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Title: 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)

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.