt that the first contact should be the neurosurgeons to assess the patients, but they are aware that not all patients would be treated neurosurgically. Patients were admitted through different pathways, so referral to neurosurgeons often happened at a late stage when there was already cord compression and patients were less likely to have a good outcome from surgery (Section 5.2.2).

Another problem identified within the current study was that the availability of expertise for complex spinal thoracic surgery may be limited. The same issue was also identified in a recent audit where patients were referred to orthopaedics for surgical opinion, but the local service does not specialise in spinal surgery (Sui, Fleming and Kehoe 2012). On the other hand, there were views amongst the participants in the current study that the NICE guidelines (2008) are enormously long and lacked supporting evidence, with a bias towards the surgical perspective and lack of representation from the radiotherapy perspective (Sections 4.5 and 5.3.1). Their rationale was that many of the patients are elderly and may not be suitable for surgery so the guidelines offered limited support in decision making for this group of patients. What emerged was the inconsistency or the lack of understanding in the decision making process amongst all concerned.

Eleraky, Papanastassiou and Vrionis (2010), and Tancioni *et al.* (2010), have suggested a multidisciplinary team approach in the management of MSCC that includes a medical and radiation oncologist and a spine surgeon/neurosurgeon

would be helpful. The current study also suggests this. However, the possibility of patient involvement in this team and in the decision making process was not expressed.

Despite the patients need for more information, discussions around prognosis varied between patients and their carers' in the current study. There was vacillation between wanting to know and not wanting to know, which one carer described as 'a mixed bag' (Section 5.2.4). This supports the study by Eva *et al.* (2009). However, within this study, patients and carers want to take control of their lives in order to make immediate or long-term plans, decisions about continuing their jobs and preparing their children to cope with the bad news (Section 5.2.4). However, the type of information varied. For example, one carer said he wanted to know "whether it's good or bad or indifferent". Schapira, Nattinger and McHorney (2001), suggest using a qualitative method to explore how patients interpret and assign meaning to probabilistic information.

Cherlin *et al.* (2005), used questionnaires and in-depth interviews with family caregivers to elicit their need for prognostic information. The authors found family caregivers had difficulty hearing the news, ambivalence about what they wanted to know and difficulty in understanding the bad news. These difficulties related to ineffective communication about end of life issues. In the current study, some carers found information on prognosis a burden to know, thus did not desire to know. However, they expressed a need for prognosis information as the patient's condition deteriorated (Section 5.2.4).

Within the current study, some patients may not verbalise a need for information immediately for reasons that they needed time to comprehend the information before they could ask questions. Another factor was the fear of dying. However, this was sometimes interpreted as not wanting to know by their oncologists (Section 5.2.4). Their approach varied and was linked to whether the patient asked questions or opened up a discussion around end of life. Some patients may not know what to ask and expressed anxieties and fears

when they read information about suffering in pain and dying in an undignified way (Section 5.2.3). This can be a source of misunderstanding (Hardey 1999; Prior 2003).

Some carers felt they were given second hand information by their spouse and were not necessarily consulted, and when they *were* included they had difficulty discussing their concerns in the presence of their spouse. However, in Section 5.2.3, evidence suggests that doctors sometimes face a dilemma whether to give information about the patient's condition to their carer. Some patients did not want their doctor to inform their spouse of their condition. Communication channels, establishing who knows what, and respecting the patient's preferences are complex. Thomas, Morris and Harman (2002), and Vivar, Whyte and McQueen (2010), assert that attention must be given to the carer's role for their contributions in the patient's care as they are co-carers. Evidence from the current study indicates that communication of information to patients and their carers is an ongoing and paced process and its scope varies.

There was also the difficulty in predicting the prognosis in different cancer pathways and the treatment response (Section 5.2.4). Some healthcare professionals talked of not wanting to take away the patient's hope unless there was no treatment available. Therefore, discussions about prognosis are inherently fraught with concerns about taking away a patient's hope. Daugherty & Hlubocky (2008), surveyed 729 oncologists in the United States about their approach to disclosing prognosis and found that whilst 98% (714/729) of physicians would disclose the terminal nature of the illness, fewer (57%: 416/729) would give an estimated time frame to death. Studies suggest that medical staff are reluctant to discuss prognosis with their patients due to the difficulties in estimating this (Harrington and Smith 2008; Grunfield *et al.* 2006 Rose et al, 2004).

Some patients found that their diagnosis of MSCC enabled them to re-prioritise their life, while others found it hard to strike a balance. Some patients had continuing worries: difficulties coping with immobility, returning to work, fear of

deterioration and coping with relationships and home management. Older patients seemed to adopt a positive attitude to overcoming cancer. Patients who remained mobile talked about their fears and were uncertain if and when they would lose their mobility and independence. Healthcare professionals had mixed views about giving information to patients regarding their future symptoms (Section 5.2.4). There existed a preference to help patients to remain hopeful whilst balancing this against wanting to give realistic information. There was also a notion of 'wait and see' in relation to the outcomes of treatment.

As the patients and carers became more aware of the consequences of MSCC, they recognised they had to take control of their situation in coping with uncertainty. Some patients and carers accepted and knew the progression of cancer was beyond their control and discussed spending quality time with family. Some talked about whether to continue working or cutting down the hours. Others talked about being positive and taking 'one day at a time', 'living for now' and 'I'm still living'. Some older patients took comfort in their religious faith and that gave them a sense of meaning. Whilst some patients accepted their condition, they were still trying to find a balance with alternative treatment possibilities versus spending quality time with family. Similar evidence showed patients spoke of having a positive attitude and finding other ways of coping after the initial shock at diagnosis (Eva *et al.* 2009).

The notion of finding a balance was also about patients and carers being in control, rather than cancer controlling them, and this is evident in the sub-theme "*battle plan – what is the next step*" (Section 5.3.2). Patients who had defied the odds of a poor prognosis and lived longer than expected with cancer were hopeful they would survive as they did before. Some healthcare professionals felt patients might be unrealistic about their prognosis.

Many patients revealed that they were worried about the demands on their spouse and felt that support should be available to help them cope (Section 5.3.3). This is commonly reflected in end of life issues faced by patients, who

want inclusion and recognition of their family (Curtis *et al.*2001). Healthcare professionals, on the other hand were arranging support that they felt was best for the patient without putting these additional demands on the carers. It appears that all parties were unaware of the intentions of each other. Vivar *et al.* (2010), found that when diagnosed with recurrence of cancer patients and their families needed to adapt to the uncertainty caused by the unpredictability of the disease. However, there is a difference in MSCC cases, Eva *et al.* (2009), describe that patients did not survive long enough to adapt to their disability, and hence there was ambiguity in their plans. In the current study, the patients and carers struggle between wanting to prolong life and palliative intent, while at the same time grieving their impending loss.

6.5 Support beyond the treatment of MSCC

In this study, the patients' and carers' support needs varied during the transition from hospital to home/district hospital/hospice. The Phase Two findings indicated that it was primarily the patient's mobility that dictated the support they required. Patients and carers have multifaceted needs and these needs changed over time and they might not necessarily get the support required.

In the current study, there appear to be variations in the availability of and referral to other agencies. Pursuing rehabilitation services for patients varied depending on the patient's age and their geographical areas. Healthcare professionals in the current study faced challenges in referring patients for rehabilitation. Community rehabilitation and rehabilitation centre staff were reluctant to accept patients with MSCC as they perceived patients with cancer would not improve (Sections and 4.6 and 5.4.1). Patients were either not aware of access to rehabilitation support or were not offered rehabilitation despite several studies reporting that patients with MSCC benefit from a structured rehabilitation programme (Guo *et al.* 2003; Garrard *et al* 2004; Ruff *et al.* 2007a; 2007b; Saarik and Harley 2010; Tan and New 2012).

However, in the current study, those patients who did receive rehabilitation, the services provided did not necessarily meet the patient's needs (Section 4.6).

Garrard *et al* (2004), commented that many rehabilitation staff members have little experience of managing dying patients and suggest staff would benefit from support by the palliative care teams. This strengthened the need for joint working amongst specialised health providers to have an integrated health service to see to the needs of patients with MSCC.

Rehabilitation allows patients and carers to gain mastery over their situation and thereby achieve empowerment and have some sense of control and quality of life (Zimmerman 1995; Sherwood 2004; Given, Given and Sherwood 2001; 2012). More needs to be done to support patients and carers to maximise the quality towards the patient's end of life (Scottish Government 2008). This study highlights the problems with both continuity of care and need attention. Often patients were treated very quickly in an acute setting and then the patient's practical needs were not followed up, or there was a delay in delivering equipment aids, or assumptions were made without further assessment (Section 5.4.1). There were also variations in the referral to palliative care. Lung cancer patients, when diagnosed with MSCC with a short life expectancy, had palliative care access arranged immediately on discharge. However, if a patient was referred from a district hospital for specialist treatment, and if they were discharged home afterwards, there was a possibility of the patient not receiving the support they required. Palliative care nurses were not involved unless patients were referred to them for pain control.

In a recent report, Goodwin *et al.* (2012), highlighted that integrated care is important to better co-ordinate the care being provided by a number of different professionals and health agencies to meet the needs of patients. However, the setback is that its implementation is still being debated. For example, one patient felt that the district nurse did not undertake any follow up and she had difficulty obtaining practical, emotional and financial help, meaning that levels of support were variable (Section 5.4.1).

In relation to the patient's place of care once they became paralysed, the findings suggest disparity in the patient's and carer's experiences in the

transition from hospital to home (Section 5.4.1). Peters and Sellick (2006), compared 32 in-patients and 26 home-based patients receiving palliative care services in Australia. The home-based patients reported higher quality of life, feeling more in control and had lower depression scores. However, in the current study, choices influenced the patient's views of the carer's capacity in coping at home and this supports the studies by McCall and Rice (2005), and Tang (2003), in advanced cancer cases.

This study highlights that sometimes patients, carers and community staff may not have been involved in a discussion about the availability of support in the community (Section 5.4.1). Carers and primary care healthcare professionals described hospital's plans for patients care as 'prescriptive'. Some of the primary care professionals reported receiving fragmented information which delayed the patient going home. A similar communication problem was reported by McIlfatrick (2007), on the palliative care needs of patients with cancer, diseases of the respiratory system, circulatory and the nervous system. Studies by Field (1998), and McIlfatrick (2007), found that patients with cancer were more likely to receive palliative care compared to other conditions. The current study found variations in the initiation of palliative care for patients with MSCC (Section 5.4.1).

Studies have shown that the impact of recurrence caused great suffering in families with the spouse taking over the running of the family often experiencing psychological stress (Northouse *et al*, 2002; Jiwa *et al*. 2008; Vivar *et al*, 2010). Similarly, in the current study, patients who remained mobile on discharge found that their needs increased as their physical capabilities deteriorated and this increased the demands on their spouse or carer (Section 5.4.1). Studies have found strong associations between patient and carer satisfaction with accessibility to care in advanced cancers (Lorenz *et al*. 2008; Morse and Fife 1998). Although the carers in the current study appreciated the support they received, when support is imposed on patients and carers this can cause distress and resentment on the part of the carers (Section 5.4.1). As I have shown in my findings, some healthcare professionals in the acute setting may

not have a discussion of future symptoms with patients or carers (Section 5.2.4). Therefore, patients and carers may not know or anticipate progression of the disease and hence would not understand the decisions made.

Patients and carers described great efforts to regain a sense of normality after treatment and experienced constant fears of the end. For example, a carer did not understand why the hospice staff used the hoist or the purpose of the bowel regimen, and felt that the patient's independence was taken away (Section 5.2.4). Although Peppercorn *et al.* (2011), suggested individualised care for patients with advanced cancer, I believe social support needs to be an ongoing conversation not only with the patient and carer but between health agencies.

The reality of being paralysed and disabled was not fully felt until patient and carer were home, and this realisation could be emotional. One patient talked about her loss of confidence and was concerned about being seen in public and not having the ability to walk again. For those patients who were mobile, they expressed the fear of losing their mobility and independence. Patients talked about the triviality of being told to 'think positive' or 'living with cancer' by others. The thought of physical and social constraint was debilitating and patients expressed difficulty living with cancer.

Studies on other cancers have reported the motivational aspects of support groups having a positive impact on group efficacy and individual self-efficacy (Docherty 2004; Wilson 2008; Power and Hegarty 2010). However, patients within this current study perceived that such groups might not be helpful. The patients' and carers' views about support groups were negative. They felt support groups weighed them down with negative talk about cancer which they did not want to be reminded of. Only one patient talked about the benefits of listening to other patients. Moreover, carers were overseeing their spouse's hospital appointments and children's needs. Therefore, trying to get a balance was difficult for patients and carers.

The need for psychological support was not necessarily recognised by healthcare professionals unless they knew their patients well. This has also been reported by other studies: Simpson and Whyte (2006), and Geiser *et al.* (2006). In the current study, patients said they were happy with the support from their spouse and family, while at the same time they had difficulty expressing their emotions to them because they too were emotionally involved. Some patients stated that it would help them to talk to someone who was not emotionally involved, as and when the need arose. Some patients perceived friends and family expected them to move on, having had cancer for a long time. In addition, some patients did not have friends or neighbours who lived nearby. There was a sense of being abandoned as their illness progressed (Section 5.4.1). Patients felt loneliness and distress after treatment, but this can be unrevealed and needs exploring. Some patients talked about 'journeying alone' and being lonely. In a gynaecological cancer study, Sevil *et al.* (2006), found that women who expressed a need for psychological help had a higher loneliness level (Sevil *et al.* 2006).

Fawzy (1999), explained that patients with advanced cancer fear abandonment by family and medical staff as they are going through a personal mourning and thus may experience depression and anxiety. Healthcare professionals need to clearly verbalise their commitment to remain available (Fawzy 1999). However, this current study adds new knowledge that verbalising commitment or giving a telephone number is not sufficient as the participants in my study were reluctant to bother healthcare professionals, but would welcome a call from them just to ask how they were getting on, every now and again (Section 5.4.1). Some consultants referred patients to the Macmillan Centre for emotional support, however, as I indicated in Section 5.3.1, not all patients considered these centres helpful. This is an area healthcare policy makers need to address in order to ensure quality end of life care.

A study by Kennedy *et al* (2011), showed that some healthcare professionals were more disease-orientated and that emotional aspects could be neglected. In this study, some oncologists felt that nurses should be able to provide

generic psychological help to patients. In a review, McIlfratrick (2010), identified an increase in end-of-life education in nursing programmes. However, students and newly qualified nurses felt ill prepared to provide end-of-life care. In the current study, the reasons nurses gave was they lacked knowledge of different cancers to provide emotional support but did recognise the importance of this support. This suggests that nurses require further education to fully integrate palliative care within cancer care and this finding is in line with the findings of Mahon & McAuley (2010).

In the current study, one patient compared her experience of seeing a counsellor and a psychologist. She explained the difference a psychologist made in her life was that she helped her structure her thoughts and make plans. But this service was discontinued as her consultant thought she was coping. This suggests patients who had depression previously and patients who had immediate completion of treatment, needed to be assessed to determine whether they need psychological support.

Another concern raised by patients was the lack of information on monitoring of their tumour. They felt there was a lack of urgency to their follow up appointment, giving them a sense of uncertainty of what to expect (Sections 5.4.1 and 5.4.2). Patients expressed fears of not knowing whether their treatments were effective and were puzzled why there was no surveillance from the healthcare professionals, as they normally would have had during their primary cancer treatment. Leydon *et al* (2000), suggested that monitoring of tumours by scans seemed vital for patients to maintain hope. In the current study, patients had no idea that they would not have their scan if there was no treatment planned. This underlines that healthcare professionals need to have a discussion with the patient of what future investigation or monitoring entails.

Despite well recognised initiatives to integrate palliative support for those with metastatic cancer, data on practice showed facilitating the transition from active oncology to palliative care occurred late (Dy *et al.* 2008; Guo *et al.* 2010; Peppercorn *et al.* 2011). This can seem fragmented to patients (Sections 5.2.3

and 5.4.1). It is perhaps not surprising that some patients thought that palliative care services were rationed to the final months of life (Section 5.4.1). While the patient continued to receive non-curative treatment, there was the risk of not being supported by a palliative care nurse. The Scottish Government action plan 'Living and dying well (2011)', advocates a person centred approach based on the needs of patients and carers rather than diagnosis. This indicates a need to consider a blended approach of oncology/palliative services for patients who develop acute onset of MSCC and are discharged back to the community.

In the current study, carers were finding it hard to balance the demands of care and were experiencing anticipatory grief. The knowledge that the end is near allowed the carer to see to the comfort needs of their loved one rather than anticipate further treatment. Moreover, it allowed the patient to have their wishes expressed at the end of life. The findings here suggest patients' and carers' needs vary at different times in the illness trajectory and support needs to be flexible.

6.6 Summary

In summary, the three key themes portraying MSCC when presented as an acute condition, can be challenging and complex to manage. Accurate diagnosis is further compromised by the fact that MSCC can develop and overlap at different points in the trajectory of cancer. It influences all facets of the patients and carer' lives and they need timely information, and moreover, those needs change over time. It is evident that the lack of information on the process of care, decision making process, disease pathway, treatment and follow up causes uncertainty, thus enduring the inconsistencies. More importantly it signifies finality of life for patients. However, patients and carers expressed a wish to take control of their lives and this is linked to having information to make immediate and future plans.

The findings of this study add new knowledge to the management of MSCC. All stakeholders experienced uncertainty because of the unpredictability and life threatening nature of MSCC. There was a sense of seeking some structure and

direction in its management. Patients and carers want timely information, want involved in discussions about their immediate and long term plans, and to understand the decision making process and be able to negotiate support. Healthcare professionals also need timely information to inform decisions about patient treatment and care, as a multidisciplinary team. However, they need to include patients and/or carers as key players and need to embrace the concept of collaborative decision making with multi-agencies to optimise the overall care of patients with MSCC.

Franks *et al.* (2000), suggest some form of needs assessment is necessary to identify the patients and carers level of palliative support needs. McIlpatrick (2007) and Ferris *et al.* (2009), suggests an integrated approach to palliative care. In the current study, the findings suggest MSCC is a significant event which is unpredictable and the strategy adopted requires a collaborative approach which includes transition from acute oncology to palliative care.

The linkage from the data to theory is described as emic-etic or micro-macro (Morse and Field 2002). The process of theorising has revealed “the insignificance of the significance and the significance of the insignificant” from the data of the key stakeholders (Morse and Field 2002). These findings are recontextualised to form the proposed theory which can be considered as a contribution to middle range theory that is applicable to other similar conditions or (Morse and Field 2002; Smith and Liehr 2008).

6.7 Developing a theory of collaborative decision making in MSCC

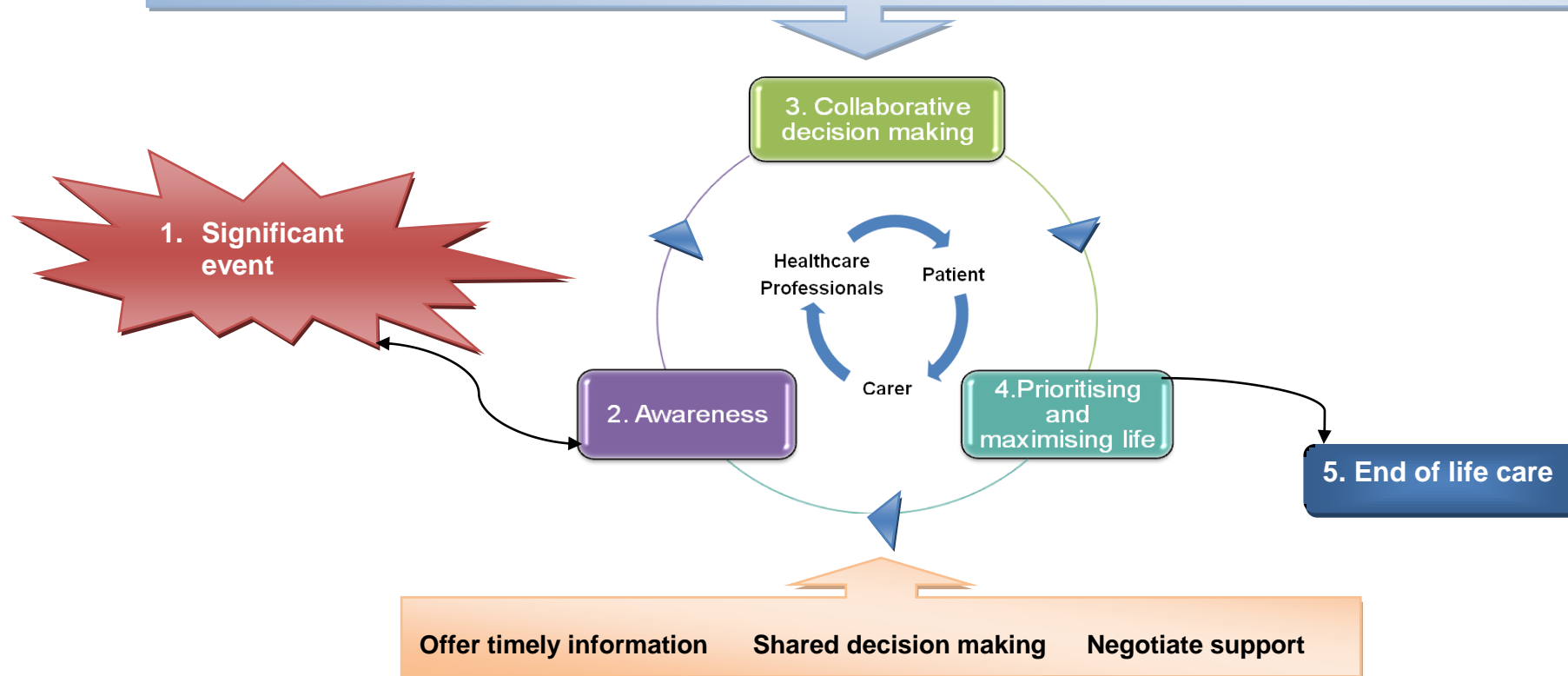
As seen in the previous section, Figure 16 illustrates the abstraction of concepts at both level 1 and level 2 of theory development. As a result of the discussion, the constructs of uncertainty and enduring inconsistencies seemed to be the key message that all stakeholders were struggling to find a balance in the management of MSCC. This further culminates with level 3 abstraction, resulting in a proposed theory; which is illustrated in Figure 17. This theory of

collaborative decision making in MSCC, recognises that MSCC is widely acknowledged to be an oncological emergency. To place the emphasis on involving patients in their own care in MSCC, the structure is seen as a process and not a linear journey. The rationale being that some patients may still be receiving their adjuvant treatment and some will have prolonged survival based on their response to treatment and the extent of tumour control. However, MSCC also signifies the finality of life which is represented as end of life. The main concepts for the building blocks of this theory are: significant event; awareness; collaborative decision making; prioritising and maximising life; and end of life care that would help enable the patient's journey in MSCC. The concepts are explained after Figure 17.

Figure 17: Level 3 abstraction - Theory of collaborative decision making in MSCC

Assumptions of the theory:

- A critical window of opportunity exists in recognising signs and symptoms of a threatening condition.
- Balancing acute interventions with progressive advanced disease.
- Patient and carer require opportunities to collaborate in decisions at the end of life.
- Prioritising and maximising patient preferences in the midst of acute intervention.
- Transition from acute care to palliative care



This theory allows patients, carers and healthcare professionals to process strategies and guidance to reduce the uncertainty that is inherent in MSCC. The concepts of the theory of collaborative decision making include: significant event, awareness of MSCC, collaborative decision making, prioritising and maximising life and end of life care.

1. Significant event

In this study, MSCC is described as a significant event that can result in irreversible paralysis with loss of bladder and bowel control. As a result, it will impact on the patient's survival and quality of life, and normally signifies transition towards the end-of-life. The onset of MSCC may cause confusion, distress or creates feelings of fear, uncertainty of the unknown and a sense of hopelessness for patients and carers. People can construct uncertainty as a problem or they can be disposed to interpret and manage it as a potentially positive force within the social context in which they live. The healthcare professionals' perspectives were of dealing with a condition with limited treatment options which can be complex.

2. Awareness

Evidence from this study shows that conversations about awareness of signs and symptoms of MSCC, potential benefits and uncertainty of treatment outcomes, prognosis, deterioration of condition and the palliative intent of treatment often did not occur or occurred late in the patient's trajectory of cancer. The key issue from this study is that patients had difficulty in comprehending the new or vague symptoms they experienced or recognising their significance. Therefore, patients at high risk of MSCC or bony metastases should be informed about the signs and symptoms of MSCC. Awareness is about providing patients with the information about their likely cancer pathway and exploring their goals for the future. This would empower patients and/or carers to know when, how, and where to get help urgently. The findings from this study suggest that often patients were followed-up by their tumour specific consultant. Therefore, information about MSCC should be embedded during the patient's consultation with their tumour specific consultant and reinforced by their general practitioner.

The current study also identified that carers and/or family members look for information for the patient so they understand when assistance may be required. Supporting carers includes providing them with signs and symptoms of MSCC and involving them as a partner in the patient care and this did not always happen, but was important to carers in this study. People are also embedded within social networks that influence how they make decisions. Carers are part of that network. A key population-based study in Canada estimated that at least 2.5% of all people with cancer experienced one or more episodes of spinal cord compression in the five years preceding death (Loblaw, Laperriere and Mackillop 2003). This suggests that information about the recurrence of MSCC should also be provided to patients on discharge.

The concept of awareness includes giving timely information and tailored education to all stakeholders. Awareness also encompasses informing general practitioners, community staff, and medical staff out with oncology through tailored education. Raising awareness and education on the early signs and symptoms of MSCC to healthcare professionals should be from a collaborative perspective. In an ideal situation, patients, carers and healthcare professionals will be aware of MSCC, because they will be communicating at the same level.

3. Collaborative decision making

It is evident that all stakeholders can make decisions. The patients and carers in this study perceived that healthcare professionals were not working together as a multidisciplinary team and the patients and carers were often not included in the decision making process. This study draws attention to the fact that each discipline can make decisions in isolation thus contributing to problems of communication across and within disciplines. The resulting decisions could therefore sometimes be fragmented and not clearly communicated and understood by all the key stakeholders.

As the key stakeholder, the patients, alongside their carers', were not always involved in important discussions and they felt left in the dark about how their problems were being managed especially around the time of onset of MSCC, and initial treatment. Patients and carers need to navigate through a complex

system, often not knowing what treatment or support is available to them. The healthcare professionals in the study stressed: “treatment is a team decision, not a surgical decision”; “what we need is a multidisciplinary team to manage MSCC”; and “we need to identify what our goals are” and “it was shared decision making”. Although in Chapter 2, section 2.8, the wider literature on oncology suggests that a ‘shared decision making’ approach is not helpful in the treatment decision (Menard et al. 2012), Da Silva (2012), argues that there is no agreed definition for ‘shared decision making’. Moreover, it can be used as a tool to identify the goals of patients. Shared decision making requires all stakeholders involved in patient care to be informed, engaged and decisions reviewed. For shared decision making to be effective, this has to be acknowledged by the healthcare professionals in partnership with the patient and carer (Da Silva 2012). Moreover, Brock (1991) and Jefford and Tattersall (2002), found that most patients preferred shared decision making with their multi-disciplinary team. In the current study, shared decision making is not just about treatment decisions; it also encompasses support beyond treatment and end-of-life care.

Collaborative decision making is about effective communication between and amongst healthcare professionals within the acute setting and across health agencies (including the patient and/or carer). Boon *et al.* (2004:3), defined collaborative care as “practitioners who normally practice autonomously from each other; however, they share information concerning a particular patient who is being treated by each of them”.

However, findings from this study, confirm collaborative decisions should include the patient and/or carers. It is also about respecting opinions and making shared decisions among healthcare professionals, the patient, and/or carer and working closely together in delivering optimal care to meet the preferences of the patients with MSCC. The evidence from the literature shows that collaboration between care providers, coordination of care and patient involvement contribute to better quality of life (Canadian Health Services Research 2005). A mechanism suggested by Jiwa *et al.* (2008) is to harness an effective information technology strategy to ensure practitioners in different

care sectors have access to the same data on patients to improve continuity of care.

It is also about understanding that requirements for support vary at different times within the trajectory of cancer. The level of care needs to be explained and reviewed taking into account patients and carers views. Therefore, support is through negotiation and a mutual approach. It is also about recognising that patients and carers need help to make adjustments to deal with the consequences of disability and end of life issues.

4. Prioritising and maximising life

The process that an individual moves through during the experience of MSCC depends on several factors; whether they have functional independence or whether there is a threat to it and whether there are further treatment options. Whilst patients said they accepted their cancer had progressed and was beyond their control, they still had hopes for a prolonged survival. However, a discussion about treatment intent would let patients make a balanced decision. This concept is also about dealing with the complexity of MSCC with an unpredictable outcome.

There was also a sense of recapturing what was most important to them and to take stock of what they could still do and the time they had left. The experience of MSCC often initiates a re-prioritisation of life's priorities. The key focus here is about the patients and carers coming to terms with the reality of dying.

5. End of life care

Evidence from this study shows the acute care setting was challenging in managing MSCC and that the transition from active treatment to palliative care could be less than optimal. This is supported by studies which reported negative consequences for patients who lacked an insight into their disease stage, resulting in late end of life planning and late access to palliative care services (Innes and Payne 2009; Guo *et al.* 2010). The preparation for the transition from curative to palliative care is necessary to reduce suffering and to improve the patient's quality of end of life. The main issue is the tension

between acute intervention and palliative care and this is a key problem with MSCC in that its acute onset normally indicates transition towards the end of life and goal setting and aims may be contradictory. Quality end of life care is highly individual and this can only be achieved through a process of shared decision making taking into consideration patients' and carers' preferences and needs. Therefore, in a complex condition like MSCC, treatment and care decisions are usually not made in isolation but need to include social context, interactions and changes in the disease or situations which are not necessarily limited to one setting such as acute care.

6.8 Strengths and limitations of the study

In this section I reflect on the research process and consider the strengths and limitations of this study. The body of knowledge on key stakeholders' perceptions and experiences in the acute management of MSCC is limited. This thesis makes a unique contribution to the current state of knowledge in MSCC as it illuminates the perspectives of the key stakeholders when MSCC presents. This study explores the patient's journey in MSCC and provides in-depth information about how patients' and carers' experiences and perspectives change over time and illuminates the tensions between acute intervention and planning end of life care.

By utilising a qualitative paradigm, this study has obtained a level of detail and understanding that would not be possible through the use of a quantitative paradigm (Silverman 2000:8). A case study approach using real patients as the focus of the case analysis has illuminated how care is provided in the clinical setting and has presented the illness trajectory from all perspectives providing a more holistic approach (Yin 2009). The findings of this study contribute to greater knowledge and understanding of MSCC and the construction of a theory to illuminate the components of collaborative decision making can inform future clinical practice. The use of focus groups and interviews provided strength to this study and these were effective in gaining rich data on key stakeholders' experiences of MSCC (Yin 2009).

This study took place in four regional health boards in Scotland and as such there could potentially be limitations to the generalisation of the findings. It is proposed that as there were considerable variations in socio-economic conditions and health services represented in the sample of eight cases, that the interpretation presented here is likely to have relevance to a range of settings. Furthermore, the emerging theory presented here can be applied, tested and refined in different contexts thus providing opportunities to unpack and illuminate decision making in MSCC.

Qualitative descriptive research using a case study approach was an appropriate method, as it enabled the collection of in-depth information; however, it was time consuming to gather data from different sources, especially from healthcare professionals who may work different shifts or have gone on their day off or on leave. In addition, this study dealt with vulnerable patients who were at the end of their lives. Access to longitudinal data in the patient's journey in MSCC took time, as some of the patients were still receiving treatment, or became unwell. One patient died before the second interview was possible and another was not well enough to participate. Despite these limitations, the findings from this case study indicate that MSCC is a complex condition, fraught with uncertainty and all stakeholders endured inconsistencies at all levels. In addition, these results indicate that the needs of carers and patients must be addressed when planning any supportive care. Future support also needs to assist both patients and their carers to manage ongoing stressors and to maintain resources which can have a positive effect on each person's quality of life.

6.9 Chapter summary

This chapter has incorporated and discussed the experiences of patients, carers and healthcare professionals in the management of MSCC in relation to relevant literature. The synthesis presented within the discussion identified that patients diagnosed with MSCC and their carers face vague new symptoms, a significant event, and they face multifaceted aspects of uncertainty in the trajectory of MSCC. The current study has highlighted that an acute onset of MSCC warrants emergency treatment. Moreover, it normally signifies that

patients are facing their end of life. For patients and carers manoeuvring through the acute setting and different health agencies, proved complicated and many of their needs were unmet.

At the same time, they wanted information and some sense of structure so they were able to think ahead and plan for whatever time they had left to live. Their support needs vary between individuals and may change over time. However, patients may not necessarily have the information to help them understand and make decisions and endure uncertainties.

Importantly, healthcare professionals knew they had to make decisions, but the lack of guidance resulted in them often trying to 'play safe' in the management of the patients. Due to the lack of guidance or protocol, healthcare professionals also endured inconsistencies and provided what they thought would be best for the patients. However, these decision making processes may not be known to the patients and carers and they continued to endure uncertainty.

The findings in this study represent an in-depth exploration of the boundary between the acute management of a complication of advanced cancer and transition to end of life care in MSCC. The analysis illustrates the challenges, tensions and conflicts from the perspectives of healthcare professionals in their decision making process in MSCC. More importantly, it draws attention to the patients and carers difficulties in navigating a complex system.

The discussion presented levels one, two and three abstractions leading to the development of a proposed theory in MSCC. The discussion reveals that all key stakeholders make decisions albeit with different goals. This places healthcare professionals in an enabling role: through collaborative decision making they can enable patients towards make decisions in their end of life care.

Chapter 7: Conclusion and Recommendations

This chapter concludes this research by providing key findings with recommendations to inform patients, carers, healthcare professionals and suggestions for future research. This qualitative study has sought to explore the perceptions and experiences of patients, carers and healthcare professionals in the management of metastatic spinal cord compression (MSCC) in a region in Scotland. Using case study as a research strategy this study highlights the management of MSCC is complex due to the threatening and unpredictable nature of the condition. There is a distinct need to recognise the complex reality of MSCC and the resulting tensions, conflicts and challenges faced by all stakeholders. Optimal service provision is based on negotiating support, according to the needs of patient and carer. Patients are more likely to benefit from a blended acute oncology and palliative care that would allow healthcare professionals to provide optimum care.

7.1 Original contribution to knowledge on MSCC

Metastatic spinal cord compression is normally a condition with acute onset. The orientation in management remains towards acute care rather than palliative care which produce tensions and challenges in meeting the needs and support required by patients and carers. MSCC is a complex condition requiring multiple interventions and care co-ordination by a variety of healthcare professionals across healthcare agencies. All stakeholders make decisions and the evidence suggests MSCC has a significant impact on a patient's quality end-of-life. The theory of collaboration decision making can inform key stakeholders about strategies to deal with uncertainty and inconsistencies in the management of MSCC.

7.2 Recommendations for patients

The findings in this study raise a number of implications for patients as outlined below:

- The most urgent implication for patients is to provide information on early signs and symptoms of MSCC to patients. There is a need to update

awareness and address new concerns to help patients cope and to provide patients with timely information about treatment or change of treatment plans, pathway of disease, effectiveness of treatment, side effects of treatment, and prognosis. Patients want information about them as an 'individual'. In addition to the information the consultant has given to the patient, a designated healthcare professional should reinforce this. Education can be further facilitated through visual aids and leaflets.

- A progress chart at the patient's bedside indicating, for example, 'patient is due for stairs assessment tomorrow' – healthcare professionals will then have an idea of the immediate plans for the patient. This information would also benefit carers when they visit the patient.
- There is a need to have a discussion with patients about functional deterioration. Giving information and working alongside patients and carers would enable them to make decisions rather than assuming the needs of their care.
- Provide psychological support to patients immediately after treatment, to enable coping abilities and find meaning and adapt to a diagnosis of MSCC. This may be input from the palliative care team/telephone support. Offer psychological support to patients who have suffered depression before.
- It is important to emphasise the availability of oncology team and a telephone number for contact and emergencies should be provided. Patients and carers reported being hesitant about contacting NHS 24 as they felt they might not get immediate help. To overcome this, NHS 24 staff should be made aware of the guidelines. Similarly, locums should be made aware to phone the advice service if MSCC is suspected.
- Support for children and adolescents who are faced with a dying parent.

7.3 Recommendations for carers

From the findings of the study, the following recommendations are for carers.

- Carers want information about how to recognise the signs of deterioration and how to cope with changes in the patient. Information and education to carers can be facilitated with visual aids and leaflets.
- Service providers need to address the concerns of carers in order for them to support their loved ones to experience a quality end of life.
- Provision of support should be flexible, discussed and negotiated with not only the patients but also in consultation with the carers.

7.4 Recommendations for healthcare professionals

- There is a need for clarity in the local referral pathway.
- A multi-disciplinary team specific to MSCC may be beneficial in improving continuity of care. The team should include patient and/or carer and in particular palliative care team or a palliative clinical nurse specialist. The use of 'shared decision making' as a tool in patient centred care – to identify each patient's preferences, values and needs.
- As patients may require and process information incrementally, a patient's concerns inventory (PCI) may be beneficial to allow them to express their anxieties and needs.
- Unitary documentation for all healthcare professionals involved in the patients' care for MSCC to ensure continuity of care. This would provide clarity and guidance for mobilising the patient, follow-up on rehabilitation; and the equipment needs of patients. In addition, a tick-box in the care pathway to remind healthcare professionals to document what had been discussed, or any updated information given to the patients.
- Nursing staff need to be sensitive to where patients are placed in the ward as seeing other patients in an advanced stage of cancer may evoke anxiety and fear.

- Perform neurological examination and functional assessments of patient shortly before discharge may be useful as a patient's mobility can deteriorate rapidly.
- An awareness of MSCC should be raised in all staff. For example, through discussion groups that includes primary, secondary and tertiary healthcare professionals using a tailored approach - 'whole clinical picture'.
- The primary care team has a vital role in the support of cancer patients and their families. Keeping the primary care team informed about the patients is crucial; however, the support provided must be flexible and negotiated. Healthcare professionals need to understand that patients and carers deal with different health providers and getting their concerns addressed needs collaboration between the different settings. Providing support in the form of telephone calls would benefit patients and carers. It could create a platform for carers to voice their concerns in providing support to their loved ones.
- Rehabilitation services for patients with MSCC should be embedded in their care.

7.5 Recommendations for policymakers

- Develop a collective strategy for managing MSCC in Scotland.
- Evaluate MSCC provision against the quality care standard.
- Institute an ICD code for MSCC for effective mechanisms to identify those patients who are approaching their end of life.
- A single electronic end of life care register to better co-ordinate care which is accessible to all health care settings.
- It is recommended that NICE guidelines or pathway be made simple.

7.6 Recommendations for future research

This study has made a contribution to the knowledge base of MSCC through the perceptions and experiences of patients, carers and key healthcare professionals. The study has identified concepts such as significant event, awareness, collaborative decision making, prioritising and maximising life and end of life care. However, further research is needed:

- The proposed theory of collaborative decision making in MSCC requires further development, testing and refinement.
- To investigate the use of a clinical radiological predictive tool to inform decisions about positioning, mobilisation and rehabilitation.
- Investigate the use of orthosis to relieve pain in MSCC.
- To evaluate the views of rehabilitation staff to understand their decision making process in determining MSCC patients' suitability for rehabilitation.
- To evaluate patients' and carers' experiences in receiving rehabilitation input.
- Undertake a review of current information and resources on MSCC awareness. This could aid in the production of MSCC awareness materials.

7.7 Dissemination of findings

The findings from this research will be made available through various approaches including journals, conferences and posters. These will be made accessible to patients, carers, healthcare professionals, the MSCC cord compression steering group and cancer organisations.

7.8 Reflections on the process of this study

My experience of undertaking this research has been a steep learning curve; from despair combing through the vast amount of data to the joy of discovering a theory. I have heard other researchers say 'your theory would drop out from the sky' – there was anxiety provoking when nothing seemed to happen as I wrote my discussion chapter. However, I felt a sense of elation when the theory did develop. It was not an easy process as my mind kept going into overdrive.

Although qualitative research is a useful means of collecting sensitive data and obtaining a deeper understanding of a phenomenon, I found it an emotional journey, particularly when hearing participants' stories on facing end of life. I also found it a privilege that participants trusted me to hear their stories. The process of transcribing can be both emotionally draining and distressing to hear peoples' experiences. I feel the opportunity to debrief is important for a researcher as support in this area is neglected. Another difficulty in analysis was seeking to make sense of the different stakeholders' perspectives and finding common themes – there was a need for constant movement between the eight case studies which can be very paralysing for the mind.

Although, I recruited key healthcare professionals who were involved in the management of patients with MSCC, there are healthcare professionals' perspectives that have not been captured in this study. For example, radiotherapists who provide radiotherapy treatment to patients - despite them having being invited. It would have been valuable to capture the views from other primary cancer groups such as haematology, renal and gynaecology. However, some patients were too ill or did not want to participate in the study. Overall, this journey has been a valuable training in opening my mind to qualitative research and data analysis has challenged me intellectually.

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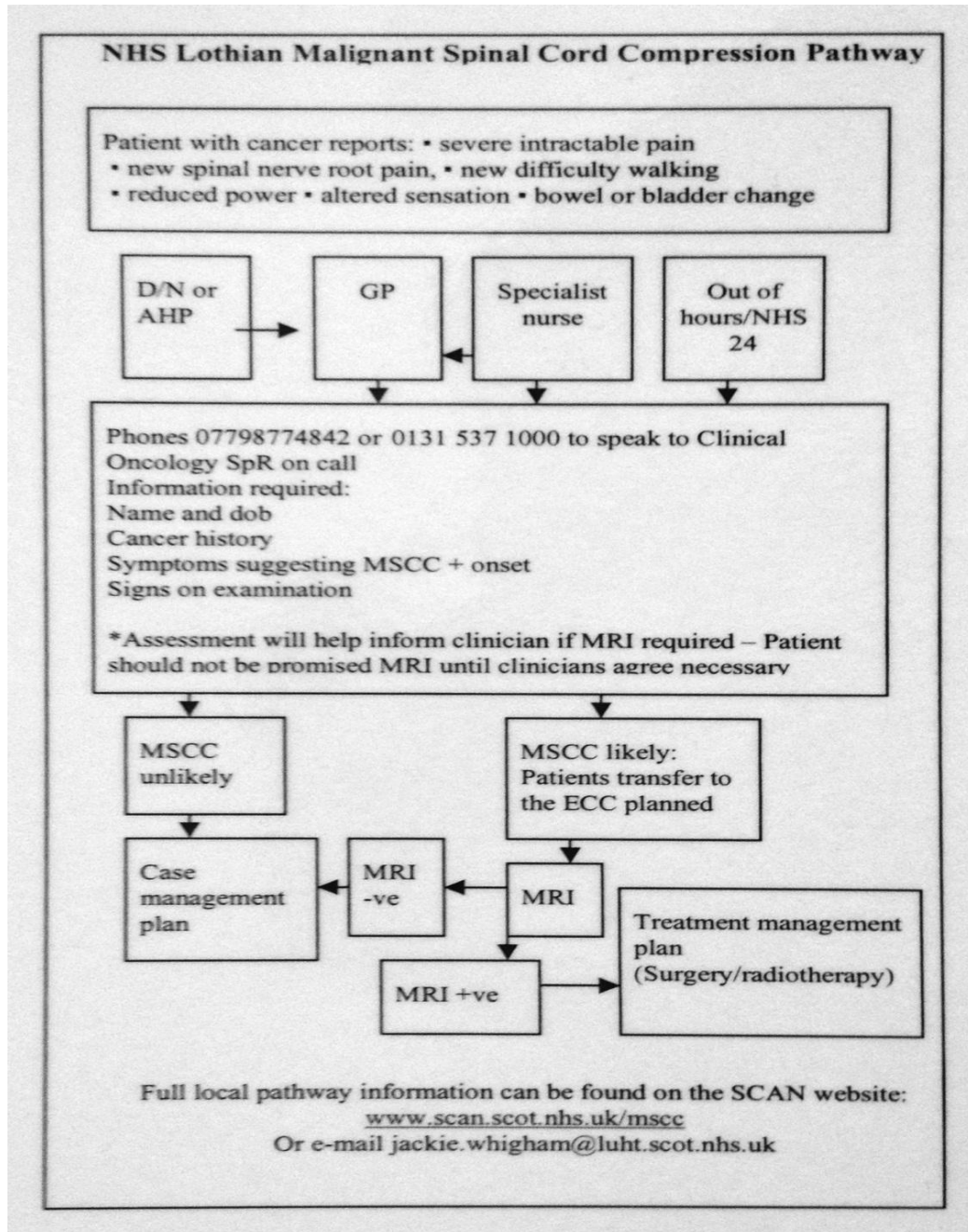
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Appendices

Appendix 1: Lothian MSCC Referral Pathway



Lothian MSCC Referral Pathway (back of card)

Information for clinicians – Signs and symptoms of Malignant Spinal Cord Compression



Patient has a history of cancer and may have one or more of the following, and *may* have been previously diagnosed with bone metastases.

- Severe intractable progressive pain especially thoracic
- New spinal nerve root pain (burning, numb, shooting)
- Any new difficulty walking
- Reduced power/altered sensation in limbs
- Bowel/bladder disturbance

If you suspect MSCC, refer to your local NHS referral pathway guideline for *Malignant Spinal Cord Compression* www.scan.scot.nhs.uk/mscc **or call 07798774842 or 0131 537 1000 and ask for the on-call Clinical Oncology SpR at the Edinburgh Cancer Centre for advice**

Appendix 2: Medline search strategy

Medline search strategy: 1st January 2000 – 9th August 2012		
No.	Search terms/keywords	Number of hits
1	(MM “Spinal cord compression”)	5688
2	(MM “Spinal cord neoplasms+”)	7096
3	(MM “Neoplasm metastasis+”)	30221
4	“Metastatic spinal cord compression”	160
5	“Malignant spinal cord compression”	62
6	1 or 2 or 3 or 4 or 5	42434
7	(MM “Patient participation”)	8134
8	(MM “Patient satisfaction”)	18360
9	(MM “Consumer participation+”)	15191
10	(MM “Consumer satisfaction+”)	25758
11	“Patient attitude”	95
12	(MM “Patient-Centered Care”)	4903
13	“Decision making, patient”	67
14	“Patient experience”	1054
15	“Patient perspective”	697
16	“Patient journey”	124
17	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	46468
18	6 and 17	6
19	(MM “Palliative Care”)	18694
20	(MM “Terminal Care+”)	28526
21	19 or 20	44085
22	6 and 21	165
23	6 and 21 (Limit: year = January 2000 - August 2012; English Language; human; adult)	29
24	(MM “Quality of Life”)	44007
25	“Coping”	28728
26	“Psychosocial aspects of illness”	24
27	24 or 25 or 26	71559
28	6 and 27	35
29	6 and 27 (Limit: year = January 2000 – August 2012; English Language; human; adult)	21
30	“Healthcare professionals”	5933
31	“Multidisciplinary team”	5678
32	“Decision making, clinical”	43
33	30 or 31 or 32	11593
34	6 and 33	8
35	“Caregiver experience”	33
36	“Caregiver perspective”	16
37	“Caregiver support”	237
38	35 or 36 or 37	285
39	6 and 38	0

Appendix 3: Level of evidence (SIGN 2012)



Annex B: Key to evidence statements and grades of recommendations (2012)


Levels of evidence

- 1++ High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias
- 1+ Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias
- 1- Meta-analyses, systematic reviews, or RCTs with a high risk of bias
- 2++ High quality systematic reviews of case control or cohort or studies
High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal
- 2+ Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
- 2- Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
- 3 Non-analytic studies, e.g. case reports, case series
- 4 Expert opinion

Grades of recommendations

- A** At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; *or*
A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results
- B** A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; *or*
Extrapolated evidence from studies rated as 1++ or 1+
- C** A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; *or*
Extrapolated evidence from studies rated as 2++
- D** Evidence level 3 or 4; *or*
Extrapolated evidence from studies rated as 2+

Good practice points

-  Recommended best practice based on the clinical experience of the guideline development group

Appendix 4: Summary of studies - The impact of MSCC on patients' experience

Author	Year	Country	Care setting	Aim	Type of study
1. Cowap, J., Hardy, J.R. & A'Hern, R.	2000	UK	Hospital	To review the presenting features of patients with MSCC and to determine the functional outcome of patients at diagnosis, treatment and at follow up.	Quantitative - retrospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Medical records of patients diagnosed with MSCC from August 1987-September 1995.	Retrospective analysis of patient's medical records (n=166) regarding functional outcome and performance status using the Eastern Cooperative Oncology Group (ECOG) performance scale.		The median survival was 82 days (range, 1-1349 days). Limb weakness was identified as the most common followed by back pain, sensory loss and sphincter dysfunction. Back pain may not have been documented. The majority of patients (92%) received radiotherapy, only 20% showed an improvement in neurological function. The authors suggest poor performance scale and neurological status on admission indicate patients require high level of care. 23 patients (14%) had recurrence of MSCC (10 at previous site and 11 at a new site). Highlight patient's short life expectancy after diagnosis of MSCC. There was delayed presentation of MSCC. Functional outcome after radiotherapy is uncertain. MSCC can recur after treatment.		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
2. Conway, R., Graham, J., Kidd, J., Levack, P. & other members of the Scottish Cord Compression Group.	2007	UK	3 oncology centres in Scotland	To present further findings from the Scottish Cord Compression study.	Quantitative-prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Data of patients collected at 1 month after diagnosis of MSCC.	Assessment include: mobility; pain using the Visual Analogue Scale (VAS), Karnofsky performance Status (KPS); semi-structured questions Schedule for Evaluation of Individualised Quality of Life-Direct weighting (SEIQoL-Dw); Hospital Anxiety and Depression Scale (HAD); and survival. Patients (n=128) were interviewed 1 month after diagnosis of MSCC.		Survival was short (median 59 days) but varied between different primary cancer groups. Patients reported continued pain after radiotherapy. The benefit from radiotherapy was not immediate. Planning for future care should involve a discussion with what was important for patients, for example, place of care. Poor performance status at 1 month after diagnosis was also associated with a lower QOL but individual scores were high and not all patients with low performance status had low QOL scores. Mood was reported as normal in most patients. Some patients rated their QOL to be high and at the same time rated high levels of emotional distress and patients who had low QOL scores rated low levels of emotional distress. Life expectancy is short in MSCC and varied in different primary cancer groups. The effectiveness of treatment is uncertain. Pain issues were not addressed. The study indicates the difficulty in capturing information on patients' emotional well-being.		SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
3. Huang, J.& Jatoi, A.	2009	USA	Tertiary medical centre	To assess the needs and outcomes of patients with solid tumours who had become non ambulatory as a result of cord compression.	Quantitative-retrospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Medical records of patients with a radiographic confirmation of MSCC. Treatment included corticosteroids, radiation and surgical decompression. Study was carried out between 1999 and 2006.	Retrospective analysis of patient medical notes (<i>n</i> =39).		<p>Patients who become non ambulatory after diagnosis of MSCC do poorly with a median survival of 76 days (range, 4-1975 days). The majority of patients required bladder and bowel care. 64% patients did not regain mobility. 33% patients went home without assistance. Stress the importance of palliative care in meeting patients' end-of-life needs. Suggest patients may benefit from an early discussion of hospice resources. Authors acknowledged study cannot capture whether patients have severe morbidity. Unable to capture the emotional status of patients.</p> <p>Findings indicate poor survival. Treatment outcome is uncertain. End of life needs may not have been addressed. Patients may have unmet needs.</p>		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
4. Guo, Y., Palmer, J.L., Bianty, J., Konzen, B., Shin, K., & Bruera, E.	2010	USA	Cancer Centre	To determine presence of advanced directives and do-not-resuscitate (DNR) orders among patients with MSCC.	Quantitative-retrospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Electronic medical records of patients with MSCC. Review was carried out from September 2005 to August 2008.	Retrospectively reviewed 88 patients' medical records for advance directive and do-not-resuscitate (DNR) orders. The mean age of patients was 55 years (range, 24-81).		<p>The median survival time was 4.3 months for patients with MSCC. The authors suggest patients were not aware of the urgency to have an advanced directive and do-not-resuscitate (DNR) order. Among 59 patients who had died, 26 (46%) had a DNR note. There was a short interval between DNR order and death (16.5 days) – this indicates a need for communication about end of life goals of care. The authors suggest the physicians can consider the development of MSCC as a baseline in prognostication and to initiate a palliative discussion.</p> <p>Strong evidence of short survival times for MSCC patients. Decision making around treatment intent may not have been discussed with patients and family members.</p>		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
5. Aass, N. & Fossa, S.D.	2005	Norway	Regional Cancer Hospital	To identify prognostic factors and prospectively evaluate daily life function and pain experience in hormone resistant prostate cancer patients with MSCC treated with radiotherapy.	Quantitative - prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients with MSCC from hormone resistant prostate cancer. Study period May 1996 to October 1999. All patients received 30 Gy given in 10 fractions except patients treated to large fields received 40 Gy in 20 fractions.	Used Barthel Activity of Daily Living (ADL) Index. Patients (n=49) were given the questionnaire at pre and post radiotherapy.		Median survival 3.5 months (range, 0.3-36.0). Improvement in mobility, daily function and sphincter control. Barthel ADL Index was not sensitive to differentiate between paralysis and paresis. Patient's mobility, daily life activities and sphincter control did not improve at the end of radiotherapy. Radiotherapy treatment was started at a median of 4 days (range, 1-66 days). The authors suggest prostate tumours may be slow to response to radiotherapy. Another possible reason was patients and/or their doctors may not have recognised the early symptoms of MSCC, therefore, there may have been a longer delay in receiving treatment. Difficult to detect functional deterioration with Barthel ADL Index. Limited study to patients with primary prostate cancer. Treatment outcomes with radiotherapy were uncertain.		SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
6. Schoeggel, A., Reddy, M. & Matula, C.	2002	Austria	Department of Neurosurgery	To demonstrate the mobility, continence, pain and quality of life in patients following palliative de-compressive laminectomy.	Quantitative - retrospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
The study included only patients who had metastases with infiltration of the dorsal epidural parts or those who could not be operated on via an anterior approach.	84 patients met the criteria (53 male and 31 female). The average age was 60 years (range, 23-82 years). 20% of patients have been mobile pre operatively.		Post operative assessment showed mobility rose to 45% but deteriorated after 2 months. The set back in the dorsal approach is the inability to remove the tumour completely. Heterogeneous group of patients with varying prognosis made treatment choice difficult and subjected to controversy. The authors suggest a randomised prospective study is required. Palliative laminectomy with total or subtotal tumour reduction in patients with malignant spinal metastatic disease improved patients' quality of life. However, outcome would be poor if there is pre-operative paraparesis and in such instance the authors recommend laminectomy only. Decision making with regards to treatment, incision approach, primary cancer types and prognosis is complex. Regaining and maintaining mobility is unpredictable.		SIGN level 2 -

Author	Year	Country	Care setting	Aim	Type of study
7. Wai, E.K., Finkelstein, J.A., Tangente, R.P., Holden, L., Chow, E., Ford, M. & Yee, A.	2003	Canada	Division of Orthopaedics Surgery	To evaluate the efficacy of surgery in patients with metastatic spinal disease with respect to QOL.	Quantitative - prospective
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Indications for surgery included: intractable pain, neurologic deterioration, or failure of radiation treatment. Patients were excluded from the study if stabilisation was not possible, if expected survival was < 3 months. The cohort study was conducted from November 1999 to May 2001.	Patient-centered questionnaire Edmonton Symptom Assessment Scale (ESAS) to assess quality of life. Physician-determined assessment with the modified Townsend Functional Assessment. Patients (n=25) participated. Average age of the patients was 59.3 years (range, 37-77 years).	Time to death ranged from 1-21 months. Great improvement in pain relief after surgery. Other domains of improvement: tiredness, nausea, anxiety, appetite and overall wellbeing. No improvement in drowsiness, depression and shortness of breath. Only 44% had functional improvement. No outcome difference with regards to age, tumour extension. There is risk of post-operative morbidity in thoracic lesions. Neurological recovery is unpredictable. Pre-operative neurological function is a strong predictor of functional outcome. Psychological issues may not have been addressed. No definition of QOL and justification given for the choice of instruments. The abstract of the article reported positive outcomes but not the negative aspects.			SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
8. Sandalcioğlu, I.E., Gasser, T., Asgari, S., Lazorisak, A., Engelhorn, T., Egelhof, T., Stolke, D. & Wiedemayer, H.	2005	Germany	Department of Neurosurgery	To analyse factors that impact on the functional outcome of patients with surgically treated intra-medullary spinal cord tumours and to identify characteristics of different histology.	Quantitative – case series
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Patients with intra-medullary spinal cord tumours. The study was conducted between 1990 and 2000.	Functional outcome assessed with Frankel grade (Frankel <i>et al</i> 1969) and analysed against age, tumour type, site and extent of tumour. Frankel grade outcome grade as poor (A+B), fair (C), and good (D+E). 78 patients participated in the study. The mean age of patients was 43.3 years (range, 1-75 years). There were 46 males and 32 females.	Pre-operative neurological status is a strong predictor of functional outcome. Functional outcome is related to histological type and grade of tumour growth. In some cases complete tumour removal may not be possible if there was absence of a clear plane for dissection. No outcome difference with respect to age, tumour extension, however, there is increased risk of post-operative morbidity in thoracic located tumours. Pre treatment neurological status is an indicator of functional outcome. Functional outcome depends on the primary cancer histology and extend of metastases. High risk of surgical complications if tumour involved the thoracic region.			SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
9. Falicov, A., Fisher, C., Sparkes, J., Boyd, M.C., Wing, P.C. & Dvorak, M.F.	2006	Canada	General hospital	To assess HRQOL outcomes in patients undergoing surgery for spinal metastases.	Quantitative-prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients with bony spinal metastases requiring surgical intervention were included in the study. Excluded patients who had previous surgery for MSCC and patients who were unable to fill out the questionnaires. Study was conducted from April 1999 to March 2004.	85 patients were given questionnaires at 5 points – before surgery, at 6 weeks, 3 months, 6 months and at 1 year. HRQoL questionnaires include: the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), Health Utility Index (HUI-3), the European Quality of Live – 5 Dimensions (EQ-5D), Visual Analogue Score (VAS) and Eastern Cooperative Oncology Group (ECOG).		Survival was 39.1 weeks. Surgery significantly relieves pain, improves QOL and daily functional status. Pain was measured using several instrument tools. There was a statistically significant correlation between baseline global health status and survival time ($P=0.041$). No significant improvement in ECOG functional scale from pre-operative status. Surgical complications were reported as low. Survival is poor. Functional outcome may not improve after surgery. No definition for HRQOL. No justification for choice of assessment tools used. Limitations of the study – patients whose estimated survival of less than 3 months and patients who were unable to fill out the questionnaires were disadvantaged. Authors did not give the abbreviations for the assessment tools. The number of assessments and the different time points were time consuming for patients to complete.		SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
10. Fujibayashi, S., Neo, M., Miyaki, K., Nakayama, T. & Nakamura, T.	2010	Japan	Department of Orthopaedic Surgery and related hospitals	To evaluate the value of palliative surgery for spinal metastases and to identify the factors predicting satisfaction of patients and their family members after surgery.	Quantitative – prospective, survey
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients deemed fit with an expected survival of at least 3 months were eligible for the surgery. The objective of the surgery was palliative. Surgical approach total en bloc spondylectomy were excluded in the study.	Questionnaire-based survey on satisfaction of patients and their family members 3 months after surgery. 37 patients responded to the questionnaires.		80% of patients were satisfied with the outcome of surgery. However, 16 of the responses were made by family members as the patients were dead at the time of completion of questionnaire (limitations - the views of patients and their family members may differ). Improvement in pain after surgery. Patients aged below 65 years with neurological improvement correlated with increased patient satisfaction. Satisfactions of family members were influenced by pain improvement and length of the patient survival. The authors highlight that Japanese patients tend to trust their physicians to make decisions, however, in this study, the decisions were made by the patients in 23 cases, by patient and family in 12 cases, by family		SIGN level 3

		alone and by physician 1 case each. Thirty-seven (37 of 71) patients responded. Patients and carers who did not respond may have been unsatisfied or had poor outcomes. Information about patients' expectations of treatment and physician treatment intent was not discussed.	
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Author	Year	Country	Care setting	Aim	Type of study
11. Wu, J., Zheng, W, Xiao, J-R., Sun, X., Liu, W-Z. & Guo, Q.	2010	China	2 hospitals	To determine whether surgery for patients with spinal metastases could improve the quality of remaining life and prolong survival.	Quantitative – prospective longitudinal study
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients confirmed with a diagnosis of MSCC with at least 1 neurological sign or symptom (focused on pain), restricted to a single area. Estimated survival of > 3 months. Study period from July 2007 to June 2009.	67 patients (patients in the surgery group $n=33$ and the non-surgery group $n=34$) completed the Functional Assessment of Cancer Therapy (FACT-G) questionnaire at baseline, 1, 3, 6 and 9 months. Recruited patients: surgery group $n=46$; non surgery group $n=50$		29 patients died within 9 months after diagnosis of MSCC. 67 patients completed all 5 follow up assessments. The surgery group had significantly higher QOL scores, physical well being, emotional well being and functional well being than the non surgery group over the 9 months assessment. Patient selection may be bias. There was no statistical significant difference between the 2 groups in terms of survival ($P=.056$). The authors acknowledged it is traditional for patients to be attended by family members and this may have contributed favourably in the social/family well being domain. The authors acknowledged that both groups were eligible for surgery; the decision making was left to the patients and their family members. Patient selection may be biased. There is no information about patients' preferences and choice in treatment decisions. Moreover, family members may have influenced the patients' decisions.		SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
12. Patchell, R.A., Tibbs, P.A., Regine, W.F., Payne, R., Saris, S., Kryscia, R.J., Mohiuddin, M. & Young, B.	2005	USA	Multi-institutional (7 centres)	To determine the value of surgery (randomised trial) comparing the efficacy of direct de-compressive surgery plus post-operative radiotherapy with that of radiotherapy alone.	Randomised controlled Trial
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
<p>Eligibility of patients: at least 18 years old with a tissue-proven diagnosis of cancer; MRI evidence of MESCC; to have at least one neurological sign; paraplegic no longer than 48 hours before surgery; tumour restricted to a single area; in good medical status; and expected survival of at least 3 months.</p> <p>Exclusion criteria: multiple discrete compressive lesions; radiosensitive tumours; previous MESCC; and previously received spinal radiation.</p>	<p>Randomised, multicentre, non-blinded trial with two treatment groups: surgery plus radiotherapy ($n=50$) or radiotherapy alone ($n=51$). Both treatment groups were treated with ten 3 Gy fractions. The primary end point was the ability to walk. Secondary end points were urinary continence, muscle strength, functional status, the need for analgesics and survival time.</p>	<p>Patients treated with surgery plus radiotherapy retained the ability to walk for longer than patients treated with radiotherapy alone. Of patients who could walk prior to surgery, 94% (32/34) retained mobility compared to 74% (26/35) of the patients who received radiotherapy alone, group. 32 patients (16 in each group) who were unable to walk prior to surgery; 10 patients (62%) regained mobility compared to 3(19%) patients in the radiation group. Similarly, the authors reported the 30 day mortality rates were 6% in the surgery group and 14% in the radiation group. There was reduction in the use of corticosteroids and analgesics. The authors highlight that an intention-to-treat analysis was used throughout the study. The authors acknowledged the study limitation had patient selection bias.</p> <p>Although the authors suggest the best treatment for MSCC is surgery, many of the patients may not meet the strict criteria. However, the survival time is reported as prolonged due to the ability to remove the tumour and the preservation of neurological function. In patients who were treated with radiotherapy alone; regrowth and secondary compression is more likely.</p>			<p>SIGN level 1+</p>

Author	Year	Country	Care setting	Aim	Type of study
13. Tomita, K., Kawahara, N., Kobayashi, T., Yoshida, A., Murakami, H. & Akamaru, T.	2001	Japan	Department of Orthopaedics Surgery	To propose a new surgical strategy for the treatment of patients with spinal metastases.	Quantitative - prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
<p>Patients with spinal metastases. Phase 1 Study period 1987-1991 - Retrospective analysis of 67 patients' predictive value of prognostic factors to design a new surgical scoring system. 1987 -1991</p> <p>Phase 2 Study period 1993- 1996. Prospectively evaluated 61 patients prognostic outcomes based on decisions using the surgical scoring system.</p>	61 patients included in the Phase 2 study. The mean age was 57.7 years (range, 33-72 years). There were 34 women and 27 men.		<p>The authors suggest patients with paraplegia may have a long survival period with the appropriate treatment. The authors proposed a new surgical scoring system to help clinicians in decision making. The system consisted of 3 prognostic factors and the points were added to give a score between 210: grade of malignancy; visceral metastases; and bone metastases. The treatment decision for patients will be based on this strategy: 2-3 points suggest a wide or marginal surgical excision for long-term control; 4-5 points suggest marginal or intra-lesional decision for middle-term local control; 6-7 points, palliative surgery for short-term palliation; and 8-10 points indicated supportive care.</p> <p>Further research is required to test the practicality and accuracy of the scoring system.</p>		SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
14. Omeis, I.A., Dhir, M., Sciubba, D.M., Gottfried, O.N., McGirt, M.J., Attenello, F.J., Wolinsky, J-P. & Gokaslan, Z.L.	2011	USA	Hospital	To determine the incidence and identify risk factors for surgical site infections (SSIs) in patients undergoing surgery for spinal tumours.	Quantitative – retrospective case control study
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients who had spinal tumours and had undergone surgery. Database was created to record patient information from January 1995 to February 2008.	Retrospective review of 678 patients' records. Patients who were included in the study ($n=65$) with surgical site infections (SSIs) were compared to a control group of patients ($n=162$). The mean age was 52.1 years in the SSIs group and 47.4 in the control group.		<p>There is a high risk of surgical site infections (9.5 %) in spinal tumour surgeries. The factors that increased the risk of infection were related to the use of complex plastic closures, previous surgery and radiotherapy treatment, increasing number of co- morbidities and longer duration of hospitalisation during primary surgery. Increase in age was not significantly associated with development of infection ($P=0.093$).</p> <p>There is increased risk of surgical complications in patients with an increased number of co-morbidities. The reporting of the results was confusing in terms of the number of patients who were included in the study.</p>		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
15. Murakami, H., Kawahara, N., Demura, S., Kato, S., Yoshioka, K., Sasagawa, T., & Tomita, K.	2010	Japan	Not stated	To evaluate in elderly patients the peri -operative complications and prognosis for metastatic spinal disease.	Quantitative - retrospective
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
193 patients with metastatic spinal disease underwent surgery based on Tomita's (2001) surgical strategy since 1999. Reviewed patients who were older than 70 years (32 patients were >70 years and 161 patients were younger <70 years).	Retrospective reviewed 32 elderly patients (>70 years) who underwent surgery. The mean age of the 32 elderly patients was 73.7 years (range, 70-82). 20 men and 12 women were included in the study. Pre-operative assessment on general condition based on the Eastern Cooperative Oncology Group (ECOG) and the Karnofsky performance scale. Other outcomes: prognostic score, survival time and post-operative complications.	<p>Post-operative occurrence of respiratory and delirium were significantly higher in the elderly population. The authors explained that cardiopulmonary reserve in the elderly is not enough and often cannot withstand the anaesthesia or surgical stress. There was no significant difference in achieving normal temperature after surgery for the elderly and non elderly patients. However, in radical surgery (total en bloc spondylectomy), the average time was 9.5 days in the elderly and 5.6 days in younger patients. Despite the risk of complications, the authors suggest that total en bloc spondylectomy should not be avoided due to advanced patient age. The authors suggest that post-operative prognosis could be predicted by the surgical strategy, however, this may deviate due to patient's pre-operative condition.</p> <p>Elderly patients with increased co-morbidities are at higher risk of complications post surgery. Patient selection is based on generally fit patients.</p>			SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
16. Levack, P., Graham, J., Collie, D., Grant, R., Kidd, J., Kunkler, I., Gibson, A., Hurman, D., McMillan, N., Rampling, R., Slider, L., Statham, P., Summers, D., The Scottish Cord Compression Study Group.	2002	UK	3 oncology centres in Scotland	To report details concerning symptoms (especially pain) preceding the development of malignant cord compression; delays between onset/reporting of symptoms and confirmed diagnosis; and accuracy of investigation carried out.	Quantitative-Prospective observational
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Criteria for entry to the study: a definitive diagnosis of malignant cord or cauda equine compression by MRI of the spine. Study period: 1 January 1998 to 14 April 1999.	319 patients (203 male and 116 female) participated in the study. The median age was 65 years with 89% of patients over 50 years.	<p>82% of patients were either unable to walk or only able to walk with help. Pain was the most common complaint (94%) and had been present for about 3 months (a median of 90 days). 84% of patients reported severe pain; the site of pain did not correspond to the site of compression. Weakness and/or sensory abnormalities were reported late leading to delayed diagnosis (median of 66 days). The majority of patients had reported early symptoms to their GP. The authors recommend that a referral guideline based on the index of suspicion of MSCC is required. The authors also proposed a national programme of awareness of MSCC, including educating patients. Patients with cancer with a complaint of severe back pain or nerve root pain need urgent assessment and treatment.</p> <p>MSCC is an oncology emergency. Early treatment is paramount to preserve neurological function. Patients who are at risk of developing MSCC are those who have a history of cancer when they first develop pain, age >50, known bone metastases especially in prostate or breast cancer.</p>			SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
17. Levack, P., Graham, J. & Kidd, J.	2004	UK	3 oncology centres in Scotland	To report QOL of patients shortly after diagnosis of malignant cord compression, its relation to physical disability and to emotional well being.	Quantitative-prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients diagnosed with malignant cord compression. Data collection January 1998 to April 1999.	QOL measures using Schedule for the Evaluation of Individual QoL (SEIQoL-Dw); Hospital Anxiety and Depression scale (HAD) for emotional wellbeing, Barthel Disability Index (BDI) for activities of daily living, Karnorsky Performance (KPS) to assess functional status. 261 patients participated in the study.		The majority of patients scored high on family life and marriage (91% and 39% respectively). Health and mobility were nominated by 44% and 35 % respectively and 29% on independence. The findings indicate that what the health professionals perceived was important to patients may not correspond to those of the patients. However, what contributes to quality of life varies widely between patients. Few patients were severely depressed shortly after diagnosis. Younger patients were more distressed than older patients. The authors highlight that the SEIQoL-Dw finding encourages health professionals to listen to what matters to patients. Physical function matters, however, non-physical issues may be more important. There is a lack of information on whether patients had an understanding of their prognosis shortly after diagnosis. Treatment with corticosteroids, radiotherapy and analgesics may have given the patients a sense of optimism.		SIGN level 2+

Author	Year	Country	Care setting	Aim	Type of study
18. Street, J., Berven, S., Fisher, C & Ryken, T.	2009	Not applicable	Not applicable	To examine the available literature on health related quality of life (HRQOL)	Systematic review
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Reviewed clinical studies on HRQoL assessment tools from 1966 to December 2008. There were 2 studies at level 2, 16 at level 3, and 123 at level 4.	141 clinical studies included. Reviewed the validity of existing outcome instruments used in the studies judged on correlation with the International Classification Functioning Disability and Health (ICF).		The most common patient self assessment tools used were Short Form (SF-36), SIP 5, and the Activities of Daily Living (ADL). The common cancer-specific quality of life assessment tools used were Eastern Cooperative Oncology Group (ECOG), the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30), and the European Quality of Life – 5 Dimensions (EUROQOL 5D). None of the studies defined health related quality of life or justified the choice of the assessment tool. There is no HRQOL measure to assess patients with metastatic spinal tumours. There is disparity in the choice of instruments to measure the QOL of patients with MSCC. The outcomes measures were process variables and were not a true reflection of QOL. This suggests difficulty in capturing the different domains of QOL specific to MSCC.		SIGN level 2++

Author	Year	Country	Care setting	Aim	Type of study
19. Street, J., Lenehan, B., Berven, S. & Fisher, C.	2010	Not applicable	Not applicable	To identify HRQOL questionnaire previously reported for spinal metastases and to validate the new Spine Oncology Study Group Quality Questionnaire (SOSGOQ).	Systematic review
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Reviewed clinical studies on HRQOL assessment tools from 1966 to December 2008.	Based on the previous systematic review of 141 clinical studies (Street et al. 2009), the reviewers developed a new measure Spine Oncology Study Group Outcomes Questionnaire (SOSGOQ)		The SOSGOQ questionnaire was based on the 4 domains of the International Classification of Functioning, Disability and Health (ICF): physical function; neurological function; pain; mental health; social function; and post therapy questions. The questionnaires were developed via consultation with patients with metastatic disease of the spine. Face validity assumed from consensus of an international expert working group. There is no publication validating the feasibility of this assessment tool.		SIGN level 2++

Author	Year	Country	Care setting	Aim	Type of study
20. Mitera, G., Zeiadin, N., Sahgal, A., Finkelstein, J., Chow, E. & Loblaw, A.	2010	Not applicable	Not applicable	To identify the need to develop a tool specific for MSCC to generate a meaningful data for future trials	Systematic review
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Reviewed clinical studies on quality of life measures in radiation therapy trials for patients with MSCC. No levels were assigned to the studies. There were 4 prospective and 1 retrospective studies. The review was conducted from 1950 to October 2008.	Reviewed 5 studies that assessed QOL as primary and secondary end points. 2 studies employed the Schedule for Evaluation of Individualised Quality of Life-Direct weighting (SEIQoL-Dw). 1 study used the Short Form 36 (SF36) Health survey questionnaire. 1 study used the Paediatrics Quality of Life inventory (PedsQL) and the other used Functional Assessment of Cancer Therapy (FACT-G).		Difficult to give meaning of a score on a measure. No consistent QOL measures employed across studies. Only 2 (SEIQoL-Dw and FACT-G) meet aspects of QOL, however, were not specific to MSCC and can be time consuming to complete. Concept of QOL to include cognitive, emotional and subjective components of patients. The concept of quality of life is complex and the subjective component of patient experience is important. The quality of life measures may not be relevant to patients with MSCC. The authors did not include social/family domain which can influence the quality of life of patients. The review limits studies related to outcomes after radiotherapy.		SIGN level 2++

Author	Year	Country	Care setting	Aim	Type of study
21. Hutchison, C., Morrison, A., Rice, A.M., Tait, G & Harden, S.	2012	UK	Cancer Centre	To determine patients and staff views on the provision of information to patients with a diagnosis of, or considered to be at high risk of developing MSCC.	Prospective - survey
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients diagnosed with MSCC. Staff include: consultants, registrars, radiographer, senior ward/charge nurse and clinical nurse specialist.	Survey - open and closed questions. Patients with MSCC ($n=56$) and staff ($n=50$) participated in the study. (75% male and 25% female). Staff group: 29 consultants, 7 registrars, 1 radiographer, 6 senior ward/charge nurse and 7 clinical nurse specialists.		The majority of patients (86%) wanted to be informed about the signs and symptoms of MSCC if they were at risk of developing it. 54% of staff gave prophylactic information about MSCC to patients. 45% of consultants were not sure whether prophylactic information should be given to patients (no reasons given for this response). There was a lack of clarity on whom, when and how information on MSCC should be given to patients. The authors suggest the lack of responsibility could be due to MSCC cuts across all site-specific cancers and care settings. Other possible reasons suggested were staff may not be aware of what information was available, or it may have been overlooked. Patients may not have the full information to understand their condition. Early detection of MSCC is important in decision making about treatment to improve outcomes. Patients' preferences for information have not been explored in depth.		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
22. Ruff, R.L., Adamson, V.W., Ruff, S.S. & Wang, X.	2007a	USA	Neurology Service	To determine whether directed rehabilitation affect survival, pain, depression, independence and satisfaction with life for patients who were non ambulatory after spinal epidural metastases.	Quantitative – prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients with paraplegia due to epidural metastatic spinal cord compression. Patients with poor prognosis were excluded.	Compared paraplegic patients ($n=12$) who had 2 weeks of rehabilitation to a 'No Rehab' ($n=30$) historical control group. Depression was assessed with the Beck Depression Inventory-Second Edition (BDI-II), Satisfaction with Life Scale (SWLS). Patients were followed up by telephone contacts monthly and outpatient visits 3 monthly.		Patients who received rehabilitation had longer survivals (26 weeks compared to 6 weeks for patients who did not receive rehabilitation). Fewer deaths from myelopathic complications, reduced pain level, lower depression scores and higher satisfaction with life. 26 patients (86.7%) out of the 30 patients in the 'No Rehab' group suffered clinical depression and were treated with anti-depressants. One patient from the rehabilitation group was diagnosed with depression. Highlights patients and carers coped better with structured rehabilitation programme. However, patients with a short life expectancy were excluded. Psychological issues may not have been addressed or neglected in the 'No Rehab' group.		SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
23. Ruff, R.L., Ruff, S.S. & Wang, X.	2007b	USA	Neurology Service	To determine whether the benefits of directed rehabilitation for pain, depression, and satisfaction with life, persisted for patients who were non ambulatory after spinal epidural metastases treatment.	Quantitative – prospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
See the description of previous study (Ruff <i>et al.</i> 2007a). This article reports on the patients' pain level for the remainder of their lives.	Expand on the previous study on the patient reported outcome for pain levels, depression, and satisfaction with life.		Patients in the rehabilitation group had lower depression score two weeks after completion of treatment and until death (minimal to mild depression). The 'No Rehab' group had severe depression. Patients who received rehabilitation reported less pain, consumed less analgesics, were less depressed and had higher satisfaction scores compared to the 'No Rehab' group. Same comments as above.		SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
24. Tan, M. & New, P.W.	2012	Australia	In-patient Spinal Rehabilitation Unit	To examine the rehabilitation outcomes for patients with spinal cord injury (SCI) due to tumour, the impact of pain on disability and length of stay.	Quantitative-retrospective cohort case series
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Patients with spinal cord injury due to tumour.	Review 108 patients' medical notes. The median age of patients was 61.5 years (interquartile range 53.6-74). Functional Independence Measure (FIM) scores, documented presence of pain and analgesia and length of stay.		Patients with secondary tumours causing spinal cord injury have problems with pain which affected their outcome and progress in rehabilitation. However, they do benefit from a focused specialised rehabilitation programme with careful patient selection. The authors suggest balancing the goals of rehabilitation due to the patients' short life expectancy. The authors did not describe the support, length and specific details of their rehabilitation program. Patients who were perceived to have prognosis of less than 3 months were excluded from the study.		SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
25. Eva, G., Paley, J., Miller, M. & Wee, B.	2009	UK	NHS Region	To ascertain patients' constructions of disability as a result of MSCC.	Qualitative, longitudinal case studies
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Semi-structured interviews with patients, carers and health professionals.	Used semi-structured interviews with Adapted Pawson and Tilley's Context-Mechanism-Outcome (CMO) for data collection. George and Benett's (2004) process tracing for within-case analysis and Glaser and Strauss (1967) for between-case analysis. 9 patients, 6 carers and 29 health care staff participated in the study.		Patients oscillate between acknowledging and not acknowledging their disability. The "failure to acknowledge" seemed to be a positive illusion and have psychological benefits for patients. Understanding the patients' construction of disability can help to inform the rehabilitation needs of patients with MSCC. There was no information about each patient's carer or family members and healthcare professionals' views on how they dealt with this ambiguity. Little evidence on whether the patient had an understanding of their poor prognosis. No evidence of end-of-life discussions. The time points of follow up were not stated. The use of Glaser and Strauss (1967) may not capture the broader issues of the patients' experience.		SIGN level 3

Appendix 5: Summary of study – Carers’ experience supporting the patient with MSCC

Author	Year	Country	Care setting	Aim	Type of study
1. Fujibayashi, S., Neo, M., Miyaki, K., Nakayama, T. & Nakamura, T.	2010	Japan	Department of Orthopaedic Surgery and related hospitals	To evaluate the value of palliative surgery for spinal metastases and to identify the factors predicting satisfaction of patients and their family members after surgery.	Quantitative – prospective, survey
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Patients deemed fit with an expected survival of at least 3 months were eligible for the surgery. The objective of the surgery was palliative. Surgical approach total en bloc spondylectomy were excluded in the study.	Questionnaire-based survey on satisfaction of patients and their family members 3 months after surgery. 37 patients responded to the questionnaires.	<p>80% of patients were satisfied with the outcome of surgery. However, 16 of the responses were made by family members as the patients were dead at the time of completion of questionnaire (limitations - the views of patients and their family members may differ). Improvement in pain after surgery. Patients aged below 65 years with neurological improvement correlated with increased patient satisfaction. Satisfaction of family members was influenced by pain improvement and length of the patient survival. The authors highlight that Japanese patients tend to trust their physicians to make decisions, however, in this study, the decisions were made by the patients in 23 cases, by patient and family in 12 cases, by family alone and by physician 1 case each.</p> <p>Thirty-seven (37 of 71) patients responded. Patients and carers who did not respond may have been unsatisfied or had poor outcomes. Information about patients’ expectations of treatment and physician treatment intent was not discussed.</p>			SIGN level 3

Appendix 6: Summary of studies - Healthcare professionals' experiences in managing patients with MSCC

Author	Year	Country	Care setting	Aim	Type of study
1. Yamashita, T., Aota, Y., Kushida, K., Murayama, H., Hiruma, T., Takeyama, M., Iwamura, Y. & Saito, T.	2008	Japan	Department of Orthopaedic Surgery	To investigate the short-term function recovery and duration of improvement after palliative surgery, to correlate these outcomes with the revised Tokuhashi's (2005) score, and to examine the relationship between function and neurologic deterioration.	Quantitative - retrospective
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Patients' medical records were analysed. The criteria for surgery was life expectancy of more than 3 months.	Reviewed 86 patients' clinical charts. Used the Eastern Cooperative Oncology Group Performance Status (ECOG-PS) to assess patient's physical function prior to surgery and at monthly time-point post surgery. The mean follow up was 14 months (range, 4.0– 36.0)	<p>Patients with vital organ metastases have shortened duration of improvement ($P < 0.05$). The patient's post surgical physical function is strongly dependent on neurological status. The authors found the revised Tokuhashi's (2005) score was helpful in predicting short-term improvement in physical function after palliative surgery. The authors suggest more information on the natural progression of MSCC with palliative care only and non-surgically treatment are required. Patients who might benefit from surgery are those who still have effective adjuvant therapies, for example, in breast or prostate cancers. The author suggests physicians who are planning optimal treatment for their patients should also consider the primary cancer types when helping patients and their families make informed decisions.</p> <p>The palliative treatment intent is often not discussed with patients and/or family members.</p>			SIGN level 3

Author	Year	Country	Care setting	Aim	Type of study
2. Tancioni, F., Navarria, P., Pessina, F., Marcheselli, S., Rognone, E., Mancosu, P., Santoro, A. & Baena, R.R.Y.	2010	Italy	Department of Neurosurgery	To assess the impact of a multi-disciplinary approach for treatment of patients with MSCC in terms of feasibility, local control and survival.	Quantitative - retrospective
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Study period January 2004 and December 2007.	89 consecutive patients were included in the study.		Good pain relief was achieved in the majority of patients (91%). Local relapse occurred in 10%. Median survival was 11 months (range, 0-46 months). The types of primary tumour significantly affect the survival. The combination of surgery plus radiotherapy is feasible and provides benefits for patients. The authors suggest the importance of discussing each case within a multi-disciplinary team in implementing the most appropriate treatment approach. Decision making often did not involve patient participation. Therefore, patients may not have an understanding of the treatment intent.		SIGN level 2-

Author	Year	Country	Care setting	Aim	Type of study
3. Pease, N.J., Harris, R.J. & Finlay, I.G.	2004	UK	Hospital	To develop a care pathway for the management of patients with MSCC	Audit
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Audit was carried out pre implementation and post implementation of care pathway.	Audit		Lack of supporting evidence to detect spinal instability. Used clinical features such as mechanical pain and neurological changes and radiological findings as indicators for assessing spinal stability. Compared two audits and found that mobilisation does not appear to jeopardise patient's neurological function. The authors suggest the use of collars and braces to provide functional independence, increased sense of control and reduce pain. Early mobilisation resulted in decreased complications rate and increase in patient survival. Although reported that patients' quality of life was improved, this was an anecdotal finding. Patients' perspective of their care was not explored. Criteria of spinal stability for the purpose of mobilising the patients are unclear.		Audit

Author	Year	Country	Care setting	Aim	Type of study
4. Warnock, C., Cafferty, C., Hodson, S., Kirkham, E., Osguthorpe, C., Siddall, J., Walsh, R. & Foran, B.	2008	UK	Regional cancer centre	To evaluate the care of patients with MSCC	Audit
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Two-linked study: a staff questionnaire and retrospective audit of medical and nursing documentation. Questionnaire topic includes: mobility during and after treatment; referral and treatment pathways; steroid prescription patterns; patient problems during admission; bowel and bladder management; psychological support and the impact of MSCC on sexuality.	Review of patients' medical notes and questionnaire to staff. 50 patients' notes were reviewed (38 male and 12 female). The mean age was 68 (range, 42-91). The majority of patients (43) were aged over 60 years. Fourteen (66%) consultants, 10 (71%) specialist registrars and 32 (30%) nurses responded to the questionnaire.	<p>There are delays in diagnosis. The average time from diagnosis of cancer to onset of MSCC was 24 months (range, 0 days -11 years). In the majority of patients there was no significant change in functional status after treatment. The majority of patients were nursed flat during their radiotherapy treatment. There was a discrepancy between the medical and nursing staff on issues on mobility during the treatment period and documentation practice.</p> <p>Documentation revealed patients suffered low mood, anxiety, being tearful and this was often related to loss of independence, being incontinent, and in pain.</p> <p>The authors suggest a need to develop a clear guideline on mobility, assessing spinal stability and early referral pathway to the physiotherapists.</p> <p>The evaluation reflected that the majority of patients were elderly. Review of patients' notes may not capture an in-depth understanding of the patient's concerns and needs.</p>			Audit

Author	Year	Country	Care setting	Aim	Type of study
5. Kilbride, L., Cox, M., Kennedy, C.M., Lee, S.H. & Grant, R.	2010	Non applicable	Non applicable	To explore the main issues which surround the management of patients with MSCC.	Literature review
Sample, characteristics, patient or staff groups	Methods	Key messages			Evidence
Literature review to address issues around: (1) how is spinal stability assessed; (2) what is the role of bracing/should braces be used; (3) when is it safe to mobilise the patients and (4) what position should the patient be nursed in.	35 studies met criteria and were reviewed.	<p>Most of the articles were retrospective and of a descriptive nature. The review identified a gap in evidence relating to spinal stability, bracing, patient positioning and mobilisation.</p> <p>The reviewers suggest further studies to investigate whether imaging and clinical correlated to spinal instability; patient's quality of life issues; clarifying positioning and mobilisation from the patients and healthcare professionals' perspectives and possibly a randomised controlled trial to determine the efficacy and functionality of bracing.</p> <p>Current evidence on positioning, mobilisation and the use of bracing is limited and inconclusive. The preferences of patients with a poor prognosis and their quality of life are paramount and healthcare professionals need to help patients decide on their care and treatment.</p>			SIGN level 2++

Author	Year	Country	Care setting	Aim	Type of study
6. Lee, S.H., Cox, K.M., Grant, R., Kennedy, C. & Kilbride, L.	2012	Non applicable	Non applicable	To investigate the correct positioning (or mobilisation) and examine the effects of spinal bracing to relieve pain or to prevent further vertebral collapse in patients with MSCC	Cochrane systematic review
Sample, characteristics, patient or staff groups	Methods		Key messages		Evidence
Cochrane systematic review of randomised controlled trials of interventions on positioning or mobilisation and bracing.	No studies met the inclusion criteria.		Guidelines recommend the use of spinal orthosis to relieve pain and increase spinal stability. Spinal bracing may provide comfort and quality of life for some patients with MSCC. The reviewers did not identify any studies that would guide healthcare professionals in decision making in this area. There is a lack of evidence to inform the effectiveness of bracing for patients with MSCC.		SIGN level 1+

Appendix 7: Topic guide - Healthcare professionals

The opening

- Welcome and thank you for coming to this focus group session.
- This session will take no more than an hour.
- You are free to withdraw at any point.
- Ensure you have signed the consent form.
- Recording discussion – confidentiality will be maintained.
- Let's begin by briefly introducing yourself:
 - Name (for the purpose of transcribing)
 - Professional post
- Purpose of this focus group
(Refer to flip chart on the research title, background to the study and purpose of the focus group session)

Research title: A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

Background to the study:

The literature I have found so far indicated:

- There are differences in the treatment of MSCC.
- There are inconsistencies in patient management.
- Lack of patients' and carers' information on their experience.

The purpose of interview is:

1. To gather information about your perspective in delivering care to patients with metastatic spinal cord compression.

And

2. To determine any particular issues that you would like me to explore further with patients and carers.

• **Ground rules**

- Everyone's opinion are important
- Everyone has an opportunity to speak
- There are no right or wrong answers; even negative comments are useful in gaining insight about the topic in discussion
- Please feel free to express your opinion openly
- Are there any questions before I start?

The interview questions

I would like to open to the group by asking:

- 1) Do you have any issues or opinions/thoughts from your experience in caring for patients with MSCC?
(If no response, then I will make a start at the point of referral of patients)
- 2) Referrals of patients with MSCC
I know there are several ways patients are referred for MSCC.
 - Can you tell me your experience of the referral process?
- 3) Investigations
 - Do you have any opinions about the various diagnostic investigations used for this group of patients?
Prompt: MRI, CT scan, X-rays
- 4) Clinical managements of patients with MSCC
There are several treatments in the management of patients with MSCC.
 - Can you tell me about the treatment offered to patients?

- Prompts:*
- *Corticosteroids*
 - *Radiotherapy*
 - *Surgery*
 - *Spinal stability/instability*
 - *Mobility and rehabilitation*

Literature suggests that the patient's and carer's perspectives of care in MSCC are not well represented. What do you think are the important aspects of care for the patients and carers?

(If participant discuss the above questions and covers physical care, psychological and supportive needs, then I would not ask question 4 and 5 below)

5) Physical care and psychological needs

- Can you tell me how you tend to discuss the likely physical symptoms that a patient may face in the future?
- Can you tell me how you would address patient's psychological needs?

6) Information and supportive needs of patients or those close to them

Discussing the future where no cure is possible can often be difficult.

- Can you tell me how you tend to approach questions about the future?
- Can you tell me how you tend to address patient's support needs?
- Can you tell me who do you involve?
- Can you tell me where does the support come from?

7) Focus group with GPs, District Nurses and Palliative Care Nurses

I am going to have a focus group session with GPs, District Nurses and Palliative Care Nurses.

- What aspects of care do you think might be valuable for me to discuss with them?

8) Is there anything else you would like to add?

The wrap-up

- Thank you for taking your time to attend this focus group session.
 - The information gathered today will help to generate questions for the patients, carers and healthcare professionals.
 - You would receive a summary of the discussion.
 - Before we end this session, I would like you to answer 2 questions on a piece of paper.
1. Can you write down one issue that stood out for you that is really important in the care of patients with MSCC?
 2. Can you write down one thing that stands out to you about the value of having a focus group?

Appendix 8: Interview schedule 1 – Patient

Introduction

- Patient consent
- Ensure patient is happy to go ahead with interview.
- Ensure patient is comfortable.
- Briefly go through information sheet.
- Go through consent form and ensure it is signed (emphasise confidentiality).
- This session will take no more than an hour.
- You are free to withdraw at any point.
- Recording interview – confidentiality will be maintained.
- Please feel free to express your opinion openly.

- Purpose this interview
 - ❖ In this interview, I am particularly interested to understand your views about your illness and some of the problems you may experience.
- Aim of this interview
 - ❖ I am interested in hearing your thoughts or opinions about your experience of your illness in your own words.

- Are there any questions or concerns before I start?

The interview questions

General questions

I would like start by asking:

1. Do you have any issues or opinions or thoughts about your experience of your illness?

2. Can you describe to me your experience of the symptoms?

Prompts:

Can you tell me how much you are able to do at the moment?

- Are there things that you find difficult to do as a result of your illness?
- What is your pain score in the last 24 hours?
- Were you given any information about positioning and mobility?
- Was there any help that you needed?
- Were you given any help that you needed?

3. Can you tell me any issues/concerns/worries that you had at that time?

Prompts:

- What were they?
- How did you deal with them?
- Were you offered any help in dealing with these issues?

4. Can you tell me what kind of support were you offered?

Prompts

- Did you receive adequate support at this time?
 - Was the support helpful/unhelpful?
 - What are the things that are important to you?
 - What sort of support would have helped you best during your first week?
- Were your family involved in this support needs?

Specific questions

5. Can you tell me your understanding of your diagnosis, treatment and advice given to you on your illness?

- What is your understanding of your diagnosis?
- What is your understanding of your prognosis?
 - Do you have enough information about your prognosis?
 - Can you tell me whether knowing the prognosis is important for you?
 - When do you think this should be discussed?

- Does your cord compression (paralysis) give you an idea about your prognosis?
 - What is your understanding of your treatment you have received?
 - What is going to happen to you next in relation to treatment?
 - Can you tell me how you feel about the amount of information you have been given?
 - Have you been given information on the risk of cord compression?
 - Can you tell me about your information expectations?
 - If you need information, what format do you think would be best for you?
- 6. Finally, I need to understand whether these questions actually relate to the issues that you think are important to you.**
- Am I asking the right questions?
 - Did these questions relate to your own experience?
 - Did these questions allow you to talk about what are really important to you?
- 7. Is there anything else you would like to add?**
- The wrap-up**
- Thank you for your time.
- Before I end this session, I would like you to answer 2 questions on a piece of paper.
1. Can you list the things that are really important to you with the most important first?
 2. Can you write down one thing that stands out to you about the value of having this interview?

Appendix 9: Interview schedule 2 – Patient

Introduction

- Patient consent
- Ensure patient is happy to go ahead with interview.
- Ensure patient is comfortable.
- Briefly go through information sheet.
- Go through consent form and ensure it is signed (emphasise confidentiality).
- Inform patient that participating in this interview will not affect their care or treatment.
- This session will take no more than an hour.
- You are free to withdraw at any point.
- Recording interview – confidentiality will be maintained.
- Please feel free to express your opinion openly.

- Purpose this interview
 - ❖ In this interview, I am particularly interested to check my understanding of your views about your illness and anything you want to add since our last interview.

- Are there any questions or concerns before I start?

The interview questions

General questions

I would like start by asking:

1. **Can you tell me whether there is anything additional you would like to tell me about your illness since we last met?**
2. **Can you tell me how you feel about things that are happening at the moment?**
3. **Can you tell me about any symptoms and how they affect you now?**

Prompts:

- Can you tell me how much you are able to do at the moment?
- Can you tell me how has the treatment helped with your symptoms?
- Are there things that you find difficult to do as a result of your illness?
- What are the activities that make you feel more/less comfortable?
- Are you experiencing any difficulties lying down, sitting or walking?
- If so what has been done to help you?
- Was there any help that you needed?

4. **Can you tell me what is most prominent (or focussed) in your mind at the moment?**

Prompts:

- What are they?
- How are you dealing with them?
- Were you offered any help/contact in dealing with these issues/concerns?
- In comparison with the time of your admission, can you tell me how you feel now?

5. **Can you tell me what kind of support were you offered?**

Prompts

- Did you receive adequate support at the moment?
 - Was the support helpful/unhelpful?
 - What are the things that are important to you now?
 - What sort of support would have helped you best at the moment?
- Were your family involved in this support needs?
- What do you think of the care you received when you were in the hospital?

6. **What do you know your illness?**

(If patient discuss diagnosis and prognosis)

- *What is your understanding of your diagnosis/prognosis now?*

- What is your understanding of your care and treatment you have received?
 - What is going to happen to you next in relation to your care and treatment?
- 7. Can you tell me how you feel about the amount of information you have been given on discharged?**
- Do you feel that you still have links with the hospital?
 - Were you given enough information for next appointment?
 - How do you feel about the information you have been given so far?
- 8. Finally, I need to understand whether these questions actually relate to the issues that you think are important to you.**
- Am I asking the right questions?
 - Did these questions relate to your own experience?
 - Did these questions allow you to talk about what are really important to you?
- 9. Is there anything else you would like to add?**

The wrap-up

- Thank you for your time.

Before I end this session, I would like you to answer 2 questions on a piece of paper.

1. Can you list the things that are really important to you with the most important first and the least important last?
2. Can you write down one thing that stands out to you about the value of having this 2nd interview?

Appendix 10: Interview schedule 1 – Carer

Introduction

- Carer consent
- Ensure carer is happy to go ahead with interview.
- Briefly go through information sheet.
- Go through consent form and ensure it is signed (emphasise confidentiality).
- Inform patient that participating in this interview will not affect their care or treatment.
- This session will take no more than an hour.
- You are free to withdraw at any point.
- Recording interview – confidentiality will be maintained.
- Please feel free to express your opinion openly.

- Purpose this interview
 - ❖ In this interview, I am particularly interested to understand your views on [patient's name] illness and some of the problems that you may experience in caring for [patient's name].
- Aim of this interview
 - ❖ I am interested in hearing your thoughts or opinions about your experience in caring for [patient's name] in your own words.

- Are there any questions or concerns before I start?

The interview questions

General questions

I would like start by asking:

3. **Can you tell me whether you have any issues or opinions or thoughts from your experience in caring for [patient's name] illness?**
4. **Can you describe to me how you feel about these changes in [patient] at the moment?**

Prompts

- Describe why you feel this way?
- Was there any help that you needed?
- Were you given any help that you needed?
- Can you give me your opinion of what sort of support would have helped you cope best?

5. **Can you tell me any issues/concerns/worries that you have at this time?**

Prompts:

- What are they?
- How are you dealing with them?
- Are there things that you find easier/difficult in supporting [patient]?
- What were the main issues you had to deal with?
- Were you offered any help in dealing with these issues?

6. **Can you tell me what kind of support you were offered?**

Prompts

- Did you receive adequate support at the moment?
- Was the support helpful/unhelpful?
- What are the things that are important to you?
- What sort of support would have helped you best at the moment?
- Were you involved in discussion of [patient] support needs?

7. **Can you tell me what you know about [patient] illness?**

Prompts:

(If carer discuss diagnosis and prognosis)

- a. *What is your understanding of [patient] diagnosis/prognosis?*
 - b. *When do you think this should be discussed?*
 - c. *What is your understanding of [patient] care and treatment?*
 - d. *Can you tell me what is going to happen to [patient] next in relation to care and treatment?*
- 8. Can you tell me how you feel about the amount of information you have been given?**
- a. Can you tell me about your information expectations?
 - b. If you need information, what format do you think would be best for you?
- 9. Finally, I need to understand whether these questions actually relate to the issues that you think are important to you.**
- a. Am I asking the right questions?
 - b. Did these questions relate to your own experience?
 - c. Did these questions allow you to talk about what are really important to you?
- 10. Is there anything else you would like to add?**

The wrap-up

- Thank you for your time.

Before I end this session, I would like you to answer 2 questions on a piece of paper.

1. Can you list the things that are really important to you in caring for [patient] with the most important first and the least important last?
2. Can you write down one thing that stands out to you about the value of having this one-to-one interview?

Appendix 11: Interview schedule 2 – Carer

Introduction

- Carer consent
- Ensure carer is happy to go ahead with interview.
- Briefly go through information sheet.
- Go through consent form and ensure it is signed (emphasise confidentiality).
- Inform patient that participating in this interview will not affect their care or treatment.
- This session will take no more than an hour.
- You are free to withdraw at any point.
- Recording interview – confidentiality will be maintained.
- Please feel free to express your opinion openly.

- Purpose this interview
 - ❖ In this interview, I am particularly interested to understand your views on [patient's name] illness and some of the problems that you may experience in caring for [patient's name].
- Aim of this interview
 - ❖ I am interested in hearing your thoughts or opinions about your experience in caring for [patient's name] in your own words.

- Are there any questions or concerns before I start?

The interview questions

General questions

I would like start by asking:

1. **Can you tell me whether you have any issues or opinions or thoughts from your experience in caring for [patient's name] illness since the last time I saw you?**
2. **Can you describe to me how you feel about these changes in [patient] since our last interview?**

Prompts

- Describe why you feel this way?
- Was there any help that you needed?
- Were you given any help that you needed?
- Can you give me your opinion of what sort of support would have helped you cope best?

3. **Can you tell me what is the most prominent (or focus) in your mind at the moment?**

Prompts:

- What are they?
- How are you dealing with them?
- Are there things that you find easier/difficult in supporting [patient]?
- What were the main issues you had to deal with?
- Were you offered any help in dealing with these issues?

4. **Can you tell me what kind of support you were offered since the last time I saw you?**

Prompts

- Did you receive adequate support at the moment?
- Was the support helpful/unhelpful?
- What are the things that are important to you?
- What sort of support would have helped you best at the moment?
- Were you involved in discussion of [patient] support needs?

5. **Can you tell me what you know about [patient] illness?**

Prompts:

(If carer discuss diagnosis and prognosis)

- *What is your understanding of [patient] diagnosis/prognosis?*
- *When do you think this should be discussed?*
- What is your understanding of [patient] care and treatment?
- Can you tell me what is going to happen to [patient] next in relation to care and treatment?

6. Can you tell me how you feel about the amount of information you have been given since [patient] discharge from hospital?

- Do you feel that you still have links with the hospital?
- Were you given enough information for [patient] next appointment?
- Can you tell me about your information expectations?
- If you need information, what format do you think would be best for you?

7. Finally, I need to understand whether these questions actually relate to the issues that you think are important to you.

- Am I asking the right questions?
- Did these questions relate to your own experience?
- Did these questions allow you to talk about what are really important to you?

8. Is there anything else you would like to add?

The wrap-up

- Thank you for your time.

Before I end this session, I would like you to answer 2 questions on a piece of paper.

1. Can you list the things that are really important to you in caring for [patient] with the most important first and the least important last?
2. Can you write down one thing that stands out to you about the value of having this one-to-one interview?

Appendix 12: Interview schedule – Healthcare professionals

The opening

- Introduction
- This session will take no more 30 minutes.
- You are free to withdraw at any point.
- Ensure you have signed the consent form.
- Recording discussion – confidentiality will be maintained.
- Let's begin by briefly introducing yourself:
- Name (for the purpose of transcribing)
- Professional post

Purpose of this interview

Research title: A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

The management of MSCC is an area we know little about.

The purpose of interview is:

- To gather information about your perspective in delivering care to patients with metastatic spinal cord compression.
- To determine any particular issues that you would like me to explore further with patients and carers.
- There are no right or wrong answers; even negative comments are useful in gaining insight about the topic in discussion
- Please feel free to express your opinion openly
- Are there any questions before I start?

The interview questions

I would like start by asking:

1. Can you tell me about [patient's name] illness?
2. Can you outline what you feel is the most effective overall management plan this patient can be offered?
3. Regarding mobilisation, what instruction or advice have you been able to give the nursing staff?
 - Is this your usual advice?
 - And what advice can you give the patient and their family regarding mobilisation?
 - How do you think mobilisation will affect patient's situation?
4. Moving on to other aspects of the patient's management, has any prophylaxis to prevent possible DVT been used?
5. What role do you feel surgery might have?
6. What do you feel about the patient having an orthosis or brace?
7. What do you regard as the more challenging areas in making decisions with this patient on both their care and their treatment?
 - Are these the kind of challenges that occur most often with your MSCC patient?

Literature suggests that the patient's and carer's perspectives of care in MSCC are not well represented. What do you think are the important aspects of care for the patients and carers?

8. Physical care and psychological needs
 - Can you tell me how the likely physical symptoms that a patient may face in the future should be discussed?
 - Can you tell me how you would address patient's psychological needs/end of life issues?

9. Information and supportive needs of patients or those close to them

Discussing the future where no cure is possible can often be difficult.

- Can you tell me how you tend to approach questions about the future?
- Can you tell me how you tend to address patient's support needs?
- Can you tell me who do you involve?
 - ❖ Radiological predictors

10. Interviews with GPs, District Nurses and Palliative Care Nurses

11. Is there anything else you would like to add?

The wrap-up

- Thank you for your time.

Before we end this session, I would like you to answer 3 questions.

1. Can you write down one issue that stood out for you that is really important in the care of patients with MSCC?
2. Can you write down one issue that stood out for you that is really important in the care of [patient's name]?
3. Can you write down one thing that stands out to you about the value of having this one-to-one interview?

Appendix 13: Lothian Research Ethics Committees Approval

Lothian NHS Board

Lothian Research Ethics Committees
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9346
www.nhslothian.scot.nhs.uk



Miss Siew Hwa Lee
PhD Research Student
Napier University
SNMSC, Napier University
Canaan Lane Campus
Edinburgh
EH9 2TB

Date 21 May 2009
Our Ref. 09/S1101/13
Enquiries Chris Graham
Extension 89027
Direct Line 0131 536 9027
chris.graham@nhslothian.scot.nhs.uk

21 May 2009

Dear Miss Lee

Full title of study: A case study to explore the management of patients with metastatic spinal cord compression (MSCC)
REC reference number: 09/S1101/13

Thank you for your letter of 29 April 2009, responding to the Committee's request for further information on the above research.

The further information was considered at the meeting of the Sub-Committee of the REC held on 19 May 2009. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised subject to the conditions specified below.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.



Headquarters
Deaconess House 148 Pleasance Edinburgh EH8 9RS

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Consent Form - Healthcare Professional	1	04 February 2009
Information Sheet - Healthcare Professional	1	04 February 2009
Participant Consent Form	1	04 February 2009
GP/Consultant Information Sheets	1	04 February 2009
Letter of invitation to participant	1	04 February 2009
Interview Schedules/Topic Guides	Patient 1st interview, 1	04 February 2009
Covering Letter		04 February 2009
Application	1	04 February 2009
Topic Guide - 1st Focus Group (HCP)	1	04 February 2009
Topic Guide - 2nd Interview (Carer)	1	04 February 2009
Topic Guide - 2nd Interview (Patient)	1	04 February 2009
Topic Guide - 1st Interview (Healthcare Professional)	1	04 February 2009
Topic Guide - 1st Interview (Carer)	1	04 February 2009
Investigator CV	Robert Grant	
Supervisor's CV - Dr L Kilbride		04 February 2009
Investigator CV	Siew Hwa Lee	04 February 2009
Topic Guide - 2nd Focus Group Session (HCP)	1	04 February 2009
Response to Request for Further Information		29 April 2009
Participant Information Sheet	v.2	29 April 2009
Covering Letter		29 April 2009
Protocol	v.2	29 April 2009
Correspondence		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website >
After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S1101/13 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



Mr Nicholas Grier
Chair

Email: emily.pendleton@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mrs Colette Pemberton

Appendix 14: Lothian Research and Development approval

University Hospitals Division
Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

DEN/JB/approval/2e,8

14 May 2009

Miss Siew Hwa Lee
SNMSC, Napier University
Canaan Lane Campus
Edinburgh
EH9 2TB



Lothian

RESEARCH &
DEVELOPMENT
Room E1.12

Tel: 0131 242 3330

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Email:

R&DOffice@luht.scot.nhs.uk

Director:

Professor David E Newby

Dear Miss Hwa Lee

MREC No: N/A
CRF No: N/A
LREC No: 09/S1101/13
R&D ID No: 2009/W/NEU/03
Title of Research: *A case study to explore the management of patients with metastatic spinal cord compression (MSCC)*
Protocol No/Acronym: Version 1 dated 04 February 2009

The above project has undergone an assessment of risk to NHS Lothian and review of resource and financial implications. I am satisfied that all the necessary arrangements have been set in place and that all Departments contributing to the project have been informed.

I note that this is a single centre study sponsored by **Napier University**.

Following a REC final favourable approval, copies of all final study documentation (with revised version numbers) should be sent, with the REC letter of favourable opinion, to the R&D office.

On behalf of the Chief Executive and Medical Director, I am happy to grant management approval from NHS Lothian to allow the project to commence, subject to the approval of the appropriate Research Ethics Committee(s) having also been obtained. You should note that any substantial amendments must be notified to the relevant Research Ethics Committee and to R&D Management with approval being granted from both before the amendments are made.

This letter of approval is your assurance that NHS Lothian is satisfied with this project. For approved research, NHS Lothian will provide cover for negligence for NHS and Honorary clinical staff for research associated with their clinical duties. It is not empowered to provide non-negligent indemnity cover for patients.

As Chief Investigator or local Principal Investigator, you should be fully committed to your responsibilities within the Research Governance Framework for Health and Community Care, an extract of which is attached to this letter.

Yours sincerely

Professor David E Newby
R&D Director

enc Research Governance Certificate (to be signed and returned)
 Tissue Policy (if applicable)
 MTA (if applicable) (to be signed and returned)

cc Administrators, Research Ethics Committee

"Improving health through excellence and innovation in clinical research"

Appendix 15: Information sheet – Healthcare professional



Information Sheet - Healthcare Professional

A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

You are invited to participate in this research study on metastatic spinal cord compression. Before you decide, it is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study if you wish.

What is the purpose of this study?

The purpose of this study is to explore the patient and carer experience in metastatic spinal cord compression and how we can all work together to improve care.

Why have I been chosen?

Healthcare professionals who are responsible for the care and management of patients with metastatic spinal cord compression are being asked if they would like to participate.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Please take time to think about whether or not you want to. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are free to withdraw from the study at any time without giving a reason. Your decision will not affect your future work.

What will happen to me if I take part?

Taking part in this study involves talking to a researcher to share your experiences and the decisions that you make in the care and management of patients with metastatic spinal cord compression. The interview will take no longer than 1 hour at your

convenience. You are also invited to participate in focus group sessions to explore and understand the factors that influence the decisions you make that impact on care given to patients.

Confirmation that your line manager has given you permission to take part in this study will be needed.

What are the possible risks of taking part?

The interview will involve sharing your thoughts and feelings about your experience in the management of patients with metastatic spinal cord compression. It aims to be a useful experience for you and an opportunity to participate in positive changes in the oncology service. However, if difficult or uncomfortable issues arise, I will make every effort to ensure that you have the support and time to discuss these if you wish to.

Will my taking part in the study be kept confidential?

The interview will be confidential and all the information collected at the interview will be anonymous. Your line manager will not be informed of what we discussed. Any information obtained will be kept in a safe place to which only I have access.

What will happen to the results of the study?

With your permission the findings will be shared with my supervisory team. These may be submitted to Journals for publication and presented at Conferences.

Version 1. 4th Feb 2009

Faculty of Health, Life and Social Sciences, School of Nursing, Midwifery & Social Care
Edinburgh Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

Where can I ask for information about this study?

If you would like to contact an independent person who knows about this study but is not involved in it, you are welcomed to contact:

Head of School: Dr Jayne Donaldson
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh
EH9 2TB
0131 455 5697

If you have read this information sheet and would like to take part in the study please sign the enclosed consent form, return it to

me and I will be in touch with you again shortly.

Thank you very much. I look forward to hearing from you.

Siew Hwa Lee (Research Student)
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
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EH9 2TB
Tel: 0131 455 5700
Email: S.HwaLee@napier.ac.uk

Appendix 16: Consent form – Healthcare professional



Consent Form (Healthcare Professional)

Informed Consent Form (Health care Professional)

A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

I have read and understood the information sheet and this consent form.

I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to take part in this study.

Name of participant: _____

Contact details of participant: Tel: _____

Mobile: _____

Email: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Please return this form to me:
Siew Hwa Lee (Research Student)
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh EH9 2TB
Email: S.HwaLee@napier.ac.uk
Tel: 0131 455 5700

2 copies: 1 to be returned by researcher to the participant

Version 1. 4th Feb 2009
Faculty of Health, Life and Social Sciences, School of Nursing, Midwifery & Social Care
Edinburgh Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

Appendix 17: Invitation letter – Patient/Carer



Invitation Letter (Patient/Carer)

A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

Invitation Letter (Patient /Carer)

Dear ()

My name is Siew Hwa Lee and I am a PhD student based in the School of Nursing, Midwifery and Social Care at Edinburgh Napier University..

My study is about understanding the patient's and carer's views about spinal cord compression. I would like to hear your views with regard to the problems the condition can cause. To date, little research has been done in this disease. The outcome and analysis from this study would teach us how best to meet your needs.

The first meeting will be done during your stay in the hospital and the second will be conducted later once you are discharged. I will arrange this to be at a time convenient to you. Both interviews will take less than 1 hour.

If you want to take part in this study, please read the information sheet which will tell you more about this study. Once you have read the information sheet, please inform the nurse who is looking after you know and the nurse will inform me (Lee) and I will then come and explain the study further.

Please find enclosed the information sheet, to explain further about the study.

Thank you.

Siew Hwa Lee (Research Student)
School of Nursing, Midwifery & Social Care
Edinburgh Napier University
Canaan Lane Campus
Email: S.HwaLee@napier.ac.uk
Telephone: 0131 455 5700

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Faculty of Health, Life and Social Sciences, School of Nursing, Midwifery & Social Care
Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

Appendix 18: Information sheet – Patient/Carer



Information Sheet - Patient/Carer

A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

You are invited to participate in this research study on spinal cord compression. Before you decide to take part, it is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk to your family, friends and carer about the study if you wish.

What is the purpose of this study?

The purpose of this study is to understand your and your family member/carer views about spinal cord compression and some of the problems you may experience. This will help to improve care in the future.

Why have I been invited?

Sharing your experience about your care in the hospital can help us work together to improve care. Although participating in this study may not directly benefit you, your contribution will help benefit others in the future.

Do I have to take part?

It is up to you to decide whether or not to take part. Please take time to think about whether or not you want to. If you do, you will be asked to sign a consent form. You are free to withdraw from the study at any time without giving a reason.

What will happen to me if I take part?

Taking part in this study will involve talking to me (Lee) about your experiences of spinal cord compression. The first interview will be held during your stay in the hospital and the second will take place later at a time and place convenient to yourself. Both interviews will take no longer than 1 hour and will be tape recorded to enable the researcher to listen to what you are saying. The tape recordings will be transcribed. The interview will be confidential and all the information collected at the interview will be anonymous. Any information obtained will be kept in a safe place to which only I have access. This data will be stored for five years after which it will be destroyed. You are very welcome to have someone with you during the interview.

What are the possible risks of taking part?

The interview will involve sharing your thoughts about your care. It aims to be a useful experience for you and an opportunity to participate in order to improve care. It is possible that you may feel upset or sad recalling your experiences. I will ensure that you have support and time to discuss these feelings if you wish to.

What will happen to the results of the study?

With your permission the findings will be shared with my supervisory team. These may be submitted to Journals for publication and presented at Conferences.

Version 2. 29th April 2009

Faculty of Health, Life and Social Sciences, School of Nursing, Midwifery & Social Care
Edinburgh Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

Information Sheet - Patient/Carer

Where can I ask for information about this study?

If you would like to contact an independent person, who knows about this study but is not involved in it, you are welcomed to contact:

Head of School: Dr. Jayne Donaldson.
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh, EH9 2TB
Tel: 0131 455 5697

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (Lee, Tel: 0131 455 5700). If you remain unhappy and wish to complain formally, you can do this through the Edinburgh Napier Complaints Procedure (Professor Alison McCleery, Tel: 0131 455 5004).

If you have read this information sheet and you would like to take part in the study, please inform the nurse looking after you and I will be in touch with you shortly.

Thank you very much for taking the time to read this information sheet I look forward to hearing from you if you wish to take part.

SiewHwaLee
Research Student
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh EH9 2TB
Tel: 0131 455 5700
Email: s.hwalee@napier.ac.uk

This information sheet has been written in accordance with the NRES Patient Information Guidelines
<http://www.nres.npsa.nhs.uk/rec-community/guidance/#PIS>

Appendix 19: Consent form – Patient/Carer

Consent Form (Patient/Carer)



Informed Consent Form (patient/Carer)

A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

I have read and understood the information sheet and this consent form.
I have had an opportunity to ask questions about my participation.
I understand that I am under no obligation to take part in this study.
I understand that I have the right to withdraw from this study at any stage without giving any reason and without any detriment to the care I receive.
I agree to take part in this study.

Name of participant: _____

Contact details of participant: Tel: _____

Mobile: _____

Email: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

I agree to you informing my GP that I am participating in this study YES/NO

GP Name: _____

Address: _____

Post Code: _____

Please return this form to me:
Siew Hwa Lee (Research Student)
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh EH9 2TB
Email: S.HwaLee@napier.ac.uk
Tel: 0131 455 5700

2 copies: 1 to be returned by researcher to the participant

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Care
Edinburgh Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

Appendix 20: Information letter – General Practitioner



A case study to explore the management of patients with metastatic spinal cord compression (MSCC)

Information Letter (GP)

Dear ()

My name is Siew Hwa Lee, I am a **PhD student** based in the School of Nursing, Midwifery and Social Care at Edinburgh Napier University.

My study is about exploring the patient and carer experience with metastatic spinal cord compression in order to improve practice.

I am writing to inform you that has agreed to participate in this study to share his/her experience in the management of metastatic spinal cord compression.

If you would like any further information about this study please do not hesitate to contact me.

Thank you.

Siew Hwa Lee (Research Student)
School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Canaan Lane Campus
Edinburgh
EH92TB

Email: S.HwaLee@napier.ac.uk

Tel: 0131 455 5700

Version 1. 4th Feb 2009

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Edinburgh Napier University, Canaan Lane Campus, Edinburgh EH9 2TB

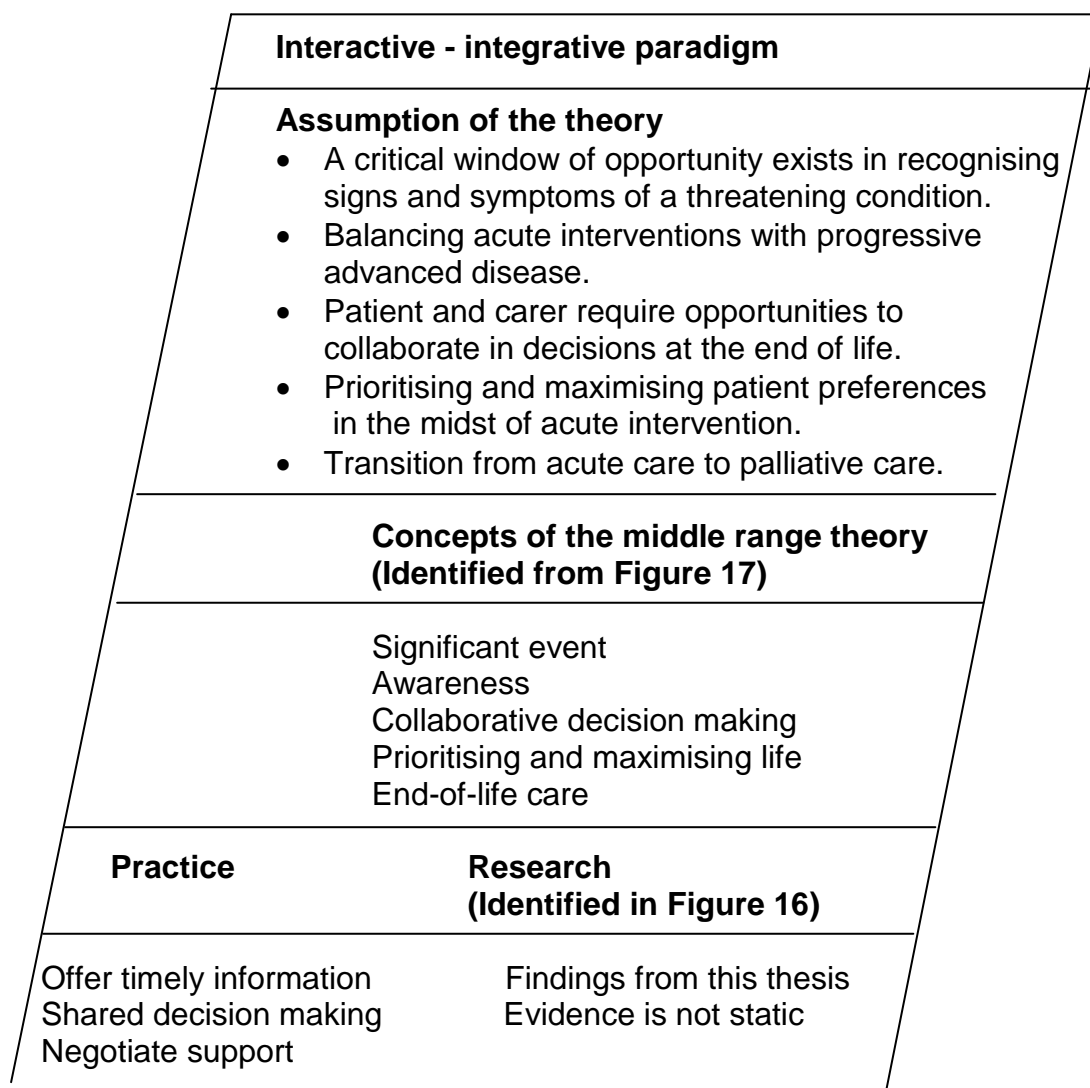
Appendix 21: Ladder of abstraction in theory development

The ladder of abstraction in middle range theory was used to illuminate the theoretical constructs which have emerged from this study. The ladder of abstraction is a structure that maps the levels of discourse or different ways of describing ideas as seen below (Figure 18).

The lowest rung of the ladder represents the discourse at the practice level (empirical level) through the senses of perceptions gathered through narratives, field notes, observations and documentations which bring about a theory to explain a phenomenon (Smith and Liehr 2008). For example, in this study, the perceptions of patients, carers and healthcare professionals were gathered through interviews, focus groups, documentation, field notes, policies, and guidelines to explain about MSCC.

The next level up the ladder is the theoretical level which is represented by concepts that characterise, define, provide clarity and facilitate the understanding of the phenomena of MSCC. This move from empirical level to theoretical level in understanding the phenomena involved inductive reasoning. In the current study, the concepts emerge from both phases of the study, literature review, scoping exercise, policies, guidelines and the wider literature. Finally, the philosophical level represents the highest level of assumption, beliefs, perspectives and points of view. The interactive – integrative paradigm describes persons as shared interacting entities, changes as probabilistic and related to multiple factors grounded in the perspective of social sciences (Smith and Liehr 2008).

Figure 18: Ladder of abstraction (adapted from Smith and Liehr 2008)



Starting at the bottom of the ladder there are four key activities evident at the initial stages of MSCC. Recognising the onset by patients, carers and healthcare professionals is linked to identifying the symptoms. Decision making at the initial stages is often rapid and complex and opportunities to involve the views of all stakeholders difficult. Analysis of data in this study supports five key concepts (Figure 17) which are central to managing MSCC and the uncertainty which permeates this condition. The onset of MSCC is a significant event which involves individualised management and decision making. Decision making should be linked to the priority outcomes for patients. The underpinning assumptions of this theory illuminate the complexity of managing MSCC.

There is potential for this theory to be refined and tested in a range of long term conditions which have acute manifestation such as acute cardiac condition, bleeding in patients with advanced cancer, pancreatic cancer and cystic fibrosis. For example, haemorrhaging may occur as a significant event in up to 10% of patients with advanced cancer (Pereira and Phan 2004). It needs tested further and refined in MSCC.

REVIEW

Metastatic spinal cord compression: a review of practice and care

Lynn Kilbride, Marie Cox, Catriona M Kennedy, Siew Hwa Lee and Robin Grant

Aim and objectives. The aim of this review was to address: (1) How is spinal stability assessed? (2) What is the role of bracing/should braces be used? (3) When is it safe to mobilise the patient? (4) What position should the patient be nursed in?

Background. Controversy surrounds the care for patients with metastatic spinal cord compression (MSCC). There is some evidence to indicate that care for patients with MSCC is based on individual clinician preference rather than evidence-based guidelines which has been shown to cause delays and discrepancies in patient treatment.

Design. A structured literature review to synthesise the available evidence about the management of MSCC.

Methods. The following databases were searched: Medline, EMBASE, Cochrane Systematic Reviews Database, SIGN (Scottish Intercollegiate Guidelines Network), NICE (National Institute for Clinical Excellence), AMED (Allied and Complementary Medicine), CINAHL (Cumulative Index to Nursing and Allied Health Literature) and BNI (British Nursing Index). Publications were selected from the past 10 years. The search yielded a total of 1057 hits, 755 abstracts were screened, and 73 articles were retrieved and examined. Thirty-five articles were included.

Results. The findings identified a gap and evidence relating to spinal stability, bracing, patient mobilisation, and positioning is limited and may be inconclusive. It is important for patients with a poor prognosis that their preferences and quality of life are considered.

Conclusion. Currently, the evidence base to underpin care is limited, and further research in this area is necessary for patients and healthcare professionals alike.

Relevance to clinical practice. Patients who suffer from MSCC suffer numerous physical, psychological and social issues. Because of lack of consensus, the current guidelines to inform clinical decision-making of professional staff are of limited benefit.

Key words: cancer, clinical guidelines, evidence-based practice, nurses, nursing, systematic review

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Introduction

Controversy surrounds the care for patients with metastatic spinal cord compression (MSCC). Approximately 10 people per 100,000 a year suffer from this condition, and their outcome is known to be very poor (Posner 1995, Levack

et al. 2002). MSCC is a serious complication of cancer disease. The symptoms of MSCC range from minor sensory disturbance and autonomic changes to severe pain and irreversible paralysis. MSCC is defined as 'compression of the dural sac and its contents (spinal cord and/or cauda equine) by an extradural tumour mass. Clinical features

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School of Nursing, Midwifery and Social Care, Edinburgh Napier University, Edinburgh; *Robin Grant*, MBChB, MD, FRCP (Glasgow), FRCP (Edinburgh), Consultant Neurologist, Edinburgh Centre for Neuro-Oncology, Western General Hospital

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include any or all of the following: pain (local or radicular), weakness, sensory disturbance, evidence of sphincter dysfunction' (Loblaw & Laperriere 1998, p. 1613).

The onset of metastatic spinal cord compression is a medical emergency and warrants immediate intervention to minimise damage to the spinal cord and preserve neurological function. Prognosis and quality of life are related to the patient's pretreatment ambulatory status and rapid diagnosis, and treatment required (Levack *et al.* 2002). There is some evidence to indicate that the care for patients with MSCC is based on individual clinician preference rather than evidence-based guidelines (McClinton & Hutchison 2006). The lack of such guidelines has been shown to cause delays and discrepancies in patient treatment (Levack *et al.* 2002, (McClinton & Hutchison 2006). The National Institute for Health and Clinical Excellence (NICE) recently developed recommendations for the diagnosis and management of adults with malignant spinal cord compression (NICE 2008) in response to a recommendation from the Department of Health. Using stakeholders (healthcare professionals, patients and carers) NICE produced a draft guideline that after a consultation period was adapted and published for guidance to the NHS in England. The NICE (2008) recommendations identify assessment of spinal stability as the main factor in decision-making relating to bracing, mobilisation and positioning of patients.

This current literature review synthesises the available evidence about the management of MSCC to inform clinical decision-making and indicates areas for future research. Based on previous audits and conferring with a range of healthcare professionals, questions were formed surrounding assessing spinal stability, the role of bracing in MSCC, patient mobilisation and patient positioning.

Assessing spinal stability

Criteria for assessing spinal stability are essential for appropriate treatment of MSCC patients. Spinal instability can potentially affect treatment, mobilisation, bracing, physiotherapy recommendations and quality of life issues for MSCC patients. From both nursing and physiotherapy perspectives, there are concerns about mobilising the patient when it is unknown whether the spine is stable. Diagnosis of spinal stability is important both before and after treatment, as some forms of treatment such as radiotherapy or laminectomy have the potential to destabilise the spine (Galasko *et al.* 2000, Klimo *et al.* 2004, Villavicencio *et al.* 2005). Instability is often cited as a criteria for surgical intervention (Siegal & Siegal 1989, Byrne 1992, Loblaw & Laperriere 1998, Abraham 2004, Bilsky & Smith 2006, NICE 2008), which, in

selected situations, has become a preferred initial treatment for MSCC (Patchell *et al.* 2005). Therefore, criteria to assess spinal stability are essential to inform care for patients.

Guidelines that are widely referenced are detailed in White and Panjabi's (1978, 1990) *Clinical Biomechanics of the Spine*. These authors devote a chapter to the assessment of spinal stability. White and Panjabi (1978) consider the following points essential when assessing stability: biomechanics, flexibility and anatomy; and emphasise that the cervical, thoracic, lumbar spine and cauda equina must be assessed separately to provide a more accurate picture of spinal injury and instability.

Another set of spinal stability guidelines were formulated by Kostuik and Weinstein (1991). This set of guidelines is based on the column structure of the spine. The vertebral column is divided into six columns, and the spine is regarded as stable if fewer than three columns are disrupted by the metastasis (Kostuik & Weinstein 1991). The spine is regarded as unstable if three or more columns are disrupted and 'markedly unstable' if four or more columns are involved. Additionally, an angular deformity of the columns of 20 degrees or more also indicates that the spine may be unstable.

Despite the existence of guidelines to inform professional decision-making surrounding the management of spinal instability, there remain inconsistencies in the day-to-day management of patients with MSCC. The recently published NICE (2008) guidelines indicate the importance of establishing level of instability, but there remains ambiguity given that many patients with MSCC have advanced cancer and may require palliative care rather than clinical interventions.

Bracing

Several nursing and patient care guidelines continue to recommend bracing in patients with MSCC (Poste & Fidler 1980, Sundaresan *et al.* 1981, Held & Peahota 1993, NICE 2008). For example, two guidelines recommend using bracing as a conservative treatment for upper cervical spinal lesions (Poste & Fidler 1980, Sundaresan *et al.* 1981). Additionally, Held and Peahota (1993) suggest that MSCC patients use a brace post-treatment to stabilise the spine when out of bed. More recently, NICE (2008) have suggested external spinal support for patients who have mechanical and/or imaging evidence of spinal stability who are not suitable for surgery.

With regard to bracing patients, a scoping exercise of clinicians in the central belt of Scotland undertaken by the authors revealed that the use of bracing is rare and ad hoc in patients with MSCC. Accordingly, we identified a need to

undertake this literature review to help inform clinical practice and decision-making.

Patient mobilisation

There are similar inconsistencies in the guidance surrounding mobilisation. An important factor in an MSCC patient's quality of life is the ability to remain mobile to care for themselves (Barton *et al.* 2001, Abrahm *et al.* 2008). Recent evidence emphasises that MSCC patients are diagnosed late in the progress of the disease, and may have lost the ability to walk (McClinton & Hutchison 2006). Those patients unable to walk have a poorer prognosis, and some have reported in a recent study that they feel overwhelmed dealing with both cancer and the disability of sitting in a wheelchair (Eva & Lord 2003). However, as treatment (both surgery and radiotherapy) can improve ambulation outcomes (it has been reported that 68–75% of non-ambulatory patients regain ambulation status after treatment) (Sundaresan *et al.* 1995, Aass & Fossa 2005, Patchell *et al.* 2005), an important question facing physiotherapists and nurses is 'when after treatment is it safe to mobilise patients?' Additionally, as more practitioners recommend rehabilitation programmes for MSCC patients, guidelines evaluating a patient's readiness to mobilise are essential (McKinley *et al.* 2000, Eriks *et al.* 2004).

Patient positioning

Little has been written about how to position MSCC patients. McClinton and Hutchison (2006) identified positioning as a topic requiring further investigation in their audit. In general, it is known that the supine position causes pain in MSCC patients (Gilbert *et al.* 1978, Obbens & Posner 1987, Bilsky *et al.* 1999) However, some guidelines do recommend this position in early stages (NICE 2008). How a patient is positioned contributes to quality of life, especially in those patients with a poor prognosis. Therefore, an exploration of the evidence to inform decision-making around positioning is important.

Aims and objectives

The overall aim of this literature review was to explore the main issues that surround the management of patients with MSCC. From the initial literature review and a scoping of practice, the following questions were identified:

- How is spinal stability assessed?
- What is the role of bracing/should braces be used?
- When is it safe to mobilise the patient?
- What position should the patient be nursed in?

Methods

Search strategy

The Medline search strategy that was applied to the databases is detailed in Table 1. The following databases were consulted for the search: Medline (1997–2007), EMBASE (1997–2007), Cochrane Systematic Reviews Database, SIGN (Scottish Intercollegiate Guidelines Network), NICE (National Institute for Clinical Excellence), AMED (Allied and Complementary Medicine) (1997–2007), CINAHL (Cumulative Index to Nursing and Allied Health Literature) (1997–2007) and BNI (British Nursing Index) (1997–2007). Publications were selected from the past 10 years (1997 onwards). A few articles in foreign languages seemed to be relevant from the abstracts (translated into English); however, these articles were not translated and included because of limited resources.

Table 1 Search strategy: Medline

No	Search terms/key words	Number of hits
1	(MM 'Spinal Cord Compression')	4846
2	(MM 'Spinal Cord Neoplasms+')	6279
3	(MM 'Neoplasm Metastasis+')	25 642
4	1 or 2 or 3	36 228
5	1 or 2 or 3 (limit: human, adult)	15 819
6	1 or 2 or 3 (limit: human, adult, Publication 1998– 2008)	6586
7	Spin* n5 stable	654
8	Spin* n5 instabil*	1440
9	Spin* n5 stabil*	3185
10	Spin* n5 untabil*	2
11	7 or 8 or 9 or 10	4933
12	11 and 5	152
13	11 and 6	71
14	(MM 'Braces') or (brace* or orthos?s)	8338
15	14 and 5	24
16	14 and 6	17
17	(MM 'Supine Position')	554
18	Position* or (patient position*)	299 850
19	(MM 'Bed Rest')	1215
20	17 or 18 or 19	300 932
21	20 and 5	160
22	20 and 6	97
23	(MM 'Rehabilitation+') or rehab*	221 071
24	(MM 'Mobility Limitation') or (mobilisation or mobility or mobilise)	83 750
25	Ambulant or ambulatory or ambulation	99 880
26	23 or 24 or 25	392 620
27	26 and 5	343
28	26 and 6	173

Search category	Number of hits	Screened and quality assessed (abstracts reviewed)	Full article retrieved and reviewed	Included	Excluded
'Spinal cord compression' or 'neoplasm' or 'neoplasm metastasis' AND					
Spinal stability/instability	107	81	37	20	17
Braces and Orthoses	54	36	7	3	4
Supine position or patient positioning or bed rest	402	296	18	8	10
Ambulation or mobilisation or rehabilitation	494	342	11	4	7

Table 2 Search results

Initial inclusion criteria comprised randomised controlled trials directly addressing spinal stability, bracing, mobilisation and/or positioning of patients diagnosed with metastatic spinal cord compression. It was known from a scope of the literature that few articles fulfilling these criteria were identifiable. As a result of the overall lack of research in these areas, it was decided that any published research addressing spinal stability, bracing, mobilisation and/or patient positioning in metastatic spinal cord compression would be appraised and included in this review to assure that the evidence-based literature was fully explored. In addition to these identified criteria, the review team met to discuss and agree those studies suitable for inclusion in this review.

Results

The search yielded 1057 hits. Of these 1057 articles, the 755 hits that included abstracts (the remainder only yielded titles or were part of correspondence) were screened by two researchers, and 73 articles were retrieved and examined (Table 2). The inclusion criteria that were applied to the selection of abstracts and articles are detailed in Table 3. Thirty-five articles were deemed relevant for inclusion. Initial inclusion criteria comprised randomised controlled trials directly addressing spinal stability, bracing, mobilisation and/or patient positioning in patients diagnosed with metastatic spinal cord compression; however, as no randomised controlled trials were identified in the search, this criteria had to be relaxed to identify and amass relevant information.

SIGN provide review guidelines for a range of research methods. In this review, the purpose was not to exclude studies on the basis of quality but rather to inform the conclusions and recommendations. The SIGN guidelines informed the development of a standard format for summarising the methodological information and outcomes of individual studies and used as the format for the presentation of included and

Table 3 Criteria for inclusion in this review

Types of studies
Meta-analyses and systematic reviews
Randomised controlled trials
Primary quantitative studies
Primary qualitative studies
Descriptive studies
Systematic reviews
Non-systematic reviews
Types of interventions
All interventions carried out by health care professionals aimed to support adults with malignant spinal cord compression in relation to
Spinal stability
Bracing
Mobilisation
Patient positioning
Types of outcome measures
Impact of interventions on patient outcomes
Effectiveness of nursing interventions

excluded studies (Tables 3 and 4) <http://www.sign.ac.uk/methodology/checklists.html> (retrieved 24th March 2009).

Discussion

Stability

Definitions of spinal instability in MSCC vary; all definitions found for spinal instability are included in Table 5.

There is a lack of consensus and a lack of evidence on which guidelines are the most effective in assessing spinal instability. Loblaw *et al.* (2005) found no articles focussing expressly on MSCC and assessing spinal stability in their systematic review. The current reviewers located few studies where the primary focus was stability assessment and MSCC. However, a few key articles addressed some useful guidelines for stability assessment.

Table 4 Summaries of included articles

Reference	Summary
1 Aebi (2003)	<p>Type of study: Literature review</p> <p>Aim: To review MSCC natural history, symptoms, diagnosis and treatment specifically in the context of elderly patients</p> <p>Method: A review citing 58 references; however, no mention was made about whether the review was systematic and how articles were sorted through.</p> <p>Key messages: In some cases, CT as an imaging technique may be more useful than MRI. Confirms that there is a debate over the definition of an unstable spine, Denis' classification for traumatic spinal fractures may not be appropriate to assess stability for surgical procedures. Treatment decisions should be made on a case by case basis involving both practitioner and patient.</p>
2 Bilsky and Smith (2006)	<p>Type of study: Treatment guidelines</p> <p>Aim: To establish a framework (NOMS) to aid physicians in choosing treatment for epidural spinal cord compression</p> <p>Method: The authors use personal clinical knowledge as well as referenced studies. Authors do not state how they performed literature search.</p> <p>Key messages: If patients have 'high-grade SCC' and spine is unstable or tumour is radio resistant, patients should receive surgery (if patients are systemically able to withstand surgery). If tumour is radiosensitive patients should receive radiotherapy.</p>
3 Bilsky and Azeem (2007)	<p>Type of study: Treatment guidelines</p> <p>Aim: To establish a framework (NOMS) to aid physicians in choosing treatment for epidural spinal cord compression</p> <p>Method: The authors use personal clinical knowledge as well as 10 referenced studies. Authors do not state how they performed literature search.</p> <p>Key messages: Authors discuss a system of criteria (NOMS) that can be used to assign treatment to patients with MSCC. Assessing mechanical instability is an important aspect of this system of criteria and authors discuss problems and possible solutions when assessing spinal instability.</p>
4 Bilsky <i>et al.</i> (1999)	<p>Type of study: Literature review</p> <p>Aim: To review treatment options (mostly focusing on radiotherapy vs. surgery) for patients with MSCC</p> <p>Method: 90 references, author states that most studies were retrospective, no information about how author searched for studies and/or criteria for inclusion in the review</p> <p>Key messages: Role of different treatment methods is still developing. Physician awareness (e.g. early diagnosis, updated knowledge of different treatments) helps improve QOL for MSCC patients.</p>
5 Borm <i>et al.</i> (2004)	<p>Type of study: Retrospective study</p> <p>Aim: To determine in a sub-group of patient with degenerative spine disease and coexistent spine tumours, that should raise the suspicion of a spinal tumour.</p> <p>Method: Review charts, imaging studies in relation to symptoms, intensity of image-based diagnostics and outcome after treatment for degenerative spine disease and spinal tumour. A comparison was made between the clinical findings of the patients with combined pathology and those with only spine tumours.</p> <p>Key message: In spinal tumours back pain was exacerbated by the recumbent position, discogenic or radicular pain is exacerbated by the standing position or walking and is severe in a resting position. Because it was a retrospective study, the authors were not able to demonstrate a statistically significant difference in back pain in the matched-pair analysis. There is a tendency for back pain under loading with degenerative spine disease. Because there is back pain under loading in combine pathology, spinal tumours may be misdiagnosed. The authors found that 0.5% of patients with symptoms and radiological evidence of degenerative spine disease turned out to have spinal tumours.</p>
6 Coleman (2006)	<p>Type of study: Descriptive study</p> <p>Aim: To describe the clinical features of and morbidity associated with skeletal metastases</p> <p>Method: The author uses personal clinical knowledge as well as 38 referenced studies. Author does not state how he performed his literature search.</p> <p>Key messages: The skeleton is often affected in metastatic disease and morbidity depends on the location of the metastases as well as the nature of the primary cancer. Treatment for patients should be individualised.</p>

Table 4 (Continued)

Reference	Summary
7 Dirksmeier and Kang (2001)	<p>Type of study: Literature review</p> <p>Aim: To describe patient evaluation which can be complicated due instability of the spine as a result of metastatic disease</p> <p>Method: No details on method</p> <p>Key message: Described how the structure and stability of the spine can be altered and its importance when considering treatment options. According to the authors, the definition of clinical instability by White and Panjabi is applicable when evaluating metastatic spine lesions and making therapeutic plans. There is also discussion about basing stability on column structure of spine, while some proposed radiographic criteria and the need for surgical stabilization. There is evidence in the literature of lack of clear consensus in defining 'spinal stability' in metastatic disease. Concluded that patients with some residual neurologic function and if fit for surgery may benefit with newer fixation methods.</p>
8 Fourney <i>et al.</i> (2003)	<p>Type of study: Literature review</p> <p>Aim: To discuss patterns of spinal instability secondary to metastatic disease and management of spinal instability for surgery.</p> <p>Method: No mention was made about whether the review was systematic and how articles were sorted through</p> <p>Key messages: Guidelines for spinal instability secondary to trauma cannot be used. Recumbency alleviates pain resulting from spinal instability.</p>
9 Fourney <i>et al.</i> (2003)	<p>Type of study: Retrospective study</p> <p>Aim: To retrospectively review the effect of posterior stabilisation surgery on patients with metastatic disease of the atlanto-axial spine.</p> <p>Method: Retrospective review of 19 patient records. Outcomes include occurrence of death, degree of ambulation and flexibility after treatment.</p> <p>Key messages: Authors recommend stabilisation surgery rather than treatment of rigid orthoses for patients with metastatic disease of the atlanto-axial spine. Surgery allows patients to continue ambulating during the remainder of their lives without the hassle/discomfort of an exterior orthosis.</p>
10 Galasko <i>et al.</i> (2000)	<p>Type of study: Literature review/descriptive study</p> <p>Aim: To outline the background of how spinal instability in MSCC is identified and affects patients. Authors also outline treatment methods for spinal instability in MSCC.</p> <p>Method: Review of educational literature for physicians about MSCC, presentation of author's own findings (retrospective analysis of patient records), review of general MSCC literature.</p> <p>Key messages: Many physicians fail to identify spinal instability due to MSCC properly. Author focuses on benefits for patients who have had operative intervention for spinal instability and also concludes that patients with spinal instability are not being referred in a timely manner.</p>
11 Gupta <i>et al.</i> (2007)	<p>Type of study: Prospective study</p> <p>Aim: To evaluate the diagnostic efficacy of dynamic MRI in craniovertebral junction (CVJ) abnormalities</p> <p>Method: 25 patients with (CVJ) abnormalities were recruited for dynamic MRI analysis</p> <p>Key messages: Dynamic MRI has potential to be a useful diagnostic tool for cord compression and spinal instability in the cervical spine.</p>
12 Gurusingh 1997	<p>Type of study: Textbook guidelines</p> <p>Aim: To provide guidelines for the diagnosis and treatment of patients with spinal tumours</p> <p>Method: Author cites numerous academic articles</p> <p>Key messages: In relation to research questions, author recommends that MSCC patients have physiotherapy after treatment and be mobilised once they can cope with the pain.</p>
13 Hatrick <i>et al.</i> (2000)	<p>Type of study: Retrospective study</p> <p>Aim: To assess how surgery affects key outcomes (e.g. pain, ambulation) in MSCC patients (referred for surgery by oncologists)</p> <p>Method: 42 patients records review for outcomes after stabilisation and/or decompression surgery: pain, neurological deficit (on a Frankel scale), motor deficit (on a Frankel scale) and survival length</p> <p>Key messages: Spinal instability pain in patients with MSCC should be managed surgically. Patients are mobilised 'early on' after surgery.</p>

Table 4 (Continued)

Reference	Summary
14 Heary and Bono (2001)	<p>Type of study: Literature review</p> <p>Aim: To examine the literature concerning surgical treatment of MSCC</p> <p>Method: Authors do not detail how they searched for studies and/or criteria for inclusion in the review.</p> <p>Key messages: Surgical intervention should be evaluated on a case by case basis, but patients with a life expectancy of longer than 3 months and spinal instability are good candidates. They also detail techniques of various surgical procedures.</p>
15 Husband <i>et al.</i> (2001)	<p>Type of study: Prospective study</p> <p>Aim: To compare the diagnostic value of plain films versus MRI for metastatic spinal cord compression.</p> <p>Method: Participants were either given automatic diagnosis of MSCC due to sensory tests and plain film results ('non- MRI mandatory' group, although this group later received MRI) or if sensory tests or plain film results were unclear then participants also received an MRI ('MRI mandatory group'). Radiographic findings were compared within groups</p> <p>Key messages: MRI is a more effective method in detected vertebral collapse as well as being able to capture multiple compression sites in patients. Overall MRI is a more sensitive method.</p>
16 Jacobs (1999)	<p>Type of study: Review article</p> <p>Aim: To review management of malignant spinal cord compression</p> <p>Method: Author did a review of current literature but it is not a systematic review</p> <p>Key messages: It is important to distinguish pain caused by MSCC and degenerative joint disease. Pain is almost always the first symptoms in MSCC, may occur at any level, progressive, may be axial, referred or radicular and maybe aggravated on lying down. In degenerative joint disease pain rarely occurs beyond the low cervical or low lumbar spine and relieved on lying down. MRI is superior in detecting epidural, vertebral and paravertebral metastases.</p>
17 Jacobs and Perrin (2001)	<p>Type of study: Literature review</p> <p>Aim: To describe different methods of identifying and treating (with a focus on surgery) MSCC.</p> <p>Method: Authors do not detail how they searched for studies and/or criteria for inclusion in the review.</p> <p>Key messages: Surgical intervention in MSCC has advantages over radiotherapy. MRI superior imaging method with ability to detect MSCC earlier than other methods.</p>
18 Jenis <i>et al.</i> (1999)	<p>Type of study: Literature review</p> <p>Aim: To describe methods of diagnosis and treatment of metastatic disease of the cervical spine.</p> <p>Method: Authors do not detail how they searched for studies and/or criteria for inclusion in the review.</p> <p>Key messages: There are special considerations when treating MSCC in the cervical spine. Authors cite Kostuik's guidelines for assessing spinal stability as well as Poste and Sundaresan's guidelines for bracing.</p>
19 Khaw <i>et al.</i> (1999)	<p>Type of study: Retrospective study</p> <p>Aim: To describe the pattern/s of vertebral metastases in patients with MSCC</p> <p>Method: 328 patient records were reviewed and MRI images were analysed with regard to collapse, compression, site and extent of metastases, pattern of fracture etc.</p> <p>Key messages: Summarises the benefits of using MRI as imaging method and as an essential tool in preparation for surgical management of MSCC.</p>
20 Levack <i>et al.</i> (2002)	<p>Type of study: Prospective study</p> <p>Aim: To document symptoms (especially pain-related) of suspected MSCC, to document delays between presentation of symptoms and MSCC diagnosis.</p> <p>Method: Examination of 319 patient records</p> <p>Key messages: There are delays in reporting symptoms and diagnosis of MSCC. Plain films and bone scans only identify a minority of MSCC cases.</p>
21 Loblaw <i>et al.</i> (2005)	<p>Type of study: Systematic review</p> <p>Aim: To describe diagnosis and management of patients with suspected or confirmed MSCC</p> <p>Method: A review of 5 prospective cohort studies, one cross-sectional study, 5 retrospective studies and one population-based study.</p> <p>Key messages: Diagnostic and treatment delay should be reduced with respect to patients with symptoms of MSCC. MRI has high specificity in identifying MSCC and is the favoured imaging technique. Treatment regimes should consider a number of variables including spinal instability.</p>

Table 4 (Continued)

Reference	Summary
22 Maher de Leon <i>et al.</i> (1998)	<p>Type of study: Literature review</p> <p>Aim: To describe diagnosis, (nursing) management and treatment of patients with MSCC.</p> <p>Method: 15 articles were reviewed, authors do not detail how they searched for studies and/or criteria for inclusion in the review</p> <p>Key messages: With regard to nursing management of MSCC: patients with MSCC are assumed to be unstable. Recommends prophylactic DVT therapy with anticoagulant medication and antiembolic stockings.</p>
23 McClinton and Hutchison (2006)	<p>Type of study: Retrospective audit</p> <p>Aim: To assess current practice in diagnosis, management and rehabilitation of patients with MSCC.</p> <p>Method: Examination of 174 patient records.</p> <p>Key messages: There are delays in diagnosis and gaps in patient knowledge. Few patients are referred for surgery, mobility status poor amongst this group of patients, formal plans documented in only a minority of patient records for mobilising/rehabilitating patients.</p>
24 Mercadante (1997)	<p>Type of study: Literature review</p> <p>Aim: To describe the mechanisms of pathogenesis of bone metastasis</p> <p>Method: Describe management of metastatic bone disease and its complications</p> <p>Key messages: The management of metastatic bone disease continues to be a difficult problem. The goal is to achieve palliation through different methods. Suggested to address psychological, social, and spiritual aspects in the pain management of patients with advanced cancer.</p>
25 North <i>et al.</i> (2005)	<p>Type of study: Retrospective study</p> <p>Aim: To assess surgical outcomes in patients with MSCC of the lumbar spine</p> <p>Method: Reviewed 139 patient records, outcomes of interest (all after surgery) included: neurological and pain outcomes, complications and survival</p> <p>Key messages: Surgery improves neurological and ambulation outcomes. Patients are aggressively mobilised as soon as possible after surgery.</p>
26 Parsch <i>et al.</i> (2003)	<p>Type of study: Retrospective study</p> <p>Aim: To evaluate the efficacy of a rehabilitation program for MSCC patients and describe symptoms, and survival rates of these patients</p> <p>Method: Reviewed 68 patient records, outcomes of interest included: FIM scores (assigned retrospectively), patient survival and mobility</p> <p>Key messages: The authors advocate rehabilitation program for MSCC patients as patients had a noted average increase FIM scores during rehabilitation.</p>
27 Patchell <i>et al.</i> (2005)	<p>Type of study: Randomised control trial</p> <p>Aim: To assess the efficacy of decompressive surgery for patients with MSCC</p> <p>Method: Based on several criteria, patients were selected for surgery + radiotherapy or radiotherapy alone. Primary outcome measure was patient's ability to mobilise</p> <p>Key messages: Significantly more patients were able to walk after surgery+radiotherapy treatment. Spinal stability assessed according to Cybulski's guidelines.</p>
28 Pease <i>et al.</i> (2004)	<p>Type of study: Retrospective study/descriptive study</p> <p>Aim: To develop a care pathway for MSCC patients</p> <p>Method: Literature review, focus group discussion with physiotherapists, surgeons and other consultants working with MSCC patients, implementation of new care pathway</p> <p>Key messages: Once a care pathway was developed and implemented for MSCC patients, they recorded earlier mobilisation of MSCC patients after treatment. Criteria of spinal stability for the purposes of mobilising the patient are unclear. Authors assessed spinal stability according to mechanical pain and any neurological deficit.</p>
29 Pilitsis and Rengachary (2001)	<p>Type of study: Literature review</p> <p>Aim: To review the role of vertebroplasty in the treatment of metastatic disease</p> <p>Method: Authors do not detail how they searched for studies and/or criteria for inclusion in the review</p> <p>Key messages: Vertebroplasty can be a complementary treatment to radiotherapy and/or decompression for MSCC patients by providing pain relief as well as further strengthening the spine.</p>

Table 4 (Continued)

Reference	Summary
30 Schiff (2003)	<p>Type of study: Review article</p> <p>Aim: To review the epidemiology, pathophysiology, symptomatology, diagnosis, and management of the causes of spinal cord dysfunction related to cancer</p> <p>Method: Author review current literature and use clinical knowledge and 77 references for this article. This is not a systematic review.</p> <p>Key messages: Described the spinal column is divided into three segments: the anterior vertebral body, posterior vertebral body and spinal arch. To maintain spinal stability, preservation of at least two of the segments is necessary. In ESCC, pain is often severe, limiting mobility and the use of spinal braces is recommended. The use of braces can be quite uncomfortable and may be limited to patients with true spinal instability.</p>
31 Shimada <i>et al.</i> (2006)	<p>Type of study: Retrospective study</p> <p>Aim: To describe symptoms of cauda equina tumours to allow earlier diagnosis.</p> <p>Method: Examination of 28 patient records.</p> <p>Key messages: Lower back pain increases in the supine position. Symptom of onset is most usually pain without motor weakness or sensory change.</p>
32 Stubblefield and Bilsky (2007)	<p>Type of study: Literature review/treatment guidelines</p> <p>Aim: To describe barriers to rehabilitation in patients with MSCC</p> <p>Method: The authors use personal clinical knowledge as well as 47 referenced studies. Authors do not state how they performed literature search</p> <p>Key messages: Practitioners should look at neurologic, oncologic, medical, pain and support factors when designing a rehabilitation program for patients. Patients with pain caused by spinal instability difficult to rehabilitate without the option of surgery.</p>
33 Tang <i>et al.</i> (2007)	<p>Type of study: Retrospective study/descriptive study</p> <p>Aim: To evaluate which factors predict functional gains for MSCC patients in rehabilitation program.</p> <p>Method: Examination of 63 clinical records, outcomes of interest included FIM scores, length of rehabilitation and Tokuhashi scores</p> <p>Key messages: Authors recommend rehabilitation for MSCC patients as they improve functional outcomes. Authors recommend the Tokuhashi score to evaluate which patients have the best potential for improvement in a rehabilitation program.</p>
34 Wise <i>et al.</i> (1999)	<p>Type of study: Retrospective study</p> <p>Method: $n = 80$ patients who had surgical treatment for metastatic disease of the spine were reviewed</p> <p>Key messages: Major complication rate was relatively low. Complication risk increases with worsening preoperative neurological status and increasing bone destruction.</p> <p>Aim: To determine the surgical complication, survival rates, and risk factors for complication occurrence of patients with metastatic disease of the spine.</p>
35 Zimmerman <i>et al.</i> (2002)	<p>Type of study: Prospective study</p> <p>Aim: To evaluate occipital-cervical fixation as a treatment for stabilising the cervical spine in MSCC patients</p> <p>Method: 20 patients evaluated after they underwent occipital-cervical fixation with Ransford loops. Outcomes of interest included pain and neurological function post treatment.</p> <p>Key messages: Occipital-cervical stabilisation relieves pain and increases stability (thereby increasing quality of life) in MSCC patients.</p>

Excluded articles

Reference	Reason for exclusion
Aass, N. and S. D. Fossa (2005) 'Pre- and post-treatment daily life function in patients with hormone resistant prostate carcinoma treated with radiotherapy for spinal cord compression.' <i>Radiother Oncol</i> 74(3): 259–265.	The authors do not address when and how to mobilise patients post-treatment. Article cited in background.
Ahn, H., P. Mousavi, <i>et al.</i> (2006) 'Stability of the Metastatic Spine Pre and Post Vertebroplasty.' <i>J Spinal Disord Tech</i> 19(3): 178–182.	Authors do not address criteria for assessing spinal stability.
Bucholtz, J. D. (1999) 'Metastatic epidural spinal cord compression.' <i>Seminars in Oncology Nursing</i> 15(3): 150–159.	Although the abstract mentions expert nursing care in the rehabilitation phase of MESCC, no mention is made of how to position MESCC patients or which positions are ideal.

Table 4 (Continued)

Excluded articles	
Reference	Reason for exclusion
Chen, Y., H. Hsu, <i>et al.</i> (2007) 'Transpedicular partial corpectomy without anterior vertebral reconstruction in thoracic spinal metastases.' <i>Spine</i> 32(22): E623-E626.	The author did not describe spinal assessment for instability in this study.
Chow, E., J. Wu, <i>et al.</i> (2003). 'Radiotherapeutic approaches to metastatic disease.' <i>World J Urol</i> 21(4): 229-242.	The authors do not address spinal stability/instability; the article's focus is radiotherapy treatment and which clinical features of MSCC warrant different radio-therapeutic treatments.
Conway, R., J. Graham, <i>et al.</i> (2007) 'What happens to people after malignant cord compression? Survival, function, quality of life, emotional well-being and place of care 1 month after diagnosis.' <i>Clinical Oncology (Royal College of Radiologists)</i> 19(1): 56-62.	The authors do not address when and how to mobilise patients post-treatment.
Cook, A. M., T. N. Lau, <i>et al.</i> (1998) 'Magnetic resonance imaging of the whole spine in suspected malignant spinal cord compression: impact on management.' <i>Clin Oncol (R Coll Radiol)</i> 10(1): 39-43.	The authors do not address spinal stability/instability.
Cowap, J., J. R. Hardy, <i>et al.</i> (2000) 'Outcome of malignant spinal cord compression at a cancer centre: implications for palliative care services.' <i>Journal of Pain and Symptom Management</i> 19(4): 257-264.	The authors do not address when and how to mobilise patients post-treatment.
Coward, D. D. and D. J. Wilkie (2000) 'Metastatic bone pain. Meanings associated with self-report and self-management decision making.' <i>Cancer Nurs</i> 23(2): 101-108.	Article not directly relevant to MSCC patients positioning/mobilisation.
Eysel, P. and B. Herbsthofer (2001) 'Dorsal compression of the epidural cord due to free sequestral lumbar prolapse.' <i>Arch Orthop Trauma Surg</i> 121: 238-240.	The authors do not address spinal stability/instability in relation to MSCC.
Gabriel, K. and D. Schiff (2004) 'Metastatic spinal cord compression by solid tumors.' <i>Semin Neurol</i> 24(4): 375-383.	Defining criteria for spinal instability addressed in article is not relevant to patients with MSCC.
Garner, C. (1999). 'Cancer related spinal cord compression.' <i>American Journal of Nursing</i> 7: 34-36.	The article was a general overview of MSCC and did not address details like bracing, mobilisation or positioning.
Ghogawala, Z., F. L. Mansfield, <i>et al.</i> (2001) 'Spinal radiation before surgical decompression adversely affects outcomes of surgery for symptomatic metastatic spinal cord compression.' <i>Spine</i> 26(7): 818-824.	Authors do not discuss the definition of spinal stability.
Graham, P. H., A. Capp, <i>et al.</i> (2005) 'A pilot randomised comparison of dexamethasone 96 mg vs 16 mg per day for malignant spinal-cord compression treated by radiotherapy: TROG 01.05 superdex study.' <i>Clinical Oncology</i> 18: 70-76.	The authors do not address patient ambulation/positioning post-treatment.
Guo, Y., B. Young, <i>et al.</i> (2003) 'Prognostic factors for survival in metastatic spinal cord compression: a retrospective study in a rehabilitation setting.' <i>Am J Phys Med Rehabil</i> 82(9): 665-668.	The authors do not address spinal stability/instability, ambulation or patient positioning although the focus of the article is patient rehabilitation.
Hardy, J. R. and R. Huddart (2002). 'Spinal cord compression—what are the treatment standards?' <i>Clin Oncol (R Coll Radiol)</i> 14(2): 132-134.	The authors do not address spinal stability/instability; the article's main focus was the use of MRI for diagnosis.
Helweg-Larsen, S., P. S. Sorensen, <i>et al.</i> (1999) 'Prognostic factors in metastatic spinal cord compression: a prospective study using multivariate analysis of variables influencing survival and gait function in 153 patients.' <i>Int. J. Radiation Oncology Biol. Phys.</i> 46(5): 1163-1169.	The authors do not address patient ambulation/positioning.
Kanaskie, M. and C. Tringali (2008) 'Promoting Quality of life for geriatric patients in acute care and critical care settings.' <i>Critical Care Nursing Quarterly</i> 31(1): 2-11.	The authors do not address patient ambulation/positioning; the article's focus is on palliation.
Kienapfel, H., M. Koller, <i>et al.</i> (2004). 'Integrated outcome assessment after anterior cervical discectomy and fusion.' <i>Spine</i> 29(22): 2501-2509.	The study is on cervical degenerative disc disease, authors do not address assessment of spinal stability/instability.

Table 4 (Continued)

Reference	Reason for exclusion
Klimo, P., Jr., C. J. Thompson, <i>et al.</i> (2005) 'A meta-analysis of surgery versus conventional radiotherapy for the treatment of metastatic spinal epidural disease.' <i>Neuro Oncol</i> 7(1): 64–76.	The authors do not address spinal stability/instability; the article's focus is outcomes of ambulation according to treatment and other secondary outcomes.
Lemke, D. M. and L. Hacin-Bey (2003) 'Metastatic compression fractures–vertebroplasty for pain control.' <i>J Neurosci Nurs</i> 35(1): 50–55.	The authors do not address patient ambulation/positioning post-treatment.
Levack, P., Graham J., <i>et al.</i> (2004) 'Listen to the patient: quality of life of patients with recently diagnosed malignant cord compression in relation to their disability.' <i>Palliative Medicine</i> 18(7): 594–601.	The authors do not address patient ambulation/positioning post-treatment.
Loblaw, D. A., N. J. Laperriere, <i>et al.</i> (2003) 'A population-based study of malignant spinal cord compression in ontario.' <i>Clinical Oncology</i> 15: 211–217.	This study was a retrospective descriptive study which offered no insight into treatments for MESCC outside of surgery and radiotherapy (i.e. use of physiotherapy).
Loughrey, G. J., C. D. Collins, <i>et al.</i> (2000) 'Magnetic resonance imaging in the management of suspected spinal canal disease in patients with known malignancy.' <i>Clin Radiol</i> 55(11): 849–855.	The authors do not address spinal stability/instability.
Lowey, S. E. (2006) 'Spinal cord compression: an oncologic emergency associated with metastatic cancer: evaluation and management for the home health clinician.' <i>Home Health Nurse</i> 24(7): 439–46; quiz 447–448.	The author does not address patient ambulation/positioning; the article's focus is early detection of MSCC.
Maranzano, E., F. Trippa, <i>et al.</i> (2003) 'Management of metastatic spinal cord compression.' <i>Tumori</i> 89(5): 469–475.	Although this review was highly informative and provided some original sources for this review paper, no original research or conclusions of these authors were relevant to the current review.
McKinley, W. O., M. E. Huang, <i>et al.</i> (1999) 'Neoplastic versus traumatic spinal cord injury: an outcome comparison after inpatient rehabilitation.' <i>Arch Phys Med Rehabil</i> 80(10): 1253–1257.	The authors do not address patient ambulation/positioning post-treatment.
McKinley, W. O., R. T. Seel, <i>et al.</i> (1999) 'Nontraumatic spinal cord injury: incidence, epidemiology, and functional outcome.' <i>Arch Phys Med Rehabil</i> 80(6): 619–623.	The authors do not address when and how to mobilise patients post-treatment.
Rades, D., F. Fehlauer, <i>et al.</i> (2006) 'Prognostic factors for local control and survival after radiotherapy of metastatic spinal cord compression.' <i>J Clin Oncol</i> 24(21): 3388–3393.	The authors do not address spinal stability/instability; the article's focus is radiotherapy treatment and which clinical features of MSCC warrant different radio-therapeutic treatments.
Rades, D., T. Veninga, <i>et al.</i> (2006) 'Prognostic factors predicting functional outcomes, recurrence-free survival, and overall survival after radiotherapy for metastatic spinal cord compression in breast cancer patients.' <i>Int J Radiat Oncol Biol Phys</i> 64(1): 182–188.	The authors do not address when and how to mobilise patients post-treatment.
Rades, D., J. Walz, <i>et al.</i> (2006) 'Short-course radiotherapy (RT) for metastatic spinal cord compression (MSCC) due to renal cell carcinoma: results of a retrospective multi-center study.' <i>Eur Urol</i> 49(5): 846–852; discussion 852.	The authors do not address spinal stability/instability or mobilisation after treatment.
Ripamonti, C. (2007) 'Decreases in pain at rest and movement-related pain during zoledronic acid treatment in patients with bone metastases due to breast or prostate cancer: a pilot study.' <i>Support Care Cancer</i> 15: 1177–1184.	Article is not relevant as authors do not address movement after problems with spine metastases.
Salvati, M. C. L. P. F. R. M. C. P. D. R. (1998) 'Metastatic spinal cord compression. Clinical remarks.' <i>Minerva Chirurgica</i> 53(9): 727–730.	Article not available in English.
Schoeggel, A., M. Reddy, <i>et al.</i> (2002) 'Neurological outcome following laminectomy in spinal metastases.' <i>Spinal Cord</i> 40(7): 363–366.	The article was a general overview of MSCC and did not address details like bracing, mobilisation or positioning. The authors do not address when and how to mobilise patients post-treatment.

Table 4 (Continued)

Excluded articles	
Reference	Reason for exclusion
Song, J., J. Mizuno, <i>et al.</i> (2006) 'Clinical evaluation of traumatic central cord syndrome: emphasis on clinical significance of prevertebral hyperintensity, cord compression, and intramedullary high-signal intensity on magnetic resonance imaging.' <i>Surgical Neurology</i> 65(2): 117–123.	Information was not relevant as the article discusses trauma rather than metastases.
Walker, J. A. (2002) 'Caring for patients with a diagnosis of cancer and spinal metastatic disease.' <i>Nurs Stand</i> 16(42): 41–44.	The authors do not address patient ambulation/positioning post-treatment.
Wu, J. S., G. Monk, <i>et al.</i> (2006) 'Palliative radiotherapy improves pain and reduces functional interference in patients with painful bone metastases: a quality assurance study.' <i>Clin Oncol (R Coll Radiol)</i> 18(7): 539–544.	The authors do not address timing of mobilisation of patients.
Yen, D., V. Kuriachan, <i>et al.</i> (2002) 'Long-term outcome of anterior decompression and spinal fixation after placement of the Wellesley Wedge for thoracic and lumbar spinal metastasis.' <i>J Neurosurgery Spine</i> 9(1): 6–9.	The authors do not address criteria for defining spinal stability.

Dirksmeier and Kang (2001), in their literature review of spinal instability caused by metastatic disease, reference White and Panjabi (1978, 1990) for guidelines about how to assess spinal instability. These authors argue that it is difficult to assess spinal stability in metastatic disease because of a lack of consensus in the literature and that White and Panjabi's (1978, 1990) definition is most useful when evaluating metastatic spine lesions and planning therapy. Jenis *et al.* (1999) and Dirksmeier and Kang (2001) reference Kostuik and Weinstein (1991) guidelines as a useful way to assess spinal instability (for the purposes of surgery), although these guidelines have never been rigorously tested as a tool to determine whether and when patients can mobilise post-treatment.

The studies addressing spinal stability guidelines and metastatic cord compression concur that looking at three factors mechanical pain, neurological changes and radiological findings is integral in assessing spinal stability (Bilsky & Smith 2006, Bilsky & Azeem 2007). For example, it is common knowledge that pain exacerbated by movement and alleviated with immobility (i.e. mechanical pain) can be indicative of spinal instability (Mercadante 1997, Jacobs & Perrin 2001, Coleman 2006).

In practice, there are probably many guidelines in use for establishing spinal stability especially for patients undergoing surgery. However, guidelines may not be cited in research articles. For example, despite detailing several preoperative assessments for patients (e.g. MRI), various clinical and neurological tests as recommended by Jenis *et al.* (1999), Hatrick *et al.* (2000) do not detail which criteria they used to classify patients as unstable in their retrospective study of MSCC patients referred for surgery.

Instability in the cervical spine

Three recent articles have given particular focus to metastatic disease of the cervical spine (Jenis *et al.* 1999, Zimmerman *et al.* 2002, Bilsky & Azeem 2007). Although mechanical pain, pain exacerbated by motion and relieved with rest, can be a symptom of instability in the cervical spine (Jenis *et al.* 1999), Bilsky and Azeem (2007) argue that no good models or guidelines exist for assessing spinal instability for patients with tumours in the cervical spine. In response, these authors have created the Neurologic, Oncologic, Mechanical Instability and Systemic Disease and Medical Comorbidities (NOMS) framework. NOMS provides a framework for surgeons, radiation oncologists and medical oncologists to make assessments and decisions on the choice of treatment. The assessment takes into consideration neurologic (N), oncologic (O), mechanical instability (M) and systemic disease (S) (Bilsky & Smith 2006). The degree of epidural spinal cord compression (ESCC) are graded as 0–3 on MRI scans, with grade 0 indicating involvement of the vertebral body with no epidural compression; grade 1 is epidural impingement without compression; grade 2 is compression with cerebrospinal fluid seen; and grade 3 is compression without CSF seen. Grades 2 and 3 are considered as high-grade spinal cord compression. They argue that surgery may be more necessary for patients with tumour in the cervical spine (even radio-sensitive tumours) because of the greater possibility of mechanical instability. This makes the need for guidelines all the more important.

Imaging techniques and spinal instability

It is necessary to address the contributions of different radiological methods in the assessment of stability. MRI is

Table 5 Definitions of spinal instability

Study	Defintion of spinal instability
White & Panjabi 1978	'The loss of the ability of the spine under physiologic loads to maintain relationships between vertebrae in such a way that there is neither damage nor subsequent irritation to the spinal cord or nerve roots, and, in addition, there is no development of incapacitating deformity or pain due to structural changes.'
Cybulski 1989	(1) anterior and middle column destruction (greater than 50% collapse of vertebral body height). (2) Collapse of two or more adjacent vertebral bodies. (3) Tumour involvement of middle and posterior columns (possible forward shearing deformity). (4) Iatrogenic (laminectomy with failure to recognise anterior and middle column disease). Additionally, that instability is more like to occur when posterior half of the spinal column is affected
Mercadante 1997	'Spinal instability is due to bone loss of one or more vertebral bodies tending to collapse resulting in kyphosis.'
Mahe de Leon <i>et al.</i> 1998	Patients who have MSCC are assumed to have an unstable spine. (This guideline is mainly with regard to nursing practices.)
Pilitsis & Rengachary 2001	A vertebra which has collapsed to one-third its height
Zimmerman <i>et al.</i> 2002	With specific regard to lesions in the occipito- cervical region, the presence of a tumour indicates that this spinal area is unstable
Patchell <i>et al.</i> 2005	Cybulski's guidelines; Additionally, patients with pathological spine fractures, evidence of bone in the spinal canal
Byrne <i>et al.</i> 2006	Cybulski's guidelines; bony impingement

the preferred imaging method to detect compression as it is highly sensitive and specific (Godersky *et al.* 1987, Khaw *et al.* 1999, NICE 2008). Although MRI cannot unequivocally confirm spinal instability in patients, it is clear that MRI is the superior imaging technique for detection of both compression and signs of instability (Godersky *et al.* 1987, Mahe de Leon *et al.* 1998, Jacobs 1999).

Despite the efficacy of MRI, the role of plain films and CT in detecting signs of spinal instability was investigated in this review as patients sometimes need to wait for MRI imaging. NICE (2008) recommend that no plain films be used to diagnose MSCC. This recommendation seems to be supported in the literature. Some authors state that, for plain films to detect lesions, vertebral collapse has to be more than 50% (Khaw *et al.* 1999, Heary & Bono 2001), and the ability of plain film to detect discrete fracture is questionable (Galasko *et al.* 2000). In their guideline, NICE (2008) suggest a targeted CT scan with three plane reconstruction to assess MSCC. However from the literature, it is questionable, whether CT is the best imaging method to assess spinal instability in MSCC (Gupta *et al.* 2007).

From this review, it can be concluded that it is very difficult to obtain agreement as to when the spine is unstable. This is due to the number of variables to take into account and the different imaging modalities. Criteria must be objective, simple and reproducible if they are to be used to direct patient management. NICE (2008) base many of their recommendations on the assessment of spinal stability; however, from this review, it is unclear what

guidelines for stability are best suited for patients with MSCC.

Bracing

Clinical care guidelines recommend bracing in patients with metastatic spinal cord compression; however, there is little clinical evidence to substantiate these guidelines (Mercadante 1997, Jenis *et al.* 1999, NICE 2008).

Jenis *et al.* (1999) cite Poste and Fidler's (1980) guidelines for using a cervical collar as a conservative treatment in the event of early identified cervical lesions. There is currently no evidence base for the use/functionality of bracing. Some authors advise that when there is suspicion of cervical lesions, patients should be fitted with a cervical collar to help stabilise the spine and reduce neck movement (Mahe de Leon *et al.* 1998, Heary & Bono 2001, Pease *et al.* 2004). However, none of these authors have cited any original research or studies to support this statement. In fact, Heary and Bono (2001) point out that there is a lack of evidence for the long-term benefit of bracing in the literature and that the (cervical) collar's effectiveness in preventing an impending pathological fracture is unknown.

In addition to potentially stabilising the spine, it is argued that a rigid spinal orthosis may also help relieve pain and may be a conservative alternative to vertebroplasty (Galasko *et al.* 2000, Pilitsis & Rengachary 2001, Jenis *et al.* 1999, NICE 2008). However, Pilitsis and Rengachary (2001) indicate that bracing may reduce a patient's quality of life. This is important as improvement on quality of life, along with palliation, is a primary treatment goal for MSCC (NICE

2008). Research studies are needed to clarify the role of bracing in metastatic spinal cord compression and what effect bracing has on spine stabilisation, pain relief and quality of life and whether there is any overall benefit of external orthoses for MSCC patients.

Mobilisation

The literature indicates that plans to mobilise patients are disparate, and Pease *et al.* (2004) state that practitioners often report uncertainty about knowing when to mobilise patients. Mobilising patients is strongly tied to the stability of the spine. Some guidelines claim that if MSCC patients have considerable movement related pain or are at risk of progressive neurological deficits from an unstable spinal fracture, it is extremely difficult to plan rehabilitation programmes for these patients (Stubblefield & Bilsky 2007). It is known from the local scoping exercise undertaken by the authors that plans for mobilisation vary. An audit identified no comprehensive plan for individual patient mobilisation or positioning (McClinton & Hutchison 2006). For example, incremental movement was planned for 33% of patients, although the rationale for this was not recorded in physiotherapy notes.

From the literature, the recommendations for mobilisation vary. Some recommend the patient should mobilise when they can cope with the pain or as soon as possible post-treatment (Gurusinghe 1997). However, others contend there is no evidence for waiting until completion of radiotherapy treatment before beginning mobilisation (Pease *et al.* 2004). Wise *et al.* (1999) recommend mobilising patients and starting physical therapy on the first or second day post-treatment (after surgery) unless there are contraindications. In Fourny *et al.*'s (2003) retrospective study, following stabilisation (but not decompression) surgery, patients were mobilised as soon as possible (2003). In the Hatrick *et al.* (2000) study, MSCC patients referred for both stabilisation and decompression surgery were mobilised early without using spinal orthoses. After vertebrectomy, patients in the North *et al.* (2005) retrospective study were 'aggressively' mobilised without the aid of external orthoses, and the majority of patients unable to ambulate prior to surgery ($n = 139$) regained ambulatory status after treatment.

There is a lack of consensus between mobilising patients early to improve quality of life and delaying mobilisation until spinal stability status is confirmed (Pease *et al.* 2004). The aforementioned studies encourage early mobilisation to increase quality of life especially in patients who do not have long projected survival times post-surgical treatment. However, when patients do not undergo stabilisation surgery and

when they have longer projected post-radiotherapy treatment survival time consensus on criteria for mobilisation are required.

Positioning

Patients with an unstable spine or with stability status unknown are usually nursed in a supine position and recommended bed rest (Pease *et al.* 2004, McClinton & Hutchison 2006, NICE 2008). Fourny and Gokaslan (2003) note that recumbence may relieve pain caused by spinal instability.

However, the supine position can also increase pressure/pain for MSCC patients, and there are several anecdotes of patients sleeping in an upright position to relieve pain (Bilsky *et al.* 1999, Bilsky & Smith 2006). For example, Shimada *et al.* (2006) found that lower back pain increased in 50% of cauda equina compression patients when lying down or in a supine position. They also state that pain increases at night (although it is unclear whether this pain is attributed to positioning or temporal considerations) (Aebi 2003, Shimada *et al.* 2006).

Some patients have experienced a depressed mood when laying supine for extended periods of time (Pease *et al.* 2004). Further complications such as DVT, chest infection, pressure sores and urinary tract infections can pose additional problems (Pease *et al.* 2004). An additional complicating factor to positioning is the increased pain experienced by patients with spinal instability whilst sitting or standing because of increased axial load on the spine (Bilsky *et al.* 1999).

One article discussed positioning and pain in MSCC patients who have co-morbid degenerative disease of the spine (Borm *et al.* 2004). Borm *et al.* (2004) found diagnosis of spinal tumours can be difficult if there are concurrent signs of degenerative changes in the spine. Their study found no significant difference in the frequency of back pain either at rest or under loading for both spinal tumours and degenerative disease of the spine. It was observed that a combination of back pain at rest without back pain under loading only occurred in patients with spinal tumours, but it was not of statistical significance. Clear guidelines are needed for how to correctly position patients to maintain spinal stability and relieve pain.

Conclusion

There remains a gap in the evidence base to inform guidelines and clinical decision-making in the management of MSCC. Despite the recently published NICE guidelines, this review has demonstrated that evidence relating to spinal stability,

bracing, patient mobilisation and positioning is limited and may be inconclusive. Practitioners therefore need to ensure robust assessment of patients needs and ensure effective communication between key members of the team including the patient and/or family members. The preferences of patients with a poor prognosis and their quality of life are paramount in care decisions. Furthermore, despite the emergence of NICE guidelines, more research is required to provide an evidence base to guide the care management decisions of healthcare professionals caring for people with MSCC.

Most of the studies located for this review were retrospective or descriptive studies. A randomised controlled trial regarding spinal instability guidelines would be difficult to design and carry out with our current level of knowledge; however, prospective descriptive studies regarding imaging and clinical correlates of spinal instability would be a step towards producing a clear set of guidelines for spinal stability assessment and MSCC. Randomised trials would be possible measuring bracing efficacy, as well as descriptive and qualitative studies investigating quality of life issues. Descriptive and qualitative studies could further clarify mobilisation and positioning from a physician/nursing/patient point-of-view. Additionally, once clear guidelines are established for spinal instability, guidelines for patient mobilisation and positioning may become more apparent.

Relevance to clinical practice

Patients who develop MSCC suffer numerous physical, psychological and social issues. They are faced with poor prognosis and are dealing with a significant deterioration in their health status. The care for people with MSCC needs to be individualised to reflect their preferences. To achieve this, healthcare professionals have to be able to interpret guidelines and recommendations to assist their own decision-making around care management and help patients decide on their care and treatment, as to date there is no consensus on the usefulness of these tools in practice. Currently the evidence base to underpin care is limited, and further research in this area is necessary for patients and healthcare professionals alike. This paper provides a review of the current literature and has identified areas for future research linked to spinal stability, bracing, positioning and mobilisation.

Contributions

Study design: LK, MC, CK, SHL, RG; data collection and analysis: LK, MC, CK, SHL, RG and manuscript preparation: LK, MC, CK, SHL, RG.

Conflict of interest

None.

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Appendix 23: Publication 2

Patient positioning (mobilisation) and bracing for pain relief and spinal stability in metastatic spinal cord compression in adults (Review)

Lee SH, Cox KM, Grant R, Kennedy C, Kilbride L



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Patient positioning (mobilisation) and bracing for pain relief and spinal stability in metastatic spinal cord compression in adults (Review)
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[Intervention Review]

Patient positioning (mobilisation) and bracing for pain relief and spinal stability in metastatic spinal cord compression in adults

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ABSTRACT

Background

Many patients with metastatic spinal cord compression (MSCC) have spinal instability but are determined, by their clinician, to be unsuitable for surgical internal fixation due to their advanced disease. Mobilisation may be hazardous in the presence of spinal instability as further vertebral collapse can occur. Current guidance on positioning (or mobilisation) and spinal bracing is contradictory.

Objectives

To investigate the correct positioning (or mobilisation) and examine the effects of spinal bracing to relieve pain or to prevent further vertebral collapse in patients with MSCC.

Search methods

The Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE, CINAHL, CANCERLIT, NICE, SIGN, AMED, TRIP, National Guideline Clearinghouse and PEDro database were searched; the last search was run in February 2012.

Selection criteria

We selected randomised controlled trials (RCTs) of adults with MSCC of interventions on positioning or mobilisation and bracing.

Data collection and analysis

Two review authors independently assessed each possible study for inclusion and quality.

Main results

One thousand, six hundred and eleven potentially relevant studies were screened. No studies met the inclusion criteria. Many papers identified the importance of mobilisation but no RCTs have been undertaken. No RCTs of bracing in MSCC were identified.

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Authors' conclusions

There is lack of evidence based guidance around how to correctly position and when to mobilise patients with MSCC or if spinal bracing is an effective technique for reducing pain or improving quality of life. RCTs are required in this important area.

PLAIN LANGUAGE SUMMARY

Patient positioning or mobilisation and bracing for pain relief and spinal stability in adults with metastatic spinal cord compression

People with advanced cancer may develop metastatic spinal cord compression (MSCC), a serious complication which can cause pain and mobility problems and possibly paralysis. MSCC is the spread of the cancer to the spinal column. A diagnosis of MSCC normally indicates advanced disease and for many patients the final stages of their illness. Knowing how to manage this condition is challenging for healthcare professionals who may need to decide what interventions are appropriate. Some existing guidelines suggest strategies such as bed rest, avoiding mobility and the use of braces as ways of managing this condition. However, this needs to be balanced against the wishes of the patient, ensuring their comfort and individual preferences. If life expectancy is short then a palliative care approach, which focuses on patient preferences and priorities, is appropriate. This review tried to establish what evidence exists to help healthcare professionals and patients decide what treatment (positioning or mobilisation, bracing) is best for them. Unfortunately little research exists which can tell us the best way to manage this condition. Therefore our suggestions are twofold. Firstly there needs to be more research undertaken to find out what treatment approaches can help. Secondly, in the absence of clear evidence, healthcare professionals and patients need to discuss the options and precedence be given to the expressed wishes of patients.

BACKGROUND

Description of the condition

Metastatic Spinal Cord Compression (MSCC) is a serious complication of cancer disease. The symptoms of MSCC range from minor sensory disturbance and autonomic changes to severe pain and irreversible paralysis. MSCC is defined as "compression of the dural sac and its contents (spinal cord and/or cauda equine) by an extradural tumour mass. Clinical features include any or all of the following: pain (local or radicular), weakness, sensory disturbance and/or evidence of sphincter dysfunction" [Loblaw 1998](#). The onset of MSCC is a medical emergency and warrants immediate intervention to minimise damage to the spinal cord and preserve neurological function. Prognosis and the quality of life are related to the patient's pre-treatment ambulatory status and rapid diagnosis and treatment is required ([Levack 2002](#)).

Controversy surrounds the care of patients with MSCC. Approximately 10 people per 100,000 a year suffer from this condition and their prognosis is known to be very poor ([Levack 2002](#); [Posner 1995](#)). Current acceptable treatment approaches for MSCC include corticosteroids, radiotherapy and surgery ([Loblaw 1998](#)). A course of the corticosteroid dexamethasone is prescribed to reduce the oedema and cord compression and thereby relieve pain. There is some controversy regarding the optimal dose of dexamethasone.

The standard dose administered is 16 mg/d, in divided doses, over several days. Radiotherapy alone is the most common treatment for MSCC. Radiation therapy reduces the tumour mass thereby alleviating pain and relieving the spinal cord compression. There are different regimes of radiation therapy for spinal cord compression and the commonly prescribed regime is 3 Gy per fraction ([Kwok 2005](#)).

Surgery may be indicated, particularly for those with spinal instability or rapidly progressing loss of neurologic functions, but the number of these patients is small. Surgery is usually limited to patients with involvement of one or two vertebrae and those who have good performance status and an expected survival of more than three months ([Rades 2006](#)). The desirability of surgery plus radiotherapy as opposed to radiotherapy alone has been debated and two studies claim that where the overall condition of the patient merits intervention, a combination of surgery plus radiotherapy may provide the best outcomes ([Patchell 2005](#); [Thomas 2006](#)). [Tokuhashi 2005](#) developed a prognostic indicator as part of the assessment for surgery. This tool uses six parameters (performance status, extraspinal bone metastases, quantity of metastases in the vertebral body, metastases to internal organs, primary site, and the severity of neurological damage). Other tools to identify a patient's suitability for surgery have been developed by [Bilsky 2007](#) and [Gasbarrini 2010](#). The NOMS (Neurological assessment, On-

ologic assessment, Mechanical instability and Systemic disease) framework developed by [Bilsky 2007](#) and the algorithm for surgical treatment by [Gasbarrini 2010](#) both require further evaluation. A study analysing cost-effectiveness found that surgery together with radiotherapy was likely to be cost-effective, in comparison with radiotherapy alone, in the Canadian context ([Thomas 2006](#)). Due to lack of evidence and data from prospective randomised controlled trials (RCTs), the treatment of MSCC remains controversial ([Loblow 1998](#); [Makris 1995](#); [Prasad 2005](#)). Presently, care of MSCC patients is based on individual clinician preference rather than evidence based guidelines. The lack of such guidelines has been shown to cause delays and discrepancies in patient treatment ([Levack 2002](#); [McClinton 2006](#)).

Bracing and positioning or mobilisation are two non-invasive treatment options that clinicians sometimes prescribe for people with MSCC. The role of bracing as a treatment for MSCC is not well defined ([Lewandrowski 2006](#)). Braces can be used post-operatively to maintain the integrity of the spine, although anecdotally this treatment is criticised as being pointless as this is the purpose of the surgery. Braces can also be used long term to treat spinal instability, however, as the life span of a patient with MSCC may be short their use in this context is limited ([Lewandrowski 2006](#)). Both the cervical and thoracic spine can be braced, however, cervical bracing is the most commonly used in MSCC ([Lewandrowski 2006](#)). Positioning (or mobilisation) is a treatment that is prescribed pre-operatively, post-operatively and long term for people with MSCC. The prescription is usually bed rest or to mobilise. Bed rest usually refers to the patient being nursed supine and to mobilise refers to allowing the patient to get out of bed and walk. Clinically the rationale for bed rest is usually related to the spinal stability status ([NICE 2008](#)). An audit conducted by [McClinton](#) and [Hutchison](#) highlighted a lack of guidance on how to correctly position patients or whether or not to use braces ([McClinton 2006](#)). More recently, the National Institute for Health and Clinical Excellence (NICE) developed recommendations for the diagnosis and management of adults with MSCC ([NICE 2008](#)) in response to a recommendation from the Department of Health. These represent the best available good practice guidelines for managing patients with MSCC and allude to the use of bracing and positioning. However, the evidence that supports these recommendations is not conclusive.

Description of the intervention

Positioning (or mobilisation) for the purposes of this review refers to the instructions that patients receive about how to correctly position themselves and whether they can mobilise with MSCC. Patients with an unstable spine or with unknown stability status are usually nursed in a supine position and bed rest is recommended to prevent further vertebral collapse ([NICE 2008](#); [Pease 2004](#)). There are conflicting opinions about these interventions, with some patients encouraged to mobilise ([Walji 2008](#)).

The supine position can increase pressure and pain for MSCC patients and there are several anecdotes of patients sleeping in an upright position to relieve the pain caused by lying supine ([Bilsky 1999](#); [Bilsky 2006](#); [Gilbert 1978](#); [Obbens 1987](#)). Additionally, some patients experience a depressed mood when laying supine for extended periods of time ([Pease 2004](#)). Deep vein thrombosis (DVT), chest infection, pressure sores and urinary tract infections can pose additional complications for patients who are lying supine ([Pease 2004](#)) and, as a result, one guideline suggests that patients with a short life expectancy should be in a sitting-up position to avoid the aforementioned complications related to bed rest ([Jacobs 1999](#)). A primary goal of healthcare professionals is to rehabilitate patients. However, concerns about causing pathological fractures may mean mobilisation is discouraged amongst patients with MSCC for fear of paralysis ([Bunting 2001](#)). Additionally, it has been reported by patients with spinal instability that they suffer increased pain whilst sitting or standing due to an increased axial load on the spine ([Bilsky 1999](#)).

Bracing is an intervention that can be used to stabilise the spine through prevention or delay of further vertebral collapse and may reduce pain. Braces provide an additional form of external support to the affected area of the spine ([Lewandrowski 2006](#)). The goals of spinal bracing are restriction of motion, realignment and support ([Benzel 2001](#)). Both nursing and surgical guidelines recommend bracing for patients with cervical lesions ([Mercadante 1997](#); [NICE 2008](#); [Schiff 2003](#); [Yarbro 2005](#)). Despite these recommendations the use of bracing for patients with MSCC is controversial as there is currently no evidence base for the use or functionality of bracing in this group of patients.

Why it is important to do this review

It was important that this review of positioning (or mobilisation) and bracing was undertaken to ensure patients are cared for effectively. It was also important to ensure that healthcare professionals could draw on evidence to inform the care and management of patients with MSCC in terms of pain and spinal stability through prevention of further vertebral collapse.

OBJECTIVES

To investigate the correct positioning (or mobilisation) and examine the effects of spinal bracing to relieve pain or to prevent further vertebral collapse in patients with MSCC.

METHODS

Criteria for considering studies for this review

Types of studies

Randomised Controlled Trials (RCTs).

Types of participants

Participants of either gender with a confirmed diagnosis of MSCC.

Types of interventions

Interventions including spinal bracing and guidance for patients on positioning (or mobilisation), for example lying flat, sitting up, standing or mobilised, or both, versus patients who receive no therapy or no positioning guidance, or neither.

Types of outcome measures

Primary outcomes

- Radiologically confirmed effects of bracing on vertebral collapse under physiological load measured by vertebral column collapse rate, number of vertebrae involved in the problem area and bony impingement.
- Patient reported measures of pain relief, quality of life and satisfaction. Vertebral collapse will be measured by vertebral column collapse rate, number of vertebrae involved in the problem area and bony impingement.
 - Reported adverse events.
 - Primary outcome measures should be measured using valid and reliable assessment tools (visual analogue scores (VAS) and quality of life (QoL) scales e.g. European Organisation for Research and Treatment of Cancer (EORTC)).

Search methods for identification of studies

Electronic searches

The search strategy detailed in [Appendix 1](#) was applied to the following databases (27th January 2012 and 13th February 2012). Individual search strategies for the Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, EMBASE and CINAHL are replicated and also detailed in [Appendix 1](#).

- MEDLINE (Ovid) (1950 to week 4, January 2012).
- EBM Reviews - Cochrane Central Register of Controlled Trials (Ovid) (13th February 2012).
- *The Cochrane Library* (to Issue 1, January 2012).
- EMBASE (Ovid) (1980 to Week 4, January 2012).
- CINAHL (EBSCO) (1982 to January 2012).
- Cancerlit PDQ (Physician Data Query) 10th February 2012.

Searches of the following websites were also undertaken.

- SIGN (www.sign.ac.uk): no results, 10th February 2012.
- NICE (www.nice.org.uk) guidance (<http://www.nice.org.uk/Guidance/CG75>), date issued November 2008.
- UK Clinical Research Network (www.ukcrn.org.uk) Portfolio Database: no results, 10th February 2012.
- TRIP (www.tripdatabase.com): no results, 10th February 2012.
- NHS Clinical Knowledge Summaries (<http://cks.library.nhs.uk>) - information based on NICE 2008.
- National Guideline Clearinghouse (www.guideline.gov), 10th February 2012
- PEDro - Physiotherapy Evidence Database (www.pedro.org.au): no results, 10th February 2012.

Searching other resources

The references of all studies identified as part of this review were examined to determine if further studies could be identified for inclusion within the review. This search identified no further studies for inclusion.

Data collection and analysis

Selection of studies

Two review authors independently assessed each potentially eligible study by reviewing the titles or abstracts for inclusion in the review and for its quality. Disagreements over inclusion were resolved by discussion or with a third review author, or both.

Data extraction and management

We developed a data extraction form based on the Cochrane Pain, Palliative and Supportive Care Group template. We planned to extract the following main sets of data from each included study:

- lead author,
- date,
- study participant inclusion criteria,
- participants (diagnoses, demographics, primary cancer site, gender, age),
- interventions (spinal bracing, positioning, pain relief),
- intervention setting (hospital, hospice, home),
- outcome measures (quality of life, pain scores),
- timing of outcome measures (upon diagnosis, post surgery, post radiotherapy).

At least two review authors were identified to independently extract data into the data extraction form. One review author was to enter data into RevMan with the other checking the accuracy of this data input.

Any discrepancies were to be referred to a third review author and any errors or inconsistencies resolved.

We entered any details regarding the studies we excluded in to the 'Characteristics of excluded studies' table; if any studies had been included they would have been entered in the 'Characteristics of included studies' table. If necessary, additional information would have been sought from the principal investigator of a study for clarification of published data or missing data.

Assessment of risk of bias in included studies

We intended to assess any bias of included studies in accordance with guidelines in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011). Two review authors were to independently assess the risk of bias in included studies, with any disagreements to be resolved through discussion with a third review author as arbitrator if required. We were to contact study authors for additional information if required. We were to provide a written commentary of risk of bias within the review text. Assessment of methodological quality would have been assessed and graded using the 'Risk of bias' table available within RevMan 5.

Measures of treatment effect

Data would have been analysed using the Cochrane Collaboration's Review Manager 5 software. As no studies met our inclusion criteria it was not possible to measure the effects of intervention.

RESULTS

Description of studies

See: [Characteristics of excluded studies](#).

Included studies

The search strategy identified 1652 citations overall. We identified 41 duplicates. A total of 1611 potentially relevant studies were identified and screened for retrieval. We excluded abstracts which were not relevant to the review. For example, there were a large number relating to the range of therapies offered to people with MSCC for example surgery and radiotherapy. We obtained full text articles for 19 abstracts. Four of these articles were retrieved as there was no abstract available. These were then excluded as they were not reporting an RCT. We therefore found no studies meeting the inclusion criteria detailed above.

Excluded studies

The other eight articles were retrieved as they reported positioning and bracing recommendations and the methods used were not clear from the abstract. Seven of these eight articles were also excluded as they were not RCTs (Freundt 2010; Furstenberg 2009; Galasko 1991; Ippolito 1998; Rades 2010; Sciubba 2010; Spinazze 2005). One further study was found to be an RCT but did not report in their findings the impact of the intervention measures (positioning and bracing) in terms of the outcomes detailed for this review (Chi 2009). Reasons for exclusion are detailed in the 'Characteristics of excluded studies' table.

Risk of bias in included studies

As no studies met our inclusion criteria it was not possible to analyse the risk of bias.

Effects of interventions

Data would have been analysed using the Cochrane Collaboration's Review Manager 5 software. As no studies met our inclusion criteria it was not possible to measure the effects of intervention.

DISCUSSION

Positioning (or mobilisation) and bracing are interventions that are discussed and recommended within the literature to improve pain management and prevent further vertebral collapse amongst patients with MSCC (McClinton 2006; Mercadante 1997; NICE 2008; Pease 2004). However, as the evidence to support these recommendations is controversial this review aimed to investigate the correct positioning (or mobilisation) and examine the effects of spinal bracing to relieve pain or to prevent further vertebral collapse in patients with MSCC in order to assist healthcare professionals in their decision making.

There were no studies identified within this review that provided evidence to support the positioning (or mobilisation) or bracing techniques that should be used to manage pain or prevent further vertebral collapse, or both, amongst patients with MSCC. However, there were some studies identified that discussed these interventions and that may inform further studies or discussions. From the review of the literature, four studies (Bilsky 1999; Bilsky 2006; Bilsky 2007; Borm 2004) discussed the effect of positioning (mobilisation) on pain. Bilsky 1999; Bilsky 2006; and Bilsky 2007 suggest that when nursed in a supine position patients suffer an increased pressure or pain due to increased axial load on the spine and provide anecdotal evidence that patients request to sleep in an upright position to relieve pain. Borm 2004 found that diagnosis of spinal tumours can be difficult if there are concurrent signs of

degenerative changes in the spine. Their study found no significant difference in the frequency of back pain either at rest or under loading for both spinal tumours and degenerative disease of the spine. It was observed that a combination of back pain at rest and without back pain under loading only occurred in patients with spinal tumours, but these results were not statistically significant.

Some studies suggested that other factors than pain should be considered in positioning (or mobilisation) (Bilsky 1999; Bilsky 2007; Pease 2004). Some patients have experienced a depressed mood when laying supine for extended periods of time (Pease 2004) and other complications such as DVT, chest infection, pressure sores and urinary tract infections can pose difficulties (Pease 2004). Jacobs 1999 suggest that in light of some of these findings patients with short life expectancy should be encouraged to sit upright or to mobilise themselves.

From this systematic review, the review authors conclude that clear guidelines are needed to inform how to correctly position patients in order to maintain spinal stability and relieve pain. It is also suggested that when considering certain positions, for example lying supine, any additional physical and psychological factors that could affect patients because of this recommendation should be investigated.

There is currently no evidence base for the use or functionality of bracing. Some authors advise that when there is suspicion of cervical lesions, patients should be fitted with a cervical collar to help stabilise the spine and reduce neck movement (Maher de Leon 1998; Pease 2004). However, none of these authors have cited any original research or studies to support this statement. In fact, Heary 2001 points out that there is a lack of evidence for the long-term benefit of bracing in the literature, and that the (cervical) collar's effectiveness in preventing an impending pathological fracture is unknown.

In addition to potentially stabilising the spine, it is argued that a rigid spinal brace or orthosis may also help relieve pain and may be a conservative alternative to vertebroplasty (Galasko 1991; NICE 2008). Research studies are needed to clarify the role of bracing in MSSC and what effect bracing has on spine stabilisation, pain relief and quality of life, and whether there is any overall benefit of external braces or orthoses for MSCC patients.

There is a gap in the evidence base to inform positioning and bracing in individuals with MSCC. Despite published guidelines (NICE 2008), this review has demonstrated that evidence relating to spinal positioning and bracing is limited and inconclusive and therefore further research is required in this area.

Summary of main results

We intended to investigate the correct positions for patients with MSCC and examine the effects of spinal bracing to relieve pain or vertebral collapse, or both, under physiological load in this systematic review. The overall aim of the review was to provide evidence to assist healthcare professionals with their decision making in this area. Unfortunately the review process did not identify any studies that would guide healthcare professionals' decision making in this area. Furthermore, existing literature offers conflicting advice in terms of mobilisation and stabilisation.

From this systematic review the review authors conclude that clear guidelines are needed to inform how to correctly position patients in order to maintain spinal stability and relieve pain. Guidelines recommend using a spinal orthosis to increase spinal stability and to relieve pain (NICE 2008; White 1978; White 1990), however, from this review it can be concluded that there is no evidence to support this recommendation.

AUTHORS' CONCLUSIONS

Implications for practice

There is currently a lack of evidence regarding the effectiveness of spinal bracing for patients with MSCC. Further research and exploration of best practice in MSCC on positioning, bracing and spinal stability is required. Spinal bracing may improve comfort and quality of life for some patients but we are unable to make recommendations for practice based on this review.

Implications for research

Research to examine this topic needs to be undertaken to inform future practice. Randomised controlled trials to measure the efficacy of bracing would be possible. Descriptive and qualitative studies would be beneficial to clarify mobilisation and positioning from a physician, nursing and patient point of view.

ACKNOWLEDGEMENTS

We would like to thank Sheena Moffat, Information Services Advisor, Edinburgh Napier University, who refined and ran the search strategies for this review and the support of Jessica Thomas, Managing Editor, Cochrane Pain, Palliative and Supportive Care Review Group, UK.

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- * Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Chi 2009	This RCT did not address the specific outcomes of bracing and positioning specified within this review
Freundt 2010	Retrospective study
Furstenberg 2009	Retrospective clinical trial
Galasko 1991	Retrospective paper
Ippolito 1998	Retrospective study
Rades 2010	Review paper
Sciubba 2010	Commentary letter
Spinazze 2005	Review paper

DATA AND ANALYSES

This review has no analyses.

APPENDICES

Appendix 1. Search strategy

Search details
Database: MEDLINE (Ovid) (1950 - Week 4, January 2012)
1 Spinal Cord Compression/ (8856)
2 Spinal Neoplasms/ (10049)
3 (cord adj6 compress\$).mp. [mp=title, original title, abstract, name of substance word, subject heading word] (11700)
4 compress\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word] (92673)
5 (epidural or extradural or extra-dural or "spinal cord" or "dural sac" or "cauda equina" or "spinal column").mp. [mp=title, original title, abstract, name of substance word, subject heading word] (169137)
6 metast\$.mp. [mp=title, original title, abstract, name of substance word, subject heading word] (309497)
7 4 and 6 (2802)
8 5 and 7 (1542)
9 3 and 6 (1440)
10 1 and 6 (1004)
11 4 or 6 (399368)
12 2 and 11 (4564)
13 8 or 9 or 10 or 12 (5459)
14 randomized controlled trial.pt. (317022)
15 controlled clinical trial.pt. (83278)
16 randomized controlled trials/ (317022)
17 random allocation/ (72791)
18 double-blind method/ (112236)
19 single-blind method/ (15567)
20 14 or 15 or 16 or 17 or 18 or 19 (466167)
21 limit 20 to animal (50437)
22 limit 20 to human (425291)
23 21 and 22 (10855)
24 21 not 22 (39582)
25 20 not 24 (426585)
26 clinical trial.pt. (465272)
27 exp clinical trials/ (658195)
28 clin\$ with trial\$.tw. (1)
29 placebos/ (30346)
30 placebo\$.tw. (131982)
31 random\$.tw. (536852)
32 exp research design/ (291693)
33 26 or 27 or 28 or 29 or 30 or 31 or 32 (1109414)
34 limit 33 to animal (137432)

(Continued)

35 limit 33 to human (969521)
36 34 and 35 (36247)
37 34 not 36 (101185)
38 33 not 37 (1008229)
39 comparative study/ (1549101)
40 exp evaluation studies/ (158314)
41 follow-up studies/ (433321)
42 prospective studies/ (307204)
43 (control\$ or prospectiv\$ or volunteer\$).tw. (2410885)
44 39 or 40 or 41 or 42 or 43 (4045378)
45 limit 44 to animal (1185597)
46 limit 44 to human (2811222)
47 45 and 46 (268529)
48 45 not 47 (917068)
49 44 not 48 (3128310)
50 25 or 38 or 49 (3563872)
51 13 and 50 (1259)

Database: EBM Reviews - Cochrane Central Register of Controlled Trials (Ovid) (13th February 2012)

1 Spinal Cord Compression/ (176)
2 Spinal Neoplasms/ (53)
3 (cord adj6 compress\$).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword] (227)
4 compress\$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword] (4198)
5 (epidural or extradural or extra-dural or "spinal cord" or "dural sac" or "cauda equina" or "spinal column").mp. [mp=title, original title, abstract, mesh headings, heading words, keyword] (9043)
6 metast\$.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword] (11966)
7 4 and 6 (137)
8 5 and 7 (94)
9 3 and 6 (90)
10 1 and 6 (85)
11 4 or 6 (16027)
12 2 and 11 (36)
13 8 or 9 or 10 or 12 (118)

Database: EMBASE (Ovid) (1980 - Week 4, January 2012)

1 Spinal Cord Compression/ (10115)
2 Spinal Neoplasms/ (10648)
3 (cord adj6 compress\$).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (12916)
4 compress\$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (120236)
5 (epidural or extradural or extra-dural or "spinal cord" or "dural sac" or "cauda equina" or "spinal column").mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (204093)
6 metast\$.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer name] (410521)
7 4 and 6 (4386)
8 5 and 7 (2535)
9 3 and 6 (2282)
10 1 and 6 (1894)
11 4 or 6 (526371)
12 2 and 11 (3537)

(Continued)

- 13 8 or 9 or 10 or 12 (5610)
- 14 controlled-study.sh. (3681534)
- 15 crossover-procedure.sh. (31733)
- 16 double-blind-procedure.sh. (102763)
- 17 phase-3-clinical-trial.sh. (12924)
- 18 placebo\$.tw. (164540)
- 19 randomized-controlled-trial.sh. (296357)
- 20 single-blind-procedure.sh. (14735)
- 21 blind\$.tw. (215213)
- 22 comparative study.tw. (57320)
- 23 (control\$ adj1 trial\$).tw. (109556)
- 24 cross?over\$.tw. (40482)
- 25 factorial\$.tw. (17764)
- 26 random\$.tw. (679440)
- 27 or/14-26 (4206739)
- 28 human.sh. (12805189)
- 29 nonhuman.sh. (3780391)
- 30 28 and 29 (700996)
- 31 29 not 30 (3079395)
- 32 27 not 31 (2789445)
- 33 13 and 32 (489)
- Database: CINAHL (EBSCO) (1982 - January 2012)**
- 1 (MH "Spinal Cord Compression") (633)
- 2 (MH "Spinal Neoplasms") (797)
- 3 cord N6 compress* (0)
- 4 compress* (11478)
- 5 epidural or extradural or extra-dural or "spinal cord" or "dural sac" or "cauda equina" or "spinal column" (23972)
- 6 metast* (21071)
- 7 S4 and S6 (376)
- 8 S5 and S7 (285)
- 9 S3 and S6 (0)
- 10 S1 and S6 (133)
- 11 S4 or S6 (32173)
- 12 S2 and S11 (378)
- 13 S8 or S9 or S10 or S12 (577)
- 14 (MH "Random Assignment") (123)
- 15 (MH "Random Sample") (38)
- 16 (MH "Crossover Design") (34)
- 17 (MH "Clinical Trials+") (9473)
- 18 (MH "Comparative Studies") (217)
- 19 (MH "Control (Research)+") (60)
- 20 (MH "Factorial Design") (10)
- 21 (MH "Quasi-Experimental Studies") (37)
- 22 (MH "Nonrandomized Trials") (5)
- 23 (MH "Placebos") (655)
- 24 (MH "Meta Analysis") (827)
- 25 (MH "Clinical Nursing Research") or (MH "Clinical Research") (3081)
- 26 (MH "Community Trials") (9)
- 27 (MH "Experimental Studies") (306)

(Continued)

28 (MH "One-Shot Case Study") (6)
29 (MH "Pretest-Posttest Design") (13)
30 (MH "Solomon Four-Group Design") (2)
31 (MH "Static Group Comparison") (0)
32 (MH "Study Design") (2795)
33 (MH "Clinical Trials") (9188)
34 (MH "Systematic Review") (748)
35 TI random* (752)
36 TI singl* or doubl* or tripl* or trebl* (51229)
37 TI blind* or mask* (14161)
38 S36 and S37 (5962)
39 TI cross?over* or placebo* or control* or factorial or sham (518186)
40 TI clin* or intervention* or compar* or experiment* or preventive or therapeutic (736416)
41 TI trial* (42588)
42 S40 and S41 (29996)
43 TI counterbalance* or multiple baseline* or ABAB design* (526)
44 TI meta?analy* or systematic review* (26808)
45 S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35 or S38 or S39 or S42 or S43 or S44 (553687)
46 S13 and S45 (127)

HISTORY

Protocol first published: Issue 1, 2009

Review first published: Issue 3, 2012

CONTRIBUTIONS OF AUTHORS

Draft the protocol: MC, LK, CK

Develop a search strategy: MC, LK, CK, SM

Search for trials: MC, LK, CK, SHL, RG

Obtain copies of studies and updated search strategy February 2012: SHL

Select which studies to include: LK, CK, SHL, RG

Draft the final review: LK, CK, SHL, RG

Update the review: LK, CK, SHL, RG

DECLARATIONS OF INTEREST

None known

SOURCES OF SUPPORT

Internal sources

- Edinburgh Napier University, UK.
- NHS Lothian, UK.

External sources

- No sources of support supplied

INDEX TERMS

Medical Subject Headings (MeSH)

*Braces; Joint Instability [*therapy]; Pain Management [*methods]; Patient Positioning [*methods]; Spinal Cord Compression [*complications]; Spinal Neoplasms [secondary]; Spine

MeSH check words

Humans

