The experience of caring of carers of cardiac surgery patients after hospital discharge

Wen Hsi Chiu

DECLARATION

I declare that this thesis is my own work and that no material contained in it

has been submitted for another academic award.

Wen Hsi Chiu

November 2011

Acknowledgements

Dedication

This thesis is dedicated to my parents Shao Chien Chiu and Fon Mei Lin as well

as my sister Wen Yen Chiu.

Abstract

Background：Advances in medical technology have led to increasing numbers of people undergoing heart surgery with decreasing hospital stay and decreasing mortality (Leske & Pelczynski, 1999). With patients being discharged home quicker and sicker than in the past, the immediate post discharge period is of concern to family carers (Theobald & McMurray, 2004). Much of the literature in this area, in fact, refers to Myocardial Infarction (Stewart, et al., 2001; Kristofferson, et al., 2007), with very little attention being paid to carers of cardiac surgery patients (Davies, 2000). In order to fill in this gap, it is important to understand the experience of carers of cardiac surgery patients following cardiac surgery after discharge.

Aim： The aim of this study was to explore the experience of carers of cardiac surgery patients following hospital discharge.

Methods： This study was conducted within the qualitative research paradigm using a phenomenological approach (Cohen, 1987). Purposive sampling was used and ten participants volunteered to join the study. Three weekly diaries and two semi-structured interviews [at 6 and 12 weeks] were used to collect the data. The Colazzi (1978) method will be used to guide the data analysis.

Findings: The findings revealed that the carers considered the experience of caring for their relatives to be a journey. This consisted of three phases, which were 'walking in the dark', where carers adopted a role for which they were not prepared; 'getting on with it' where carers were more in control; 'looking forward to the future' when life was back to normal. However, each participant's journey was

an individual experience and the changes they presented in the phases, seemed generic. There were three overarching themes: 'the changing nature of relationships', 'reassurance' and 'being there' these showed how they felt about their relatives, the help they needed and the reason why they cared. These themes were not evident episodically but rather continuously for all the participants. The essence of the journey was interpreted as a process of transformation and return in which carers moved from being a person to a carer to back to a person.

Conclusions: The results of this research revealed that carers lived a journey when looking after cardiac surgery patients. The essence of it was a process of transformation and return when carers moved from being a person to a carer and back to a person. It is essential for health care professionals to review discharge planning for these short term lay carers by being aware of their experiences to help prepare them to adopt their caring role.

Table of Content

List of Tables

List of Figures

Chapter 1

Chapter 1 Introduction and background

1.1 Introduction

The impetus for this research arose from working in a cardiothoracic unit in Taiwan for four years. In Taiwan, the health system and the cultural ethos of the people demand that the immediate family members provide most of the care for ill people. They are expected to look after their ill relatives at the bedside and help nurses with some care, for example, help with feeding if the patient is unable to manage themselves; nasal gastric (NG) feeding, changing position in bed or getting patients up; toileting or bed baths, while the patients are in hospital. Patients remain in hospital generally for 14 to 30 days until their wound is healed and they require no more professional intervention. Thereafter the care of these patients falls to the main family member, most commonly a husband or wife. However, if the patient is not married or is widowed then the daughter or a niece looks after them or when this is not possible a brother or sister looks after them. It became a matter of interest to understand how this sort of care is provided in a different country with different ideas and traditions.

1.2 The caring experience of Taiwan

In Taiwan lay carers have busy lives. Most of them are female and they look after the patient and their families at the same time. Generally, the carer stays in the hospital with the patient in case care is required. This care includes washing, toileting, feeding and keeping company. This means that carer's time is particularly devoted to caring for their sick relative. However, there are occasions when the carers will need to go home and carry out their duty at home; on these occasions other family members take over the caring role and will stay with patient. The more

mechanical aspects of care, for example, changing dressings, drug administration, and documentation is the preserve of the medical and nursing staff. They will also give instruction to carers in various aspects of care delivery. For example, how to feed the relatives, using an NG tube, enema, and bed bathing. Nurses tend to work with no other professional help so that the care provided by the carers is fundamental.

In Taiwan, the cardiac surgery patient usually stays in the hospital at least 2-3 weeks or sometimes longer. If patients are not fully mobile or unable to self care, they will not be discharged home. This means that most of the patients go home with healing wounds but no drains. Carers are usually worried about how to look after the patient since their disease is related to high blood pressure which is one of the causes normally being understood by the lay carers in Taiwan (it is a common conception to lay carers in Taiwan) (Hu, 2007) and so the carers feel that it is necessary to continue to monitor this for the rest of their lives. In order to do this they buy electronic blood pressure machines to check the patient's blood pressure every day. When one becomes a patient it follows that this status continues for the rest of their lives. This results also in the perpetuation of the reciprocal role and status of carer.

Most carers will look after the patient by themselves because Taiwanese families are nuclear with generally one or two children. There is little social care in Taiwan so assistance with care is provided only by the extended family or friends. Following this experience, it then became a matter of interest to explore and understand how this sort of care is provided in a different setting with different ideas and traditions

1.3 Background to the study

In the UK, Every six minutes someone dies from a heart attack and around 2.5 million people are living with coronary heart disease (CHD) (BHF, 2008). Heart disease is the leading cause of death in Scotland (NHS Scotland, 2009). The British Heart Foundation (BHF) offers the best indication of demographic information related to cardiac disease. In 2006, heart disease accounted for around 200,000 deaths. About half of these deaths are from CHD. The death rate from CHD for people living in Scotland is 65% higher than in England (BHF, 2008). Of the estimated 2.5 million people living with heart disease in the UK most of them will need different forms of treatment including heart surgery. The number of operations carried out to treat CHD has increased. In 2008, 27,000 operations for coronary artery bypass grafts (CABG) were carried out in the UK and 17600 of the same operation were carried out in Scotland (ISD Scotland, 2009). In UK, the number of coronary angiographies has increased from 15,819 in 2004/5 to 17,320 in 2005/6.The number of CABGs and coronary angioplasties performed by NHS Scotland has continued to rise from 7,376 in 2004/05 to 8,264 in 2005/06 (BHF, 2008). For the inpatient hospital cases, there were around 428,000 inpatient cases treated for CHD in National Health Service hospitals in 2006/2007 in England , and 49,000 in Scotland (BHF, 2008). This rising figure has huge implications for how these patients are cared for both in hospital and in the community in an era of dwindling resources.

Heart surgery has developed tremendously in recent years. Although a heart operation is major surgery, techniques have advanced so much that it is now

considered to be a routine operation (Hatchett & Thompson, 2007). As a result of this, most patients leave hospital about six or seven days after their operations. However, it usually takes two to three months to make a full recovery (Davies, 2000; Hatchett & Thompson, 2007). It is recommended by hospital staff that the patients should have someone with him or her in the first few weeks after hospital discharge (BHF, 2008). All patients received a copy of booklet to help them look after themselves when they were discharged (BHF, 2008).

It is clear when patients are discharged from hospital following surgery they will experience symptoms that cause functional impairment and necessitate assistance from a family carer (Artinian, 1991; Monahan et al., 1996; Goldsmith et al., 2006). For example, the patient might have a small leaking incision wound in the chest or in the leg, with which they need help to dress from a carer. Patients may also need help with bathing or turning in bed or to get up, putting the Thrombo Embolus Deterrent stockings (TEDs) on or putting their clothes on because of pain in the chest. The carers might also need to supervise the medication for the patient. These activities would in the past have been managed by health care professionals in hospital but with patients being looked after increasing earlier at home which results in lay carers having to take on these tasks without preparations.

Cost-containment efforts by the both UK and Scotland government have led to an increase in home care of ill individuals (Bolden & Wick, 2009). Because of the severity of the symptoms and the degree of functional impairment experience by patients following cardiac surgery, caring for those people may be associated with significant carer burden and which has been a concern which has been around for

nearly twenty years or more (Artinian, 1991; Halm et al., 2006). It is worth noting that these issues have been noted for over 20 years but they remained of significant concern today. In this latter sense, carer burden is said to arise when caring for someone takes up a significant amount of the carer's time, and can also result in absence from work, a limited social life and which, in turn, can lead to a sense of isolation on the part of the carer and, conceivably, something which must have an impact on the cared-for-person as well (Santavirta et al., 2001; Kären et al., 2004;Theobald & McMurray, 2004).

The cost of heart disease to the health care system in the UK is huge and is estimated to be around £14.4 billion pounds per annum (BHF, 2008). Significantly, hospital care accounts for almost 75% of these costs. But looking only at the costs of heart disease to the health care system underestimates the total cost to the nation. Heart disease also costs the UK economy over £16.3 billion a year because of days lost due to death, illness and informal care of people with the disease (BHF, 2008). In total heart disease costs the UK economy about £30.7 billion a year (BHF, 2008).

To date, research has shown that the provision of advice, information, and family support can have a positive impact on cardiac patients following discharge (Artinian, 1993; Astin et al., 2008). The development of a support group could help the carers and patients to cope after heart disease (Stewart et al., 2001). Nearly ten years ago they suggested that such groups could reduce the anxiety of the carers.

1.4 Policy Context

The ageing of Scotland's population is a particular challenge for health care. According to the Kerr report *Delivering for Health* (Scottish Executive, 2005), a response to this challenge has been the vision to setting a new policy agenda for NHS Scotland. This agenda includes:

- a fundamental shift in the way the NHS works, from a hospital-driven service to one that is community based
- a focus on meeting the challenges of an ageing population and the rising numbers of patients with long-term conditions like diabetes and asthma
- a concentration on preventing ill-health and treating people faster and closer to home
- a national e-Health programme to support service developments, with the creation of a single electronic health record (EHR) for each patient. (Scottish Executive, 2005, p.7)

In effect, the new approach and model developed is to have increasing levels of engagement with and support of and for carers, and to involve carers as partners in the community. According to the agenda, people with ill-health would be treated faster and closer to home; this might mean that there could be people who are in an acute condition and have been discharged early needing continuous care in the community. Though this does not refer directly to cardiac disease care, this still means that this view of carers will be carried over to this particular client group. The shifting balance of care may result in professionals and carers looking after people in sicker condition; it was unclear whether these lay carers would been trained to carry out these tasks. The Scottish Government acknowledges the significant contribution that carers make and it also acknowledges their expertise

and commitment in the provision of care. Although carers as partners in care is an underpinning principle of the policy (Scottish Government, 2007), if the true partnership is to come about, there needs to be a radical shift in the relationship between the professionals and carers where there is an inherent tension in term of the status and power imbalance. For example, the trained persons with the knowledge to the lay persons without any training however equalization between these two groups may be almost impossible to achieve. As already suggested this issue was raised twenty years ago and it still has not been solved.

In a report for Carers Scotland (2007), it was shown that around 20% of carers provided 50 or more hours of care per week for their families or friends in the community. However, these carers represent those who provide care for others on a long term basis rather than those who look after people who have a much shorter-term need, for example, those who have had heart surgery. Additionally, it is evident that not all carers have the necessary experience or expertise to address the full range of the cared-for person's needs (Matthrew, 2006). It is also true that many of whom may not have access to approach the skill training that they need by the health care professionals, such as nurses. Most of these lay carers do not know what they need to know before they find themselves in a caring role. According to Kennedy et al. (2008), nurses declare that they are client or patient-centred and that clients and their unpaid carers report positive experiences of community nursing services. However, Bauer et al. (2009) suggests that services continue to fail to provide an opportunity for users and carers to say what they want and need.

For the very first time in Scotland, the Carer (Recognition and Services) Act (1995) gives carers a right and entitlement to request an assessment of their support needs, as part of an overall assessment of the cared for person's needs (Scottish Executive, 2001). The *Strategy for Carers* in Scotland reported that all individuals who care for a relative, friend or neighbour should have an established set of rights (Scottish Government, 1999). These rights include a carer entitlement to social care, to work, free choice of employment, equal pay for equal work, to protection against unemployment, to rest and leisure, to have training and education, to access services and an entitlement to a standard of living adequate for health and wellbeing. However, Seddon et al. (2007) state their concern that carer assessments are not an established feature of practice in dementia care. They also assert that the Strategy for Carers (Scottish Government, 1999) suggests that the number of carer assessments remains low. One of the difficulties with the Carer Act (1995) is that just because they have been given an entitlement to an assessment of their needs that entitlement of carers to a separate assessment of their needs does not stretch to them being given access to services as a result of that assessment. For some this may be seen as an acknowledgement that carers do, indeed, have demands placed upon them and support needs as a result of fulfilling their roles as carers, however, it my leave them feeling frustrated because they may not be able to get access to the type and range of support that their assessment may identify. This is confirmed in Seddon et al's. (2007) study which reported that practitioners they talked to voiced concerns about completing carer assessments and they were careful to avoid raising carer expectations. Although the legislation entitles carers to services, practitioners remain reluctant to complete separate carer assessments. This, in sum, this would result in carers not being able to get the support or help that they

needed most and no better off as a result of this potentially progressive legislation. The Scottish Government is aware that with Scotland's ageing population the contribution of carers is set to grow over the coming years, it has committed to develop a new Strategy for Carers in Scotland during 2009 and early 2010. Clearly, this has greater impact on those who are looking after their relatives on a long term basis, however, this does not deny that even those who are responding to the acute needs of relatives may not have the same right and may need financial support during this time. It is important to note that those rights and services have been aimed at long-term carers however it is vital that the service provided for short-term carers is not ignored.

Supporting the caring relationship can lead to improved physical and mental health for both carers and patients. Health promotion for carers is critical just as it is for patients. Supporting carers helps empower them in their caring role, reduces the impact of this activity on their own health and often enables them to care for longer than otherwise might be the case with the resultant benefits that brings both to the carer and the patient. It is important to note that many of those carers are often in an older age group. To date, and although the government emphasizes the importance of supporting carers, in 2010 it is reported that the main carers' benefit is worth just £1.52 an hour, well short of the minimum wage of £5.73 (Carers Scotland, 2010). The government has invested in carers' breaks and other support for carers. But this is said to fall far short of the action needed now (Carers Scotland, 2010). Carers are still ignorant of what they can apply for service both professional and financial from the government and their rights attached to their role. However and still a matter of concern is that the investment is designed for those carers who care for people with long term illness. Short term carers are

omitted from the policies, which creates a gap between these carers, health care professionals and policies and their needs for support and may result in the provision of inadequate support for them. For this reason, it is important to understand the role and experiences of these carers from their perspectives.

1.5 Rationale for the study

The average length of stay in hospital for patients suffering from cardiac disease and requiring surgery is 5.7 days (NHS Scotland, 2009). As a result of the introduction of keyhole techniques, this has been further reduced to an average of 3.2 days (ISD Scotland, 2009). Advances in medical technology have led to increasing numbers of people undergoing heart surgery with decreasing hospital stay and decreasing mortality.

Although individuals with cardiac disease are living longer because of treatment, which results in the prolongation of the strains of carers are rising (Scottish Government, 2007). With patients being discharged home 'quicker and sicker' than in the past, the immediate post discharge period is of concern to family carers (Tierney et al., 1993). Much of the literature in this area, in fact, refers to Myocardial Infraction (Stewart, et al., 2001; Kristofferson, et al., 2005; Kristofferson, et al., 2007) and unspecified cardiac events for patients (Wang, et al., 2008), with very little attention being paid to carers of cardiac surgery patients.

In the early twentieth century, 80% of the care of dependent people in Europe was provided by carers in the community (Walker, 1995). For nearly 20 years this has been well understood, however, despite the growing need for care at home, services remain poorly developed (Twigg & Atkin, 1994; Nolan, et al., 1996). In

order to fill in this gap, the Strategy for Carers was first introduced in 1999 in UK and later that year in Scotland, which provides carers with a right to an assessment of this needs and a mechanism to voice these. However, this appears to have had relatively little impact with a number of recent studies indicating that many carers are not aware of their rights and receives minimal information and advice, and are often poorly prepared for their role when caring for their relative (Davies, 2000; Knoll & Johnson, 2000; Robinson et al., 2009).

1.6 The Structure of the thesis

The thesis is presented in 8 chapters starting in Chapter 2 with a Literature Review which covers the background and underpinning concepts of the research. In Chapter 3, the Research Design will be outlined and discussed along with the rationale for the methods of data collection and the analysis. This is followed by Chapter 4 in which the Life Histories of the individual participants are provided. Chapter 5 gives the Findings which are presented in a series of intersecting themes and sub-themes. Chapter 6 contains a Discussion of the themes and sub-themes. This leads to Chapter 7 which contains the Conclusions of the research and then finally in Chapter 8 the Recommendations arising from the result are presented for policy, practice and future research.

Chapter 2

Chapter 2 Literature Review

2.1 Introduction

This chapter comprises a review of literature published on the subject of community caregiving experience for relatives of cardiac surgery patients following hospital discharge. An account is given of the search strategy, search results, inclusion and exclusion criteria, and method for the conduct of review. In surveying and selecting literature the researcher's general intention was to obtain detailed information in two areas:

1) caregiver burden

2) discharge planning.

Empirical evidence in these areas underlined the impact of caring, the appropriateness of support carers received, and the correlation between the amount and level of support offered, and the variable thoroughness of care possible in the home setting.

2.2 Search method

When contextualizing this study, it was necessary to clarify, amongst the broad areas mentioned above, particular subsidiary areas of interest within the literature. These included the specific caring practices of carers, and the consequences for them of committing to the caring process. Literature was reviewed using various search engines and databases including: MEDLINE, CINAHL, PsycINFO, and British Nursing Index. Keywords were used and a strategy consisting of Medical Subject Headings and text words was applied for each of the key terms. These key terms were carers, caregivers, family carers, discharge planning, after care,

patient discharge, thoracic surgery, coronary artery bypass, cardiopulmonary bypass, heart surgery, cardiac surgery, caregiver support, carers' support, information support, financial support, social support. (Tables 1 to 4). The search results are presented following the inclusion and exclusion criteria.

2.2.1 The inclusion criteria

This review identifies published prospective and retrospective studies written in English evaluating the experience of caring for cardiac surgery patients from 1990 to 2010. Studies included adult (aged 19 and over) carers of either sex who fit the profile of 'significant other' in relation to the patient. Cardiac surgery includes interventions, such as valve replacement, heart transplantation and coronary artery bypass graft (CABG). Focus on key terms indicated that the above-mentioned investigations tended to focus on two major issues: caregiver burden and discharge planning.

The earliest conception of caregiver burden was proposed four decades ago in a study published by Grad and Sainsbury (1966). Grad and Sainsbury (1966) investigated the consequences of discharging mentally ill patients from institutions and placing them in the community. Their definition of caring was accepted from the 1980s onwards. Subsequent to this most caregiving studies focused on two fundamental research articles: the first, published by Zarit, Reever and Bach-Peterson (1980) investigated the issue of burden in family carers of individuals with dementia; the second, which was published by Montgomery, Gonyea and Hooyman (1985) studied caregiving and the experience of subjective burden and objective burden on family members who cared for or assisted an elderly relative.

Although these two articles focused on caregiver burden, both did so from the perspective of family carers of dementia sufferers. It is conceivable that the burden experienced by carers in such cases – cases of long duration, often characterised by the gradual and terminal deterioration of the cared for person – is significantly different from the burden experienced by family carers of cardiac patients post discharge. It was therefore considered important that the literature review for the present study aimed to analyse the most current information, beginning with studies published in 1990. It includes work in English, embracing original research and papers as well as books which relate to the caregiving experience, and the impact of caregiving on carers.

2.2.2 The exclusion criteria

All non-English language material, non-primary research, single case studies and studies carried out before 1990 fell outside the remit of this review. Studies of carers aged under 19 were also excluded. The experience of caring for family carers under nineteen is likely to be significantly different from that studied in circumstances in which spouses or siblings fulfil the caregiving role. Studies of carers diagnosed with mental health conditions were also excluded; it was considered that the experience of caring in such cases would profoundly impact on the mental health status of the carer, and that studies of such experience would thus be idiosyncratic and unrepresentative.

2.3 Search strategy

The search strategies are represented in Tables 1 to 4. The following search methods were used:

1. electronic searches of MEDLINE (1990-2010), CINAHL (1990-2010) and PsycINFO (1990-2010), British Nursing Index (1985-2010);

2. hand search of a relevant journal – Heart & Lung: the journal of acute and critical care (1990-2010);

3. conference proceedings relevant to carers of cardiac surgery patients – Proceedings of the British Heart Foundation;

4. reference lists from relevant studies and reviews;

5. personal contact with other research workers in this field;

6. policies regarding carers from the Scottish Government, Carers Scotland and Department of Health in the UK.

Table 1: Showing the MEDLINE Search Strategy and its results (from last to first)

S20	(((MM "Caregivers") or (MM "Caregiver Support")) or carer* or ((MM "Information Needs") and (MM "Thoracic Surgery")) or (MM "Coronary Artery Bypass+") or heart bypass or Coronary Artery Bypass or cardiac surgery or heart surgery) and ((MM "Discharge Planning") or (MM "Patient Discharge") or discharge*))
S19	(((MM "Caregivers") or (MM "Caregiver Support")) or carer* or (MH "Information Needs")) and (((MM "Thoracic Surgery") or (MM "Coronary Artery Bypass+") or (heart bypass or Coronary Artery Bypass or cardiac surgery) and (((MM "Discharge Planning") or (MH "Patient Discharge") or discharge*))
S18	((MM "Caregivers") and (MM "Thoracic Surgery")) and ((MM "Coronary Artery Bypass") and (MM "Financial Support") or (MM "Social Support"))
S17	((MM "Caregivers") and (MM "Financial Support") or (MM "Social Support")) and (((MM "Caregivers") and (((MM "Thoracic Surgery") or (MM "Coronary Artery Bypass")))) and (MM "Caregivers") and ((MM "Financial Support") or (MM "Social Support")))
S16	(MM "Caregivers") and ((MM "Financial Support") or (MM "Social Support"))
S15	(MM "Caregivers") and ((MM "Thoracic Surgery") or (MM "Coronary Artery Bypass"))
S14	(MM "Caregivers") and ((MM "Patient Discharge") and ((MM "Thoracic Surgery") or ((MM "Coronary Artery Bypass")))
S13	(MM "Caregivers") or (MM "Coronary Artery Bypass")
S12	(MM "Financial Support") or (MM "Social Support")
S11	(MM "Patient Discharge")
S10	(MM "Discharge Planning")
S9	(MM "Coronary Artery Bypass")
S9	(MM "Thoracic Surgery")
S8	heart surgery
S7	cardiac surgery
S6	Coronary Artery Bypass
S5	heart bypass
S4	(MM "Caregiver Support")
S3	carer*
S2	(MH "Information Needs")
S1	(MM "Caregivers")

Total number of studies for carers=9509

Total number of studies for support=13130

Total number of studies for cardiac surgery=31310

Total number of studies for recovery period=6394

Total number of studies for carers, support, cardiac surgery and recovery =119

Table 2 Showing the CINAHL Search Strategy and its results (from last to first)

S19	(((MH "Caregivers") or (MH "Caregiver Support")) or carer* or ((MH "Support, Psychosocial+") or (MH "Psychosocial Aspects of Illness")) or (MH "Information Needs")) and (((MM "Thoracic Surgery") or (MM "Cardiopulmonary Bypass") or (MM "Coronary Artery Bypass+") or (MM "Coronary Artery Bypass, Off-Pump") or heart bypass or Coronary Artery Bypass or cardiac surgery or heart surgery) and (((MH "Discharge Planning") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") or (MH "Patient Discharge") or (MH "After Care")) or discharge*))
S18	(((MH "Caregivers") or (MH "Caregiver Support")) or carer* or ((MH "Support, Psychosocial+") or (MH "Psychosocial Aspects of Illness")) or (MH "Information Needs")) and (((MM "Thoracic Surgery") or (MM "Cardiopulmonary Bypass") or (MM "Coronary Artery Bypass+") or (MM "Coronary Artery Bypass, Off-Pump") or heart bypass or Coronary Artery Bypass or cardiac surgery or heart surgery) and (((MH "Discharge Planning") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") or (MH "Patient Discharge") or (MH "After Care")) or discharge*))
S17	((MM "Thoracic Surgery") or (MM "Cardiopulmonary Bypass") or (MM "Coronary Artery Bypass+") or (MM "Coronary Artery Bypass, Off-Pump") or heart bypass or Coronary Artery Bypass or cardiac surgery or heart surgery) and (((MH "Discharge Planning") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") or (MH "Patient Discharge") or (MH "After Care")) or discharge*
S16	((MH "Caregivers") or (MH "Caregiver Support")) or carer* or ((MH "Support, Psychosocial+") or (MH "Psychosocial Aspects of Illness")) or (MH "Information Needs")
S15	(MH "Information Needs")
S14	(MH "Support, Psychosocial+") or (MH "Psychosocial Aspects of Illness")
S13	carer*
S12	(MH "Caregivers") or (MH "Caregiver Support")
S11	((MH "Discharge Planning") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") or (MH "Patient Discharge") or (MH "After Care")) or discharge*
S10	discharge*
S9	(MH "Discharge Planning") or (MH "Early Patient Discharge") or (MH "Patient Discharge Education") or (MH "Patient Discharge") or (MH "After Care")
S8	(MM "Thoracic Surgery") or (MM "Cardiopulmonary Bypass") or (MM "Coronary Artery Bypass+") or (MM "Coronary Artery Bypass, Off-Pump") or heart bypass or Coronary Artery Bypass or cardiac surgery or heart surgery
S7	heart surgery
S6	cardiac surgery
S5	Coronary Artery Bypass
S4	heart bypass
S3	(MM "Coronary Artery Bypass+") or (MM "Coronary Artery Bypass, Off-Pump")
S2	(MM "Cardiopulmonary Bypass")
S1	(MM "Thoracic Surgery")

Total number of studies for carers=14752

Total number of studies for support=26085

Total number of studies for cardiac surgery=12699

Total number of studies for recovery period=8621

Total number of studies for carers, support, cardiac surgery and recovery =64

Table 3 Showing the British Nursing Index Search Strategy and its results (from last to first)

S20	(support or support needs) and ((carer* or caregiver* or informal carer* or family carers) and ((discharge planning or after care or Patient discharge or recovery) and (cardiac surgery or heart surgery or Thoracic Surgery or Coronary Artery Bypass)))
S19	(carer* or caregiver* or informal carer* or family carers) and ((discharge planning or after care or Patient discharge or recovery) and (cardiac surgery or heart surgery or Thoracic Surgery or Coronary Artery Bypass))
S18	cardiac surgery or heart surgery or Thoracic Surgery or Coronary Artery Bypass
S17	discharge planning or after care or Patient discharge or recovery
S16	carer* or caregiver* or informal carer* or family carers
S15	recovery
S14	Patient discharge
S13	after care
S12	discharge planning
S11	Coronary Artery Bypass
S10	Thoracic Surgery
S9	heart surgery
S8	cardiac surgery
S7	support or support needs
S6	support needs
S5	support
S4	family carers
S3	informal carer*
S2	caregiver*
S1	carer*

Total number of studies for carers=3716

Total number of studies for support=7739

Total number of studies for cardiac surgery=339

Total number of studies for recovery period=57607

Total number of studies for carers, support, cardiac surgery and recovery =1

Table 4 Showing the PsycINFO Search Strategy and its results (from last to first)

S11	((MM "Heart Surgery") or (MM "Heart Disorders")) and ((MM "Home Care") and ((carer* or (MM "Family Relations") or caregiver*) and ((MM "Heart Surgery") or (MM "Heart Disorders")))
S10	(MM "Heart Surgery") or (MM "Heart Disorders")
S9	carer* or (MM "Family Relations") or caregiver*
S8	caregiver*
S7	MM "Caregiver Burden" or MM "Caregivers"
S6	MM "Home Care"
S5	MM "Heart Disorders"
S4	MM "Heart Surgery"
S3	MM "Social Support" or MM "Needs"
S2	MM "Family Relations"
S1	carer*

Total number of studies for carers=47310

Total number of studies for support=19797

Total number of studies for cardiac surgery=4735

Total number of studies for recovery period=2541

Total number of studies for carers, support, cardiac surgery and recovery =5

2.3.1   Results of Search Strategy and Critical Review of the articles

The attempt in the critical appraisal of a research paper article is to determine whether or not the research was undertaken systematically. It is vital to determine how closely it matches this review's inclusion criteria and then assess the quality of the work when determining whether a study is appropriate to be included in a review (Aveyard, 2007). Most researchers recommend the use of a specific tool in order to develop a consistent approach to the critique of research and other information (Oxman, 1994). It has been noted that there are several tools available to assess the quality and content of articles. However, these tools may give widely differing results (Burns & Grove, 2005). Burns & Grove (2005) highlighted the importance of key qualities - aspects specifically related to the topic in question.

Pinch (1995) detailed a number of specific categories to facilitate general review of the quality and content of articles; they were as follows:

1. Author and year

2. Country

3. Designs

4. Sample and setting

5. Data collection method

6. Framework used

7. Results

However, these categories are, of themselves, not sufficient to facilitate systematic reading and critiquing of sources in order to develop a high quality literature review, or a review which would provide an adequate or robust critique of the literature. Therefore, Burns & Grove (2005) produced a modified table based on Pinch (1995) which reviewers could adopt for critiquing research articles. Burns & Grove (2005) added two columns – purpose and comments which is useful in sorting information for analysis. Although these categories added more precision, they were based around the critiquing of quantitative research articles. Russell and Gregory (2003) used a seven categories model to examine qualitative research. They proposed criteria for appraising qualitative research using these categories:

1.   clear research questions

2.   appropriate design to answer the research questions

3.   sampling method was fitting for the research design and questions

4.   the data collection was managed systematically

5.   the data was analysed appropriately

6.   the richness of the research findings

7.   how the research findings could be applied to the practice

These categories were in keeping with the world view and paradigm from which qualitative research arose and reflects whether the research contains the best standards for qualitative research. For the purposes of the current study, it was decided to combine the modified model of Pinch (1995), Burns and Grove (2005) and Russell and Gregory (2003) to skim, comprehend, analyse and synthesize sources of information from qualitative and quantitative research to review the articles. These categorises used for literature review included:

1. Authors, year and country

2. Purpose of study/ Research questions

3. Sample and setting

4. Design/ Data collection method

5. Framework use

6. Findings and results

7. Comments

A reviewing table of articles is shown in the Appendix XI. The researcher used these categories to review the validity and rigour of each article. Following these criteria, it was possible to compare, contrast and present an array of studies across the methodological spectrum.

At the first stage of the data collection process, an effort was made to incorporate different perspectives on the phenomena of caregiver burden and discharge planning in order to collect a valid and multidimensional body of information. Fifty-two articles met the initial qualifications for this literature review. These were retrieved from the above mentioned professional databases and contained one or more key search terms. However, after reviewing the inclusion criteria for those pieces of research, three articles (Aston, 2010; Paez and Allen, 2006; Taylor, 2010) were excluded. The reason for exclusion was that none of the three studies

specified caring experience or discharge planning in the population of coronary surgery patients and their family care providers.

Among the forty-nine articles left, six - Colella and King (2004), Johnson, Chaboyer, et al.(2001), Jurgens, et al.(2007), Saunders (2003), Usher and Cammarata (2009), and Whittingham (2009) - were identified as literature reviews. They were integrated into the present literature review as a means of tracking the major trends in research on caregiver burden and discharge planning.

Articles by Perry, et al.(2006), Phillips et al. (2009) and Tsukasaki et al. (2006) addressed the phenomenon of caregiver burden in Canada, the UK and Japan, respectively, without specifically alluding to the needs of coronary surgery patients and their carers. They were nonetheless retained in the present literature review as reference points to the general concept of caregiver burden and stress.

Hunt, et al. (2000) interrogated the caregivers of coronary artery bypass graft (CABG) surgery patients in Melbourne, Australia, concerning their perceived quality of life, but the issue of caregiver burden was not directly addressed. Finally, articles by Blount, et al. (2006), Naylor and McCauley (1999) and Naylor (2000) described real-life intervention programmes aimed at training care providers who deal with cardiac patients. These studies, which were conducted in the United States, were analysed for a basic understanding of potential collaborations between formal and informal carers of cardiac patients post discharge. While the studies published by Naylor and McCauley (1999) and Naylor (2000) yielded detailed commentary, the study by Blount, et al. (2006) was not commented on in detail, since its primary focus was the needs of formal care practitioners – an area not directly relevant to the present study.

Of thirty-six further articles, four - Barnes et al., (2006); Davies, (2000); Molloy et al., (2008); Naughton, et al., (2005) - were conducted in Great Britain; three - Ågren et al., (2009); Ågren, et al. , (2010); Brännström, et al., (2007) - referred to the care-giving experience in Sweden, and ten - Bull, et al. (2000); Canning, et al., (1996); Dew et al., (2004); Dougherty and Thompson, (2009); Halm, et al. (2007); Kneeshaw, et al , (1999); Lenz and Perkins, (2000); Leske and Pelczynski, (1999); Proctor, et al. (1996); Saunders, (2009), and Scott, (2000) – focused on similar issues in United States health care settings. Other investigations addressed such concerns in Australia (Mohan, et al. , 2006-2007), Canada (King & Koop, 1999); Knoll and Johnson, (2000); Lapum, et al. , (2010); O'Farrell, et al. , (2000), and Finland (Rantanen, et al. , (2004); Rantanen et al., (2008); Rantanen et al., (2009). Drawing on studies from such a wide geographical range enabled the researcher to trace variations in cultural and socio-economic factors affecting family carers of cardiac patients both inside and outside hospitals.

2.4 The context of Caring

Every individual may, at some stage in their life, either require care, or be called upon to provide care for another person. Much literature presents caring as a difficult concept to define (McCance, et al., 1997) often defining that concept by reference to the context in which it arises. Caring situations may be a natural aspect of a professional setting, as is the case for nurses, or they may be thrust upon untrained individuals obliged to respond to expedient developments within the family or social circle in domestic settings. In such situations the concept of caring may be crucially affected by the way in which the individuals involved perceive that situation and their place within it. Caregiving within the family

frequently presents physical, mental and emotional challenges which this researcher believes warrant deeper and more sympathetic understanding if the situation both for the patient and the family carer is to be improved.

'Caring' has been defined as "…doing things for people that they cannot do for themselves" (Twigg & Atkin, 1994, p.8). Morse et al. (1990) analysed 35 such definitions derived in studies of the caregiving experience from the perspective of nurses. Employing qualitative content analysis, Morse et al. (1990) identified five main categories of caring: caring defined as a human trait, a moral imperative or ideal, an affect, an interpersonal relationship and a therapeutic intervention. In summary they represent the concept of caring as comprising the patient's subjective experience, or as a physical response to the patient. Another analysis of caring is offered by McCance et al. (1997). McCance et al. (1997) sought to arrive at a summation of caregiving by cross referencing a diverse range of definitions, including dictionary definitions, and theoretical definitions developed in various literary resources and studies of caring. Their findings encompassed typical characteristics and antecedents of the concept of caring. The characteristics they defined included 'serious attention', 'concern', 'providing for', and 'getting to know the patient'. Antecedents of caring were identified as 'respect for the person', 'intention to care', and consideration of 'time involved'. The tenor of these findings seems to emphasise caregiving primarily as 'doing things for people', and meeting the needs of the individual. On the basis of such a definition it seems reasonable to speak of caregiving as an activity which is not solely identified with the nursing situation, but which must include clear consideration of the lay/family carer in the domestic setting.

Brilowski and Wendler (2005) analysed 61 articles in nursing and identified five core attributes of caring: relationship, action, attitude, acceptance and variability. In addition they identified factors such as trust, rapport, understanding of self and others, and commitment as the necessary antecedents to caregiving. Ultimately, they defined the consequences of caring as an increased ability to ameliorate the need for patients and an increased sense of personal and professional satisfaction for the nurses. This emphasises that the context of caring is a key factor in caregiving. Aside from context, caregiving may be viewed as comprising practical help carried out by one individual for the sake of another regardless either of the effects on the person cared for, or on the care.

As a consequence of the improvements in surgical techniques and medical treatment, people with disease are surviving more often and enjoying longer lives. At the same time the rising cost of hospital care necessitates speedier discharge after hospitalization (Hatchett & Thompson, 2007). This provides a new focus for caring and caregiving. There is an expectation that the frail will be cared for predominantly in the home, not by health care professionals, but by an individual who is usually a family member who has no professional training (Theobald and McMurray, 2004; Barodawala, 1996). The general concept of caregiving presupposes three important elements: the carers, the type of care demanded and the time spent providing care, with an understanding that older people were in residential care and this is changing to being looked after in their own homes and when this is no longer tenable they are moved into nursing homes. Although the early literature provided a valuable view of caring from the point of view of the health care professionals, the experience of caring by the family carers remains to be seen.

2.5 Carers and caregiving responsibilities

2.5.1 Carers

In the literature, 'carer' and 'caregiver' are terms used interchangeably to describe individuals who look after their relatives or indeed other individuals. Additional titles – 'unpaid carer', 'informal carer', 'lay carer' and 'primary carer - tend to be determined by differing interpretations of the family carer's role. In the Care 21 report (2005), family carers are defined as "Individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system" (p.4). The Princess Royal Trust for Carers Centre (2009) defined a carer as an individual of any age providing unpaid support to family or friends incapable of managing without such support. The report additionally suggests that the cared-for person in such circumstances is likely to be ill, frail, disabled or subject to mental health or substance abuse problems. In a recent report entitled 'Caring Together' The Carers Strategy for Scotland (2010) defined an individual who cares for another person without taking payment as an 'unpaid carer' or simply a 'carer'. This mirrors the view of Wiles (2003) who conducted thirty interviews with informal carers regarding their experiences of caring for a frail, ill, or disabled elderly person at home. Such individuals rarely have any formal training; most lay carers will fall into this category. Such definitions, however, are limited in their usefulness because they suggest little of the complexity of the caregiving relationship. In addition, the literature seems to neglect the important point that caregiving is not necessarily provided by the carers alone, but it is also facilitated by professionals or organizations. Publication of the recent policy document 'Caring Together: The Carers Strategy for Scotland' (2010) reinforces this point, stating that its aim is to change how services and

support are planned and delivered in co-operation with the local authorities or other organizations, and to take forward action which will benefit carers now and in the future.

Scott (2000) published a descriptive, exploratory study involving 20 end-stage heart failure patients and 18 family caregivers; the study describes a carer as "the person who has total responsibility for the physical, emotional, and technical care" (p. 85) of an individual with health problems. For the benefit of this definition, family carers are generally defined as being "unpaid relatives or friends who support people with disabilities" (Ågren, et al., 2010, p. 254). The type of support provided by such carers is dubbed 'informal' referring to help delivered outside medical establishments in community settings by untrained individuals.

For the purposes of this study, the researcher adopted a theoretical definition of carers. This was a family member without formal training providing care and assistance in order to meet a relative's needs in the community. The Scottish Households Survey (2007/2008), offers findings which suggest that family carers are found in a broad cross-section of age groups, and that individuals of adult age (ie 18 or over) predominate but that women are more likely to be carers than men,. For this reason, adults who cared for a relative were incorporated in this study.

2.5.2 Caregiving, caregiving responsibilities and caregiving experience

It is estimated that there are 6.8 million carers across the UK and 657,300 carers in Scotland (Scottish Household Survey (SHS) 2007/2008). This approximates to about 13%, or 1 in 8, of the population. The Care 21 Report offers similar findings, with a figure of 668,200 unpaid carers in Scotland (SHS, 2001/2002), which again

approximates to 1 in 8 of the population (p.80). A further report (Scottish Government, 2010) stipulates within this percentage one carer devoting at least twenty hours per week or more to caring. The Census (2001) analysed the caring population in Scotland and reported 23% of carers with caring responsibilities taking approximating over 50 hours per week. Such figures acquire added significance in light of findings published by Henwood (1998) in which it was reported that three quarters of carers received no regular formal help with caring. The implications of these statistics are clear; there is a significant proportion of informal carers confronted with the burden of caring for a family member without any formal assistance. The financial and personal cost as well as and the implications for their own health cannot be ignored (Henwood, 1998). This point deserves closer consideration. The gravity of such findings is underlined by evidence that not all carers have the necessary experience or expertise to address the full range of their relative's needs, and or have had previous negative experiences of formal care provision (Cheung & Hocking, 2004). It is certainly true that many of the carers who might be defined as family carers have nothing approaching the skill-set required in trained professionals, such as nurses. This is the reason that the issue of family caregiving should be informed by an understanding of burden as a central part of the caregiving experience.

The Carer (Recognition and Services) Act 1995 stipulates that carers have a right to address their own health and social care needs. 'Partnership for Care', the Scottish Executive White Paper on Health (2003), recognises the necessity of expert knowledge in the provision of care, and identifies the importance of proper resources for supporting and advising carers. These documents represent some formal recognition of the seriousness of the issue of caring for carers.

In addition, 'Caring Together': The Carers Strategy for Scotland (2010) aims to ensure that the voice of carers is heard, believing that this is the key driver for further change and improvements in healthcare. Their further aim is to ensure that patients and carers have clear instructions and information about care, specifically treatment and symptoms, acknowledging the full involvement of such individuals in treatment choices. The Strategy places a clear emphasis on regarding lay carers as the equal partners of professional carers, with expert knowledge and experience especially of the person they care for. Findings of a study conducted by Seddon et al. (2009) highlighted a disparity between the obligations and duties, of necessity, confronted by family carers, and the availability and types of support provided for such carers in their everyday experiences. The study indicated specifically that carers are ill informed regarding their legal rights – the fact, for instance, that they are entitled to a care assessment – and are largely unaware of how these rights apply to their individual circumstances. This again suggests that an understanding of the true scope and importance of carer experience is an urgent need.

Traditionally, informal caregiving responsibilities are delegated to the closest relatives of patients, predominantly spouses. There is a corpus of research (Ågren et al., 2010; Hunt et al. 2000; O'Farrell et al. 2000) investigating the specifics of caregiving duties performed by the spouses of sick people. These caregiving duties included monitoring the patient's progress, helping them with their tasks of daily living such as cooking, shopping and washing. Two studies in particular (Ågren et al. 2010; Dougherty and Thompson, 2009) stress the contribution of unmarried intimate partners in this respect. This inclusion emphasises the relevance of intimacy and trust, as well as legal matrimonial obligation and loyalty,

to the quality of the caregiving relationship. However, these studies predominately used a quantitative research approach. A number of these studies were only trying to identify who carers were and who they cared for and were not interested in their experience because only by knowing who they were would researchers be able to know where they could get their samples from to find out about the experience of being a carer. This could be considered to result in a static view of what is generally regarded as a superficial understanding of the carer's experience. For example, Nolan et al. (1996) has already pointed out that this is a direct criticism and a gap in the literature. However, the recent work from other researchers have not filled in this gap.

King and Koop (1999) conducted a prospective, non-randomized research study focusing on the contribution of female relatives in caregiving. This study was based on the common supposition that care of the sick is traditionally provided by women. The authors interviewed 120 cardiac surgery patients (and 60 carers) prior to procedure, and at subsequent at monthly intervals over a period of three months in order to investigate the putative correlation between care provision and the gender of patient and carer. It was found that married men expected to obtain support during the rehabilitation period from their wives, while married women preferred to refer to use the help of daughters, daughters-in-law, female friends or nurses. Of course this could be explained by the fact that it is possible that some of these men were in work and so it was important to continue with work to maintain an income while getting others to provide more of the ongoing help required. The findings thus tend to confirm a preconception that care provision is better delivered by females. Women are thought to be more attentive to the needs of sick people, and more responsive and diligent in coping with multiple caring

assignments. Halm et al. (2007) created a study employing a cross-sectional descriptive comparative design questioning 166 spouses of elderly patients during the first year after coronary artery bypass (CAB) surgery. Their findings include the observation that males are rarely perceived as natural carers in contemporary societies; their spouses, intimate partners, relatives and friends are disinclined to rely upon them fully in caregiving activities. This is of interest in light of the fact that there are increasing numbers of men who are acting as 'house husbands' providing all the day to day care of children, as well as houses. Halm et al. (2007) suggest that it is paradoxically partly in response to this biased view that men tend to underrate their own abilities as carers, and are unprepared to fulfil the caregiving role. They draw attention, however, to notable exceptions in the cases of male spouses or partners caring for wives suffering from dementia.

It is possible that the above-mentioned preconceptions regarding gender roles amongst family carers may stem from consideration of the wide range of chores for which the carer is responsible, and the necessity of managing this range of duties concurrently – requiring multi-tasking skills which, in many areas of Western culture, are stereotypically associated with the female disposition. The very challenging nature of this burden in the cases of lay carers of cardiac patients is underlined in a phenomenological-hermeneutic study created by Brännström et al. (2007). In narrative interviews of the wife who provided care for her post-operative chronic heart failure (CHF) spouse over 4.5 years, the caregiving experience is described as follows:

"It is like being a fellow passenger in the roller coaster ride that is their loved one's disease, with burdening responsibility for easing the downs and supporting the ups. This means being on primary call, always on standby to mediate security and

pleasure, i.e. to balance activity and rest, to assist with activities of daily living, medical treatment and technical devices." (p. 342). In this research, Brännström et al. (2007) describe the experience of caring by a couple responding to unpredictable illness resulting in the integrating of it into life, while enduring suffering and enjoying life. This finding should be treated with caution because it is a single case study, however it is longitudinal since it carried on for over 4 years. . However, the idea of 'integrating illness into life,' includes: living life as it has become; adapting to fatigue while struggling against it – the wife had to deal with striving to keep a check on the failing heart. However there were positive elements in her life because she found meaning in togetherness with her spouse, others, and God. This couple provided useful insights into the process of caring that shapes and determines care in people with chronic heart failure. It should be noted that chronic heart failure might be deemed to fall into realm of long term care and so only partially represents the short term carer's view. However, those who have undergone cardiac surgery or have been admitted to hospital for any reason associated with cardiac dysfunction are especially vulnerable at the point of discharge, moving from a situation of high dependency on medical technology to one in which the assurance of such need-specific and scientifically calculated support is likely to be drastically reduced, if not removed altogether. This crucial point is stressed in a report issued by Proctor, et al.(1996); "individuals generally leave the hospital at a lower level of functioning than that before hospitalization, thereby requiring assistance with medical treatment and activities of daily living" (par. 3, lines 1-3, p32). Poor physical and psychological health at discharge leads to a situation in which patients become dependent on "significant others" (Rantanen et al. 2004, p. 159) in almost every sphere of life: meals, toileting, treatment, recreation and emotional wellbeing. However, the literature on

caregiving has a predominant focus on the burdens and difficulties of carers looking after dementia sufferers or those with physical and or mental disabilities (Kahana and Young, 1990), as opposed to carers who might care for patients with acute conditions.

Scott (2000) delineated several strands of carer responsibility. These include: monitoring and technological assistance, meeting the physical needs of the care recipient, and the provision of psychological and emotional support. Similar classification of caregiving activities can be found in other studies; Knoll and Johnson (2000), for example, presented conceptualisations of the family carer's roles and responsibilities in a qualitative interpretive study of eight husband-wife dyads involved in the aftermath of cardiac surgery. In their analysis of the participants' narratives Knoll and Johnson (2000) identified three main categories of responsibility which they define as "vigilance and monitoring", "keeping things on track", and "seeking help and support".

The first category refers to a spectrum of duties the authors describe in these terms: "being both watchful and also 'on alert' especially to guard (the care recipient) against harm or error" (Knoll and Johnson, 2000, p. 68). They add to this the necessity of keeping track of the patient's progress towards physical and psychological stability and well-being. The range of basic caregiving chores within this strand includes controlling meals and intake of medication, visitation schedule, physical exercises and recreational activities. The second category embraces "the general running of the household and the meeting of immediate demands to sustain the care recipient's recovery" (Knoll and Johnson, 2000, p. 68). This strand of responsibility is often characterised by an obligation to increase the orthodox

household workload, while accepting an expedient reduction of activities related to job and social life. The third and final category embraces the caregiver's responsibility to seek and maintain supportive relationships – both material and psychological - from a range of individuals including physicians, nurses, neighbours, friends and family. All three categories of the carer's role are aimed at "returning things to normal" (Knoll and Johnson, 2000, p. 68) or, more formally, restoring stability in the patient's physical, psychological and affective status. Although their research clearly stated that all three categories of the carer's role are aimed at 'returning things to normal', it was unclear how the carer's role changed over time, which is an important element if we are to understand the caring journey.

When describing the phenomenon of caregiving, researchers (Barnes et al., 2006; Dew et al., 2004; Halm et al. 2007; Hunt et al. 2000; Rantanen et al., 2008; Rantanen et al., 2009; Saunders, 2009; Scott, 2000) commonly refer to the concept of health-related quality of life (HRQOL). HRQOL is generally understood as "well-being along physical, mental and social dimensions" (Dew et al., 2004, p. 745). This multidimensional phenomenon plays an important role in describing the goals and procedures of caregiving.

However, an evaluation of HRQOL presents a problem for researchers since there is no single definition of this concept or indeed a standard measure to estimate by. Neither is there a single method of measurement. HRQOL is commonly assessed through one of a number of specific instruments, such as Short Form–36 (SF-36) (Dew et al., 2004; Hunt et al. 2000), 15D (Rantanen et al., 2008) and the Quality of Life Index (QLI) (Scott, 2000). The SF-36 instrument evaluates quality of life across eight dimensions: physical functioning, pain, general health, vitality (i.e.,

extent of energy or fatigue); emotional well-being, role restriction in work and domestic life experience (as linked to physical health), role restriction in relation to emotional health, and social functioning (ability to communicate with others and participate in social activities). The 15D instrument encompasses 15 dimensions of physical, mental and social health: moving, seeing, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity. The QLI instrument measures well-being in four domains: health or ability to manage, family well-being, socioeconomic well-being, and psychological or spiritual well-being.

Despite the conceptual and methodological complexities, HRQOL is tackled in many investigations into the issues of caregiving in an attempt to clarify those areas in which caregiver and recipient may be affected. For example, Saunders (2009) published a study, employing a cross-sectional mixed-method correlational design, interviewing seventy-nine heart failure (HF) patients and their caregivers regarding the link between caregiving strain and quality of life. The study found that lower HRQOL among caregivers was associated with greater burden in the areas of family support, finance, schedule, and health. Carers with low self-esteem concerning their abilities to fulfil caregiving duties reported decreased HRQOL and, accordingly, increased incidence of depression. It was also found that caregivers' own health problems were a factor, negatively affecting the quality of caregiving provided. The findings of Saunders (2009) thus indicate how the concept of HRQOL may function as a multidimensional lens offering a number of valuable perspectives on the complex phenomenon of caregiver burden which is discussed below.

Caregiving is generally conceptualised as the provision of physical, psychological, emotional and social support for people with health problems. In the care of postoperative convalescent coronary surgery patients, a specific aspect of caregiving is to enable the patient's progress towards resumption of the tasks of self-care. There is a gender bias in attitudes towards caregiving in that aspects of the role are commonly associated with stereotypical female characteristics and tendencies. It is found that males typically rely on the help provided by women such as wives or intimate partners, while females refer for similar help to same-sex relatives and friends or apply to health care professionals. Caregivers perform a range of assignments aimed at stabilising the patient's physical, emotional and social status. Their negotiation of this burden is measured via health-related quality of life (HRQOL). This system of indicators, describing the carer's well-being in various areas of life, helps the researcher understand those complexities associated with caregiving which are commonly labelled caregiver burden. In conclusion, it seems that the emphasis in much of the literature and government policy is on practical and instrumental help and indicates that this care might result in a negative impact on the carer's well-being. However, in reality, carers may not be aware of the extent of what they do and there is a real danger that the more invisible aspects of caring will remain overshadowed. Therefore, it is considered to be a priority to understand the carer's experiences from their own perspective. Moreover, the majority of the above mentioned research provided some understanding of caregiving by carers (including lay carers and experienced carers); however, most of them were based on quantitative research approaches with cross-sectional designs. These studies using quantitative approaches with small samples would not be appropriate because this would make the

generalizability of the findings doubtful. Therefore, there is a need for research to be better understanding the carers' views from their perspectives.

2.6 The outcome of caregiving: Caregiver Burden

The literature it is clear that while looking after someone with some sort of disease carers are likely to carry out a wide range of activities such as personal and physical assistance, while also keeping the household going with little or no help. The most important issue however is that all the tasks that they undertake they have no training for. Of course, these carers might be able to search information or help themselves by using the internet or library facilities. Despite this one has to remember that there are still a lot of people who do not have access to such facilities particularly those in the older age groups, and for some of them this is an added burden to have to organise to achieve. However, it is apparent in the literature that carers experience burden while performing caregiving activities.

Phillips et al. (2009) rephrase the term caregiver burden "carer strain". Barnes et al., (2006) offer more detail, referring to "the physical, emotional, and social impact of the stress of caregiving" (p. 336). Three articles (Ågren et al., 2009; King and Koop, 1999; Phillips et al., 2009) identify differences between typical male and female caregiving responsibilities, and the degree of burden associated with them. The findings from these studies provided different variables or factors which appear to be related to burden during caregiving. One article from Ågren et al. (2009) especially point out the burden of care and the needs of carers, they used a grounded theory approach and interviewed thirteen spouses of patients with heart failure following cardiac surgery emergent or planned CABG, heart valve surgery, or a combination of both) and conceptualized a model of individual needs of

spouses called 'confirmation'. This model presented one of the carer's needs during caregiving. An important aspect of this study was that it provided an important component during the caregiving process namely, 'confirmation', however, it would have been more informative and helpful if this research had provided information regarding how this 'confirmation' happened over time or indeed from where the confirmation came.

The investigation of caregiver burden often starts with the identification of factors that may contribute to the emergence of this complex phenomenon. For example, O'Farrell et al. (2000) performed a cross-sectional quantitative analysis of distress as reported by two thirds of 213 female spouses of patients undergoing cardiac rehabilitation. The participants in this study named a number of factors contributory to stress, including marital life quality, sexual concerns, sources of financial support, and worries about the patient's return to work. Hunt et al. (2000) followed 123 adult patients who had undergone CABG surgery in a 12 month period, specifically investigating their carers' concerns regarding changes in the patient's quality of life. The researchers observed that stable relationships between care recipients and care providers, for instance those who were married, tended to contribute to increased overall quality of life, and a correspondingly lower level of caregiver burden.

Knoll and Johnson (2000) suggested that previous caregiving experience might counteract the incidence of carer anxiety. Their findings accord with results obtained by Scott (2000) who established a link between caregiver preparation, appraisal, and strain. The researcher gauged levels of "perceived caregiver preparation" (Scott, 2000, p. 86), self-appraisal and strain amongst 18 family

carers of heart failure (HF) patients, utilising a specially designed survey instrument. The study discovered a predictable correlation between preparation and the quality of caregiving provided by a carer. Participants stated that they were better prepared to use assets and services related to caregiving as well as deliver informal physical care, but that handling emergencies and psychosocial problems were reported to be difficult. Poor preparation for care provision provoked higher levels of stress and decreased self-esteem amongst carers. In turn, poorer self-esteem paved the way to an increase in the perceived level of burden. It should be pointed out, however, that the validity and reliability of so small a sample might be challenged. The aforementioned research highlights the impact on the carers' health resulting from caregiving. Having produced this relationship it would be good to have research which provided a correlation between two concepts to be able to test and find out if the experience was consistently found in carers and how it changed over time. Without this limitation there may be difficulties and unforeseen challenges in the provision of informed and adequate help and support to caregivers.

Rantanen et al. (2008) assimilated data from questionnaires completed by 270 patients who had undergone coronary artery bypass surgery and 240 significant others. The information obtained was analysed using descriptive and inferential statistics. Possible associations were traced between a range of background variables and health-related quality of life (HRQOL), on the assumption that investigation of the latter set of parameters might shed light upon the level of carer strain. The researchers identified the carers' gender, education and/or participation in group counselling sessions regarding the patient's health status as factors bearing no significant relation to HRQOL, while employment and the incidence of

chronic disease amongst carers were identified as factors contributing to carer strain, negatively affecting energy levels, and the amount of time available to fulfill caregiving responsibilities. Another important factor identified was the carers' age; the younger the carer, the more stable their reported HRQOL indicators, and, accordingly, the less prone they were to caregiver burden. However, it has been noted that there is no consistent tool to examine the HRQOL in the literature. Although Rantanen et al.'s (2008) gave a fundamental understanding of HRQOL in carers, caution should be exercised because this understanding is based on the view of the health care professionals. Naturally it is important for employers to know if their professional carers such as nurses have low levels of HRQOL and make alternative arrangements for their support or work patterns. However it remains that the quality of life of lay carers may be more challenged because of the isolation in which such people provide their care. .

Halm et al. (2007) employed a cross-sectional descriptive comparative design to obtain survey data from 166 spouses of coronary artery bypass (CAB) patients. They refer to caregiver burden as one of many outcomes of caregiving (OOC), ie "life changes that occur in emotional and adaptational outcomes (such as social functioning, subjective well-being, and somatic health) as a result of assuming the caregiving role". Molloy et al. (2008) conducted a cross-sectional study with 60 caregiver/patient dyads (where the patients had suffered congestive heart failure (CHF)). They suggested that the burden of informal caregiving is one of many types of 'job strain', which can be described using the Job Strain theoretical approach. As Molloy et al. (2008) explained, this approach highlights "a limited set of environmental contingencies, particularly the job design, as the main determinants of health outcomes and the main targets for intervention to improve

health" (p. 402). In other words, a person's health state is predicted by the complexity of job to which he/she is assigned.

Molloy et al. (2008) suggested, in addition, that since caregiver burden is a job strain, it complies with the relevant demand-control (D-C) model. This is centred on the notion of demand as the extent of physical or psychological load on a person performing a given job assignment. In the context of caregiving, demand refers to "the work that the caregiver does for and on behalf of the care-recipient and directly related to the degree of physical and psychosocial limitation of the care recipient" (Molloy et al., 2008, p. 403). The implication is that caregiving is a job a care recipient cannot do independently of another person. Viewed as such, care provision is associated with physical and psychological strains imposed on the carer. The degree of strain depends on the carer's control over the job demands and foreshadows the carer's health outcomes. To summarise this idea, the more the care recipient is delimited in his physical and mental capacities, the higher the demands placed on the care provider. Carers' increased demands/work load and lower levels of control over caregiving tasks are associated with higher job strain, or informal caregiver burden.

From this (the D-C model) perspective, caregiver burden can be measured through physical or psychological manifestations. For example, both Phillips et al. (2009) and Tsukasaki et al. (2006) became interested in the quality of sleep among caregivers as an indicator or consequence of care strain. Phillips et al. (2009) examined data elicited from a large sample (n = 314) of caregivers in the form of a cross-sectional survey and prospective observational design, interviewing participants within a period of five years. Carers' responses were analysed quantitatively, and it was found that sleep quality was linked to caregiving burden. Caregivers with deteriorated sleeping patterns showed higher

levels of depression and anxiety which signified increased care strain. Similar results were obtained concerning social support. Carers with fewer friends and limited social communications felt themselves more depressed and anxious.

Tsukasaki et al. (2006) undertook a cross-sectional, quantitatively analysed observation of 35 female caregivers (none of whom were taking antihypertensive and/or sleeping drugs), and established conclusions based on measurements of blood pressure, heart rate, and sleep status in a sub-sample of caregivers (n=19) with various sleep patterns: 1) no sleep interruptions, 2) waking up to use the toilet, 3) scheduled voluntary awakening to provide care, and 4) involuntary awakening to provide care. They found that carers without sleep disturbances showed higher anxiety and chronic fatigue indicators. This is an inversion of the common trend of findings among similar studies in which sleep interruptions were reported to be directly related to fatigue and distress (which, in turn, contribute to caregiver burden). Tsukasaki at al.'s (2006) unexpected results were, however, identified in a sample of younger carers (aged 40 or under) with less caregiving experience. Tsukasaki et al. (2006) hypothesised that inexperienced younger caregivers who provided care without sleep interruptions were prone to higher demands and thus greater job strain. Furthermore, those who reported scheduled waking in order to follow a specific care schedule showed less fatigue than those whose waking was involuntary. Overall, the study by Tsukasaki et al. (2006) supports the general hypothesis concerning the link between sleep quality and/ or pattern and caregiver burden. These studies contribute to our understanding of how sleep patterns and age impact on the burden of carers. Unfortunately most carers are the age they are and they can't affect that and because of the increasing aging of the population they will increasingly be older. Older people often do have broken sleep patterns which they cannot alter but when this is compounded by being wakened

47

up by their cared for person as well then the amount of sleep that they get in the night can be greatly diminished. They will have more life experience but it may not be the right experience to help them with their caring responsibilities. There is still opportunity to have a greater depth of understanding of the older carers' experience.by carrying out qualitative work.

The problem of sleep interruptions in the population of caregivers is often examined together with other manifestations of carer strain such as vulnerability (Perry et al. 2006), cognitive impairment, physical fatigue, and predisposition to clinical depression (Ågren et al. 2010), anxiety, depression, and despondency (Scott, 2000). The concept of vulnerability is crucial to our understanding of the nature of carer strain. Perry, Lynam, and Anderson (2006) examined conceptualisations of vulnerability amongst in-hospital and post-discharge participant cases, employing a feminist ethnographic method of enquiry. The participants of Study 1 (in-hospital) included 56 patients' relatives, health care professionals, and 60 patients. The participants of Study 2 (post-discharge) includes 38 family members and care recipients.

Perry et al. (2006) described caregivers as vulnerable insofar as they were subjected to higher risks of physical and mental health deterioration due to inadequacy of economic, social, psychological, familial, cognitive, or physical assets. Carers and care recipients were prone to vulnerability in consequence of several factors, including worry about the patient's disease, lack of communication with health care professionals, lack of ability or desire to discuss sensitive issues, worries about the impact of the care recipient's health problem(s) on his/her family. Among specific caregiving activities contributing to the emergence of vulnerability, Perry et al. (2006) highlighted management complexities associated with

48

"everything from bringing in food and helping with activities of daily living to mastering a considerable amount of nursing and medical knowledge" (p. 178). The researchers also discussed the issue of carer availability – ie the necessity of spending more time on family care provision (e.g., at the cost of carers' working hours) amongst factors contributing to patient and carer vulnerability. Concluding their report, Perry, et al. (2006) suggested several strategies for averting or counteracting vulnerability such as "doing the worry work" (ie when family members support the patient and each other by the simple reassurance of their presence); "protecting the patient and the family" both physically and morally; "managing informational needs" via the mutual exchange of relevant data amongst family members; and assessing the perspectives concerning the patient's health by "anticipating consequences and difficulties" (Perry et al, 2006 (p. 179)). Any or all of these strategies, they suggested, might have the effect of mediating stress for carer and patient.

Perry, et al. (2006) also investigate the influence of cultural diversity in carers' biopsychosocial reactions to care provision. The researchers focused on Chinese-Canadian and Indo-Canadian patients/caregivers in the context of Canadian health system. They reported that, in culturally diverse social systems, minority populations (in the given research context, the dominant community was the Anglo-Canadian/Franco-Canadian, Caucasian stratum, speaking English/French as a mother tongue) might experience greater caregiver burden. Common reasons for increased strain were related to difficulties in speaking and understanding the dominant-group language (ie that used to deliver health care services and information). In the setting of Perry et al.'s (2006) study Chinese-Canadian and Indo-Canadian carers/patients reported problems understanding special medical

terms/definitions regarding diagnosis, treatment, or care provision from Anglophone or Francophone medical professionals. Consequently, these participants manifested increased vulnerability to stressors associated with disease and caregiving. Although these articles capture the negative influences of caregiving on carers, the positive impact of caregiving has not been identified or reported. This of course may result from that question not being explored so far.

Based on the studies over the past twenty years, a fundamental failure of the caregiving literature was the lack of explicit investigation of the carers' perspective over time. A study by Wilson (1989) contributed a detailed consideration of carers' experiences within the field of dementia. Wilson (1989) carried out a grounded theory study with 20 relatives who looked after their demented relatives. She developed an 8-stage model of the caregiving process. Carers portrayed their experience with the course of Alzheimer's disease (AD) as: stage1: noticing – it was only perceived in retrospect that carers noticed the symptoms, because the carers did not add them up until they looked back; stage 2: discounting and normalizing – providing an explanation to explain the behavioural changes in the patient. The carers tried to normalize the situation or behaviour until they could not discount it; stage 3: suspecting – in this stage, carers started to realize the abnormal situation or behaviour; and so suspected a diagnosis stage 4: searching for explanation – carers sought for information to confirm the diagnosis of AD, however, it comprised uncertainty and problems; stage 5: recasting – this means carers recalled their memories and formulated pictures of previous events of their demented relative after diagnosis; stage 6: taking it on – carers face making a decision to take on the caring role or not, however, this is with an incomplete understanding of the responsibilities of this role; stage 7: going through it – this

means that carers t take on their role to care for their frail and demented relative. During this time they resolved their problems by trial and error; stage 8: turning it over – this occurred when carers placed their relatives in institutional care, however, they were reluctant to let go of control in direct care. The author concluded that she just offered a 'beginning knowledge' to interpret the process of caregiving. This study provides an important insight of the course of the experience of AD carers.

A later study by Nolan et al., (1996) examined the transition in carers' experience of providing care to dementia persons, and they produced a model of the caring process with 6 stages. They explained the six stages as follows:

Stage 1: building on the past – it means that carers understand the nature and quality of past interactions between themselves and the cared-for person, this could impact on the care provided by carers.

Stage 2: recognizing the need – this refers to a stage where carers become aware that their relationships are changing with the cared-for person, especially, for those with dementia or disability. During this stage, noticing, normalizing and confirmation occurred.

Stage 3: taking it on – the carers were becoming more aware of their role, however, if the carers are faced with things that were not going to improve, they may be reluctant to 'take it on'. Moreover, tension between professional and carers tend to appear during this stage because the professionals need to get the overall care moved into someone else's full time care, namely the carer..

Stage 4: Working through it – this is similar with Wilson's (1989) stage 7: 'going through it'. In this stage, carers become experts in the day-to-day aspects of their role.

Stage 5: reaching the end – this identifies the point when there is a need for the carer to be relieved of the ongoing care. This happens when the caring situation has become untenable resulting in hard decisions being made. This does not mean that carers cease to care, it simply indicates that institutional care is now required. This is also similar to Wilson's (1989) stage 8: 'turning it over'.

Stage 6: a new beginning – this is a stage that most carers found difficult. It is hard to make the decision and find a suitable institution in which to place the patient. The relinquishing of direct care provokes feelings of inadequacy and guilt However despite the wish to visit on perhaps a daily basis does offer a new beginning for the carer who has time to sleep and do the things that they want to do.

However, it is not known if this could be applied to carers with cardiac surgery because the patients can get better over time. Whilst this may be a good reflection of care provided to meet long term needs, it is difficult to see how this may elucidate the reality of short-term care. Although the two models advance our understanding of the experience of carers, it was based on carers who looked after relatives experiencing a progressive and degenerative disease. Although Nolan et al., (1996) describe the last stage with a positive aspect, it was difficult for carers to 'let go'. Therefore, 'reaching the end' might only exist within the carer's mind but not in action. However, carers who look after the cardiac surgery patients do not experience a deteriorating patient's condition; rather they have been 'cured' by surgical intervention and they are undergoing a period of recuperation when they recover from the surgical intervention. Thus it could be assumed that any prospective model will vary from the above models. We need a model which shows the short term need when the interventions are to be stage-specific and tailored to need at different times in the caring journey or direction over time

(Given and Given, 1991). Particularly if we take on board the idea that people who suffer from different conditions may have unique care trajectories which are unlike the people with long-term conditions. However, no research has been conducted to increase our understanding of the experience of carers of this group (cardiac surgery patients) and it may be premature to come to this conclusion.

In summary, caregiver burden is a multidimensional concept describing a range of predictors and consequences of workload liable to cause deterioration of life quality. Intensity of burden is directly related to the carer's age and caregiving experience: younger and less experienced carers tend to experience greater stress and anxiety, (although this finding does not hold good amongst carers of dementia sufferers). Other factors of relevance to the incidence and level of carer burden include cultural background, gender, and marital status. Male and female lay carers manifest varying bio-psychosocial behaviours associated with caregiver strain, while the quality of marital and/or intimate partnerships between the carer and patient may exercise an influence (positive or negative) on levels of carer burden. Caregiving may be a positive experience between the individuals involved, possibly strengthening love and mutual appreciation. However, caregiving is not an easy task; facing multiple challenges, even the most devoted care providers may feel themselves vulnerable, anxious and depressed.

In the next section the researcher will analyse the specifics of caregiver burden as manifested in people looking after cardiac surgery patients.

2.7 Caregiver burden in people looking after cardiac surgery patients

Knoll and Johnson (2000) made a specific study of the phenomenon of caregiving for cardiac surgery patients, obtaining interpretive descriptions of experiences shared by eight carers ranging in age from 58 to 80 years. The study reported no significant difference between the participants' emotions and reactions and those of individuals providing care for patients with other diagnoses. Three strands of biopsychosocial behaviours were found within the sample: "being stressed and tired", "feeling vulnerable", and "putting life on hold" (suborning one's own need to the needs of the patient). Although there is no proven link between the severity of carer strain and the nature of the care recipient's disease (King and Koop, 1999), some researchers (Ågren et al., 2010; Halm et al. 2007; Hunt et al. 2000) suggest that the provision of care for post-operative cardiac patients people may have specific characteristics of significance to the issue of carer burden. Although these studies provided information regarding caregiver burden of carers in cardiac surgery patients, the majority of them used quantitative design which was right for the questions they set however there is great opportunity to seek information at a deeper level. We would then have a greater understanding of the experience of this group. It would be greatly enhanced if the investigation were longitudinal aspect so that we had a picture of the whole of the caring journey in these short term situations.

During the patient's period in hospital, particularly prior to, and during, surgery the (prospective) carer may experience higher levels of anxiety, because he or she cannot directly influence the treatment process or provide immediate help and

support. This is enhanced when facing a life threatening condition. On the other hand, it is suggested that the caregiver dealing with his or her relative's needs following coronary surgery experiences a level of relief, irrespective of those needs, in the postoperative period, associated with hope that the symptomatic and functional status of the patient will continue to improve. Lenz and Perkins (2000) conducted a pre-test and post-test experimental study involving 38 patient-relative caregiver dyads in cases of coronary artery bypass graft (CABG) surgery. They found that carers in these circumstances exhibited higher levels of depression prior to surgery and at later phases of recovery than during the operative period. Perhaps this is not surprising since the carers were possibly overwhelmed by the possibility of death before surgery and afterwards also rather depressed that the reality of improvement had not happened at the point of data collection.

Ågren et al. (2009) interviewed 13 spouses of patients with heart failure developed after cardiac surgery (emergent/planned CABG, heart valve surgery, or a combination of both). The participants reported their need for security, physical and mental rest, and inner strength. During the acute stage, when the patient was on the surgical table or in the intensive care unit, caregivers commonly referred to sensations of "loneliness, uncertainty, and insecurity" (Ågren et al., 2009, p. 287). At those times, the spouses of patients desired honest and straight-forward updates concerning the status of their partners. The researchers stressed that during this critical period the carers' self-esteem and levels of confidence in their caregiving capabilities were positively affected by timely, straightforward and respectful responses from health care personnel to requests for information, clarification and advice concerning the patient's condition (particularly regarding

the decision as to whether the patient is ready for discharge or in need of further intensive therapy).

At the stages of intensive therapy and rehabilitation, family carers described sentiments summarised by Ågren et al. (2009) as a desire for mental and physical rest., the research participants endeavoured while preparing to deal with a dependent relative, "to gain inner strength, to feel better, and to forget the difficult situation for a moment" (Ågren et al., 2009, p. 288). Common amongst participants at this phase was the need of a quiet, relaxing environment in which to concentrate and compose themselves before taking on caregiving assignments. Interviewees reported surprise at the sensations of inner strength which emerged at these moments. Such feelings were, however, compromised to a degree by regret at being unable to accompany the patient during surgery. Significantly, it was the mixture, or confusion, of feelings in these circumstances which lead to carers' feelings of greatest anxiety. The general tenor of the findings from this study (Ågren et al. (2009)) suggest that caregiver burden amongst the relatives of cardiac surgery patients is not evenly distributed. The intensity of positive and negative feelings depends on the stage of treatment as well as the support provided by health care professionals. Again, in Ågren et al.'s (2009) study, the carers looked after their relatives with a progressive disease after cardiac surgery, therefore their experiences is more similar to the carers with AD patients than those who are cured by their surgery and so have a short term caring journey. .

The dynamics of caregiver burden in people looking after cardiac surgery patients was also examined by Canning et al. (1996). They interviewed primary family carers of 83 heart transplant recipients with questionnaires during the first year

post-transplant and analysed the data quantitatively. They found that participants' distress remained at the highest level throughout the two months following transplantation, decreasing by the seventh month and continuing to diminish up until the twelfth month. In the course of a linear multiple regression analysis, Canning, et al. (1996) found that the level of carer anxiety and the perception of burden correlated to a range of variables including carer employment status in the two months following surgery, quality of relationship with the care recipient, the respondents' caregiving experiences, and their self-control. Those having a poor relationship with the patient exhibited higher levels of anxiety during the first six months post-transplant. The level of distress amongst participants who manifested partial or diminished home management skills remained high throughout the year. Further significant variables were underlined by Canning et al. (1996) who stressed the link between high levels of strain and the incidence of personal health problems and or limited extended social network amongst family carers. It is important to understand that the significance of contributory factors to levels of carer stress varies within the post-operative time period, and that overall, the perceived extent of burden changes across time. It must be remembered that this was a challenging group to investigate because they are living through a stressful period in their lives which must be dominated by a feeling of possible impending disaster. These carers may not have been ideal but they were made like all of us by the experiences that had made up their lives. They also represented the usual mixture of carers and so their contribution was invaluable. Researchers must be realistic in their interpretations for everyone's life is not idyllic.

Dougherty and Thompson (2009) described the caregiving continuum for one hundred and ten intimate partners of individuals receiving an implantable cardioverter defibrillator (ICD), employing a prospective longitudinal repeated

57

measures design. The majority of carers were Caucasian females - their mean age 61 (±13 years),. Caregiver burden was assessed via survey instruments throughout the first year following surgery, and identified in terms of physical and mental health, family relationships, and care load. Immediately after the patients' discharge from hospital, intimate partners reported their own decreased physical status. Among the commonly listed symptoms were feeling rundown (62%), headaches (36%), low back pain (33%), nausea and upset stomach (28%), and soreness of muscles (26%).

As was found in the study created by Canning et al. (1996), the carers' mental health manifested significant improvement by the end of the postoperative year. Dougherty and Thompson (2009) agree further with Canning et al. (1996) in their emphasis on the relevance of the quality of family relationships to levels of caregiver burden. Dougherty and Thompson (2009) specify the obligation felt by family carers of maintaining a stable family situation, indicating that this particular pressure was most keenly felt in the period immediately following discharge from hospital. Carers described a range of responsibilities and concerns particularly associated with this area of obligation, including protecting the care recipient from stress (77%), assisting the patient with treatments (69%), anxiety concerning the partner's responsiveness to therapy (68%), sensitivity to the patient's mood changes (67%), and desire for more emotional support from the patient (64%). It is interesting to see how these concerns evolve over time; by the end of the first year following surgery the caregivers' perceptions of emotional priority in relation to their task and to the patient have clearly developed. The list of those priorities includes protection of the patient from stress (74%), anxiety concerning the partner's reaction to therapy (65%), higher responsiveness to the recipient's mood

changes (64%), and demand for more active emotional involvement from the patient (62%). Participants also reported an increase in sexual activity (specifically, increased sexual responsiveness in the patient) towards the end of the post-surgery year – a finding which may be interpreted both as a consequence of reduced stress (Canning et al., 1996; Dougherty & Thompson, 2009).

Dougherty and Thompson (2009) emphasised the role of mutuality and interpersonal sensitivity as efficient mediators of caregiver burden among those looking after cardiac surgery patients. Mutuality may be summarised as the reciprocal provision of support and encouragement between carer and patient; at discharge, carers attempted "to keep a positive attitude and a hopeful outlook about the patient's recovery" and reported a situation in which both they and the patient made an effort to keep "communication open, supporting each other, and being comfortable sharing feelings with one another" (Dougherty and Thompson, 2009, p. 439). These positive behaviours continued to be practised by participants at the end of the postoperative year. Interpersonal sensitivity is perhaps best described as the quality of sentimental acuity and consideration which informs the exercise of mutuality; in the immediate post-operative period, caregivers report making a conscious effort to be confident and upbeat, engaging in conversation about life events, while deliberately endeavouring to suppress misgivings or negative attitudes toward ICD, and generally avoiding the discussion of sad or upsetting topics. By the end of the year, partners continued to share news and encourage one another with expressions of confidence – a situation generally reinforced by the natural optimism induced by recovery and movement away from the sadness and distress associated with ICD.

While the study by Dougherty and Thompson (2009) is generally supportive of the viewpoint emerging from the abovementioned group of researchers (Lenz and Perkins (2000); Agren at al. (2009); Canning et al. (1996); Canning Dew and Davidson (1996)), emphasising the dynamic nature of caregiving and the correlation of carer strain to time-related variables, a study by Kneeshaw et al. (1999) sounds a contentious note, specifically questioning the stability of mutuality between caregiver and care recipient within the post-operative year. Employing a descriptive correlational design, Kneeshaw et al. (1999) surveyed a sample of forty-nine elderly women (aged between 65 to 87) whose primary carers were daughters (57.2%), husbands (20.4%), sons (12.3%), and nieces (4.1%). The mean age of the carers was 50 years. The majority of care providers were married, and working outside the home. Immediately following discharge participants reported an increased level of mutuality; carers were glad to see their relatives back home and openly manifested positive attitudes towards the care recipients. However, by the end of the first year post surgery a reduction of mutuality is reported, often becoming manifest as early as three months after discharge from hospital. These findings show that interpersonal relationships between the provider and recipient of care in the case of cardiac surgery patients may be affected by other factors such as caregiving load – a finding which, although at variance with a specific element in the study Dougherty and Thompson (2009), is nonetheless broadly in accord with the general suggestion regarding the dynamic variability of the caregiving experience over time.

Research conducted by Halm et al. (2007) investigated elderly caregivers (n = 166) for a year following coronary artery bypass (CAB). The study supported the hypothesis promoted in several studies already mentioned concerning the

difference in the caregiving experience between male and female carers, further associating this contrast with a specific difference in the experience of caregiver burden. Men found difficulty in assisting with medical or nursing treatments, personal care, transportation and the monitoring of symptoms. Female carers confronted similar difficulties in dealing with transportation, but were less troubled when dealing with issues of personal care and medical treatment. However many female carers did admit finding the provision of emotional support and management of behaviour problems especially challenging. Perhaps the most conspicuous finding offered by the authors of this study is the suggestion that the CABG recovery process is stable without significant changes in caregiver burden. On the latter point, it was stressed that the recovery trajectory was perceived as less burdensome when partners were satisfied with the quality of their marital life and interpersonal relationship.

Overall, biopsychosocial reactions, emotions and behaviours observed in the carer/care recipient dyads in the aftermath of coronary surgery were found to be similar to those of individuals dealing with other health problems. Articles analysed in this section stressed the variation in attitudes and perceptions on the part of the carer and care recipient throughout the period of post-surgery rehabilitation and recovery. This comparison of carers and cared for is not surprising since the 'patient' is dealing with a situation which they cannot affect but if they have trust in their surgeons they believe that the situations will improve. On the other hand the carers equally are dealing with situations which they largely cannot alter but they are having to manage both their own problems while managing their caring responsibilities and trying to support their relatives through their worries and disappointments too. The major trend revealed concerns higher levels of stress

felt by the carer in comparison with the patient in the pre-operative period and immediately after surgery at the intensive care stage. However, there remains a gap in our understanding of carers who care for patients after the immediate phase following discharge. Caregiving burden in the aftermath of cardiac surgery is linked to a range of factors related to carers background, such as sex, age, employment status, and caregiving expertise. During the postoperative period the carers rate the tasks associated with transportation, behaviour management, and emotional support as the most challenging. However, it was unknown how long this would last and how carers coped with these problems over time.

Although there is no consensus among researchers concerning the dynamics of interpersonal relationships in the first year post discharge, there is broad agreement that the quality of marital life or intimate partnership may mitigate negative reactions associated with caregiver burden. Sadly this is how life is and researchers cannot affect this but they do perhaps have a role in finding out by doing a more qualitative study how the people who are in difficult relationships can be supported to manage their caring roles more successfully.

2.8 Discharge planning

Davies (2000) used a descriptive survey to interrogate 59 carers and 60 patients following coronary artery bypass graft (CABG). He reported that carers generally consider the caring role to begin when the patient is discharged from hospital. It is unsurprising then that discharge is treated by many carers and patients as a major life event (Perreault, et al., 2005). A key aspect of this transition for many carers is the increased relevance of health and social care resources, and the intercommunication which should facilitate the carer's access to those elements of

support; good quality discharge should not be a matter of chance (DoH, 2003). Given this fact, the importance of involving prospective carers in the process of discharge should perhaps be self-evident.   However, their involvement in this phase is usually ignored by the health care professionals (Perreault, et al., 2005).

The UK Patient's Charter (DoH, 1996) states that "before the patient is discharged from hospital a decision should be made about any continuing health or social care needs that he or she may have. The hospital will agree the arrangement for meeting these needs with agencies such as community nursing services and local authorities' social services departments before the patient is discharged. The patient, and, with his or her agreement, the carer will be informed and advised at all stages." (p.2). Tierney et al. (1993) concur with this judgement, suggesting that when a discharge plan is made in hospital, a letter should be sent to the GP of the patient, and, if necessary, the District Nursing team should be contacted. Additional aspects of discharge planning may include attendance by Health Visitors, and prior identification by hospital staff, where necessary, of the need for a social worker. In the latter circumstance it should be the responsibility of the hospital to inform the social work department, in consequence of which a social worker will visit the patient in hospital to make plans around the patient's and carer's likely needs once the discharge goes ahead. Discharge planning might thus be summarised as a "systematic, multidisciplinary process by which the needs and resources of inpatients and their carers are assessed in order to enable comprehensive discharge preparation and the arrangement of appropriate community support and services on discharge from hospital" (Tierney & Closs, 1993). Generally, this is a necessity associated with cases requiring long term care; however, it cannot be denied that circumstances necessitating short term

63

care (such as recovery from cardiac surgery) are equally in need of co-ordinated systematic discharge planning. The problems inherent in making such plans for a group whose hospital stay is very short exacerbates the difficulty of making such plans in a timely manner.

In the Cochrane review (Shepperd et al. (2010)), discharge planning is defined as the development of an individualised plan for the patient prior to leaving hospital, with the aim of containing costs and improving patient outcomes. Planning should ensure that patients are discharged at an appropriate time in their care and that, with adequate notice, the provision of other services will be organised. Shepperd, et al., (2010) cite examples of patients who, with the benefit of discharge planning, had a reduced length of stay and significantly fewer readmissions to hospital. It should be pointed out, however, that despite the reviewers' avowed intention of representing carers' views, their data was drawn exclusively from evidence obtained from patient-participants, and that the perspectives of carers were omitted. In a series of reviews of the literature, Tierney & Closs, 1993; Davies, 2000; Perreault, et al., 2005 identified a lack of research that related to the discharge planning from the carer's perspective. Tierney et al did interview hospital staff and patients. They also tried to get GPs to co-operate but it was difficult to recruit them. Though of course it is important that researchers listen to those who are going to receive the care and those who do the planning in the shape of hospital staff it remains that there is lack of material from the community staff side but importantly form the lay carers who are to provide the day to say support of the patient.

2.8.1 The Reality of Discharge Planning

Hospital discharge planning provides an opportunity for bringing together the patient, healthcare team and patients' carers to address any issues or potential difficulties that may arise in the post-operative recovery period, thereby facilitating the patient's safe return home (Tierney & Closs, 1993). Planning bridges the gap between hospital and home and community care in the aftermath of an acute admission. Its success is dependent on the development of comprehensive and effective anticipatory strategies aimed at maintaining or improving patient health outcomes outside hospital care. A survey by Tierney et al. (1993) reported on the incidence of discharge planning in acute hospitals in Scotland. 319 wards in 55 acute hospitals were sent questionnaires; the response rate was 72%. The authors found that discharge planning was a much neglected area; deficiencies and problems identified included the following: fewer than 50% of wards claimed to have a written discharge policy; 50% have standards pertaining to discharge, or claim to have such standards under development;. discharge planning is clearly perceived as a multi-disciplinary process in which patients and carers should be actively involved; however, only 54% of carers (n=286) were said to be involved in the discharge decisions; 30% of wards (n=319) claimed that the patient is always involved in discharge decision making; community-based health professionals were reported as having very limited involvement with patients and the work of the ward; Health Visitors (HVs) and District Nurses (DNs) were said to be wholly uninvolved in approximately 30% and 10 % of wards respectively. (With regard to the latter finding, it should be pointed out that limitations of the involvement of nurses in discharge planning are an inevitable consequence of practical and financial restrictions in the contemporary healthcare environment).

The general implication of these findings is a situation characterised by poor communication between hospital and community staff, little consensus regarding discharge decisions between hospital staff and patients, and still less between hospital staff and prospective carers (Tierney et al., 1993). The possible consequence is a situation in which patients are discharged from hospital with little or no information and support, and in which carers feel isolated and profoundly burdened. It should be pointed out, however, that the methods of data collection and analysis utilised in Tierney at al.'s study (1993), are potentially problematic; the group conducted the study in a compartmentalised manner; i.e. separate elements of the research team did not work on the each area of the study, and all were not involved in assessing the quality of the team's data collection and analysis in composing the final report.

The findings, however from this study closely agrees with those reported by a later study undertaken by Bull and Roberts (2001). These researchers conducted an ethnographic study with health care professionals in two settings - Hospital (N=14), and community (N=7), with elderly individuals (n=2) and with a single family carer. They carried out 24 semi-structured interviews, reviewed discharge planning documents and used field notes to observe the interaction between health care professionals, patients and other participants. Their purpose was to identify the components of effective discharge planning for older people, and such factors as impede planning. On the strength of their findings they suggested that proper discharge planning occurs as part of a clearly established process, characterized by involvement of a multidisciplinary team (doctors, nurses, physiotherapists and so on), between which circles of communication should develop, in which both patient and prospective carers are included. Communications between team

66

members should commence allowing sufficient time before discharge for all to make their contribution, anticipating the needs of the patient/carer, and moving to meet them. Bull and Roberts cite the example of an elderly participant: medical staff monitored the participant's condition and formulated a prognosis, a physiotherapist evaluated the patient's mobility, an occupational therapist assessed the physical aspects of the home environment against the participant's functional ability, a social worker assessed family support, and nurses monitored the participant's progress on the ward, relayed concerns expressed by patient and family regarding the prospect of discharge, and maintained communications between team members patient and family through ongoing liaison. Bull and Roberts identified particularly the importance of involving patient and family in the process of planning – identifying the importance of their availability to queries from health care professionals, and their freedom to initiate such contact in order to communicate their concerns and apprise the team of their home situation and likely needs. Given this situation, various members of the community team were appropriately involved post discharge, depending on the participant's need for aftercare. Although this study provided some valuable points, the inclusion of only a single family carer must persuade the researcher to be cautious in accepting its conclusions as generally applicable.

A later study by Atwal (2002), offers a valuable supplement to Bull and Robert's (2001) findings. Atwal conducted a case study based on direct observation of 19 nurses, examining their interactions in multidisciplinary teams, in order to explore their perceptions of the discharge planning process. Atwal (2002) discovered that aspects of the discharge process were frequently ignored or neglected, and assessments rarely co-ordinated. In addition to this, the nursing ward handover

seemed to be regarded as a process that hindered, rather than facilitated communication. The chief cause of these oversights was found to be lack of the time necessary for effective inter-professional communication and co-ordination of assessments (Atwal, 2002). This study was conducted in three different wards in a hospital in England, and afforded valuable information. Again, however, the sample was small, precluding the possibility of generalisation. It is nonethless worth reflecting that any deficiency of the discharge planning process identified in 2002, is likely to be amplified in the current drastically straitened economic climate. It is a genuine and unhappy possibility that a lay carer in 2011 may be left alone to cope with the needs of their relative – a situation as likely to confront the short-term carer - the informal carer of a cardiac patient, for instance - as the long-term carers featured in the studies of Tierney et al. (1993) and Bull and Roberts (2001). These researchers suggest that the carer's voice has not been heard, their input not valued, in the discharge planning process. The likely consequence is a potentially damaging gap between the carer and the health care professional. It is important that this lack of communication is addressed, and the challenges and difficulties faced by short term informal carers better understood.

In conclusion, the above mentioned research provides valuable information regarding the reality of discharge planning However, it does indicate that the major problem was the lack of communication with, and involvement of, carers, both lay and professional. This might have had a major impact on the carer and the patient's experience following discharge, especially in the case of early or weekend discharges. Thus, there is a need to understand these areas further in order to enable health care professionals to provide sufficient support for carers. It is however depressing that not only the carers voice is silent but even more that so

many patients are not involved either in the planning process. It does not sit well with the Government policy that they must be involved in all aspects of their care.

2.8.2 Supporting the carer after discharge

It is becoming abundantly clear that supporting carers following hospital discharge is very important, and that there is a need for the community health care team, the carer and the patient to work closely and more effectively together. Perreault et al. (2005) conducted a survey study of 40 relatives and 98 patients, in order to investigate levels of satisfaction with discharge planning.   84% of relatives (n = 33) reported a situation in which there was no communication between clinical staff and relatives regarding discharge planning. Relatives also referred to those areas in which they felt most need of information and guidance; these included the timing of discharge, out-patient follow-up, and management of crisis situations. The level of carer discontentment reported in this study must be viewed with a certain amount of caution, since the study sample was relatively small, and the evidence was drawn from cases exclusively concerned with mental illness. It is possible that Perreault et al. (2005) are unable to accurately reflect a general satisfaction rate for carers and the patients. The study is nonetheless of value in helping to identify the nature of the information and guidance required by carers in the community at the point of discharge, and in confirming the urgent need for greater communication between clinicians, patients and relatives earlier identified by Bull and Roberts (2001). Bull and Roberts (2001) emphasised the importance of a multi-disciplinary team, comprising not only family carers and hospital health care professionals, but also community health care professionals, including district nurses, and general practitioners (GPs), as well as social workers.

This is a view mirrored in a later literature review of discharge planning of family carers published by Chapman (2006). Chapman suggested that discharge planning should be a comprehensive process involving communication between family, case manager, social worker, primary care provider and patient. Chapman points out that when family members are involved in discharge planning at an early stage, they are able to convey to the health care team essential aspects of the home context, such as the patient's cultural traditions, possible financial problems, a disabled spouse at home, or unsafe living conditions which may affect patient and carer after discharge. Such information may be crucial, enabling the health care team to modify the patient's discharge plans to meet the complex and individual needs of the case.

Lindhardt et al. (2008) conducted a phenomenological study seeking to illuminate the experiences of eight nurses in a teaching hospital, as they collaborated with relatives of frail elderly patients in the discharge process. The study suggested that the relatives were considered a resource, but that nurses also found them at times difficult and demanding, sometimes even seeking to avoid contact with them. A number of serious implications are thrown up by these findings: there is little or no planned and structured process for collaboration; though dependent on relatives for enhancing the quality of care, nurses either avoid them or are unprepared and lack confidence when encountering them; perhaps most gravely Lindhardt et al. (2008) suggest that relatives are not treated as equals by nurses, and that those who are not heard cannot possibly provide information regarding their circumstances and needs. (It is worth reflecting, also, that if it is the demanding nature of such relatives which persuades nursing staff to avoid them, it

is possible that the neediest - 'demanding' - individuals are precisely those who are likely to be overlooked).

Again, as this was a small qualitative study caution should be entertained as to the generalizability of its findings. However, the study does raise some very important points regarding the nurses' experiences of discharge planning. The authors point out that although involvement of relatives in care is rare, where they are involved, the attitudes of nursing staff towards them are the most significant predictors for effective collaboration. They continue that such effective collaboration is most likely where nurses are disposed to regard relatives as equals – co-workers facilitating the extension of care into the community setting. Where there is an entrenched sense of inequality between relatives and nurses, the efforts of Government (in the current study this is Scottish Government) to forge any kind of working relationship between carers and healthcare professionals are liable to be an uphill struggle.

It is important to understand what the consequences may be where carers are uninvolved in discharge planning. A study by Pickard and Glendinning (2002) focuses on these issues. Pickard and Glendinning (2002) used an ethnographic approach to interview a number of family carers (n =24) drawn from two health authority areas (contiguous metropolitan areas, including relatively deprived inner city regions as well as more affluent suburbs). Their purpose was to establish a clear picture of each carer's practices at home. Although the study sample was small (n=24), it yielded valuable perspectives. It was found that the participants carried out a wide variety of tasks. These ranged from the less complex aspects of personal care-giving – 'maintenance' tasks like washing and dressing – to technical and highly complex care such as renal dialysis, parenteral feeding,

colostomy and fistula care, all of which significantly overlap with the sort of tasks carried out by professional nurses. An additional difficulty for carers was the possibility of having to deal with unexpected and challenging situations, sometimes in the middle of the night. Evidence from participant interviews suggested that these challenges and difficulties were exacerbated by the fact that carers were not explicitly included in the process of decision-making and planning with regard to discharge and the post-discharge period, continuing to struggle with a wide variety of unmet needs and a lack of involvement by health care professionals. While policies geared towards assisting and recognizing carers are purposefully loose and open-ended, the evidence from Pickard and Glenning (2002) underscores the need for professionals on the front line to be rigorous in seeking to understand the texture and detail of carers' experiences. Only in this way will they have a chance of offering appropriate support and anticipating needs and difficulties.

In recent years, the idea of person-centered care is now embedded in the multidisciplinary team in the UK (McCormack, 2003). The idea of person-centred care is central to a general understanding of person-centeredness which could be recognized as a respect for persons and to do good to others. McCormack (2003) states that person-centeredness is concerned with a respect for individuals' values and their beliefs. Person-centre care is said to be an approach to service delivery and service development, ensuring that services are developed in partnership with people and their carers (McCormack, 2003). People- and family-centered care is one of the principles for guiding health care delivery (Hutchfield, 1999). This suggests that health care is responsive to individual differences, cultural diversity and the preferences of people receiving care, and is achieved partly through

providing choice in health care. It is important to note that most of the family-centered practitioners are used almost exclusively in the field of pediatrics. -However, how this could be applied to the reality of the current health care system in the field of adult patients would be challenging. For example, if a cardiac surgery patient is discharged within 7 days in the hospital, they would go to the ward, theatre, ITU, HDU, ward and then back to their home within a short period. If the person-centeredness care would apply for the patient the carer equally would have to be taken into account, and would be a challenge for the health care professionals. Moreover, how community nurses, district nurses or GPs got adequate information about the patient in a timely way and so provide sufficient support for the carer remains unclear. Giving the lack of continuity in the professional care and how this could be achieved is difficult and privilege, particularly in the current health care climate. This would add more complexity for the carers in their caring environment. This would be a case where the government applied a broader family-center care standard especially in the community. The family health care practitioners such as GPs, practice nurses or district nurses aims to provide support for the carers and patients in the community. The carers may need to rely on heir help when the patient was discharged.

However, one of the other problems of the discharge planning which was identified a long time ago by Tierney, et al., (1993), when they found that getting the letter to the GP was difficult and this produced a gap in the awareness of the GP knowing that one of his patients was leaving hospital and needing support. If the community health care professionals are ignored, then the community care will be less than useful. As the Scottish government emphasizes carers should be

looked on as partners within the health care system due to their invaluable contribution in the community (Scottish Government, 2010). , Person-centre care should be evaluated more broadly in order to support carers as well as the patient. This means that health care professionals need to get to know the person beyond the diagnosis and build relationships with carers and patients, especially treating every patient as an individual and being involved in the discharge planning at an the early stage. In this way, an outcome could be that carers would be provided with sufficient support in the early stages of recovery.

2.8.3 The post-discharge issues and lay carers

The currently shifting boundary between secondary and primary health care has led to the relocation of complex nursing from hospital to community. This transfer places greater emphasis on the role of family carers. It also blurs the boundaries between formal and informal care creating a situation in which family carers may be called upon to undertake duties and procedures commonly regarded as the domain of nursing proper (as already intimated in the findings of Pickard and Glendinning (2002) in the previous section). This in turn has important implications for the respective roles of family carers and nurses, in particular, the role of District Nurses in supporting family carers. Gerrish (2008) conducted an ethnographic study, based on observation, fieldwork and in-depth interviews, in order to examine the views and beliefs of District Nurses with regard to the element of individualized care in their everyday practice. One of the emerging themes in the data was the perception shared by district nurses that they have a role to play in supporting family carers, and their opinions as to the various manifestations of that

74

role. Crucially, the nature and scope of support was felt to be based on service capacity, rather than on carers' needs and preferences. District Nurses rely on the contribution of family members to the care of their relatives; if family members, as a general group, become incapable of making this contribution, the health and social services will come under untenable strain, confronting a level of need which outstrips service capacity. On this issue, Gerrish (2008) makes a point of fundamental significance; it is the patient who is the recipient of nursing support, not the carer. This in turn is conditional upon the hospital or GP making appropriate patient referrals. In the Gerrish study (2008) District Nurses continued to see family carers as a resource and as co-workers whose contribution is essential to providing care in the community. Gerrish also strongly suggests the importance of health care professionals understanding how carers arrange their lives post discharge, and of carers understanding what support is available to them from community health care professionals. An additional deficiency implied by Gerrish (2008) is the fact that prospective carers have little or no involvement in the care of the patient while he or she is in hospital; this is compounded by the aforementioned deficiencies in discharge planning, leading to a situation in which family carers struggle to engage with the responsibilities of their role at home. This can in part be attributed to a lack of focused research on the role of the lay carer; although many studies have sought to illuminate the nurse's view of hospital care, few have investigated the issue of care in the home (Lindhardt et al. 2008).

Research has shown that the involvement of carers in the process of discharge planning is essential, but currently inadequate. Carers frequently express frustration at this lack of involvement, complaining of poor communication, and a consequent lack of education and knowledge, which leaves them unprepared for

the task of caregiving (Perreault et al. 2005; Lindhardt et al. 2008). It was noted that some of the issues identified in much earlier studies (Tierney et al., 1993; Bull & Robert, 2001) continue to be reported in the later studies, yet the views of those researchers are still not being taken into account. There are a variety of people who will look after the patient in the community, such as a GP, a practice nurse and a district nurse; they may all be involved in the patient's care. The problems identified by Tierney et al. (1993) in discharge planning still remained some thirty years later and indeed may be even greater in the current health care climate. At the same time, the pressure of short term admissions and the demands for faster throughput make the likelihood that these failings will be addressed more distantly now than at the time when the earlier studies were conducted. The problem of ever faster throughput is further compounded by the fact that, although a named nurse may be assigned to the case of a particular patient on admission, the practical realities of shift patterns, holidays, and pressure on nursing resources often mean that the assigned individual is unable to see the case through to discharge. Even in those studies which have specifically addressed the issue of discharge planning, information on the availability of a carer was frequently unsought, or unreported (Bull & Roberts, 2001). In other words, all too frequently, little, if anything is known either about how (or whether) discharge planning has been undertaken, or if the carer has been involved in the process. There is a clear need of research into the process and the ways in which the needs of carers and patients can be met in the recovery period after hospital discharge. This researcher can find no extant research specifically designed to identify the experience of caring, particularly from a lay carer's perspective and more particularly on a short term basis.

2.9 Summary

In this chapter a range of literature has been presented in which the majority of existing evidence concerning the experience of those who look after cardiac disease patients in the home may be found. These studies indicate that such carers are a prey to anxiety, stress and depression; they have need of more information and greater support to help them overcome the problems and challenges of a task for which they are untrained and may be physically or emotionally unsuited. However, major gaps persist in the literature surrounding carers in acute caregiving.

First, the research focused primarily on the carers with AD or dementia suffers which was based on carers who look after relatives experiencing a progressive and degenerative disease. On the other hand, the carers who look after the cardiac surgery patients who recover within a short space of time only have knowledge of short-term caring which means that this particular group requires further investigation. e,

Second, the research examined predominately related to factors of burden or stress. However, there is little data which focuses on the lived experience of carers of cardiac surgery patients, and although the needs of this group may bear some resemblance to those of the cardiac event group, it is possible that they are different and this has not been properly investigated to date.

Third, the majority of the studies have been primarily conducted using quantitative approaches with cross-sectional designs. Research aimed at examining the

experience of carers from their perspectives might uncover new knowledge and increase our understanding carers' experiences and their needs.

Finally, most of the studies in discharge planning indicated that there is a need to involve carers in the design of the plan at a timely opportunity. However, the majority of research demonstrated that this was an area which needs a greater understanding. The lack of carer involvement in discharge planning compounded by health professionals' limited knowledge of carers' experiences and needs. This challenges the government's view that patients ought to receive person-centered care but how this can be implemented particularly in acute services remains unclear..

Scottish Government policy has highlighted the importance of 'caring for carers' in recent years, placing emphasis on the importance of seeing carers as partners in the health enterprise. Since the Government has clarified society's dependence on lay carers, the necessity for health care professionals to deepen their understanding of the needs of both patient and carer is clearly an urgent one, yet the support they need and the most appropriate way of meeting it remains unexplored.

In this review, qualitative and quantitative work has been included in which periods of varying duration post discharge have been investigated. Review tends to suggest that the earliest days following discharge have not been widely explored; addressing this deficiency may enable the researcher to apprehend and demonstrate longitudinal change in patterns of behaviour and experience, and thus understand more clearly the evolution of patient and carer needs. In order to understand the raw material of carer experience more deeply, a qualitative design

is appropriate; this research methodology aims at revealing the hidden meanings of textually described phenomena. The quest for such understanding is facilitated by continuous alternation between exploration of sections of text in detail, and overview of the text as an integrative whole.

Chapter 3

Chapter 3 Research Approach, Methods and Procedures

3.1 Introduction

In this chapter, the overall aim of the study is disclosed. Following an outline of research paradigms, the rationale for selecting a phenomenological approach is described. A detailed account of the methods employed in the study is also provided, including sampling (purposive), data collection (diaries and interviews), and data analysis. The quality and trustworthiness of the study is considered – an area of discussion which includes the important issue of ethical approval. The chapter concludes with a general reflection on the overall research design.

3.2 Overall Aim of the study

The overall aim of this study is to explore the experiences of family carers caring for cardiac surgery patients in the first three months following hospital discharge. Research questions:

- What does it mean to be a carer looking after a cardiac surgery patient following hospital discharge?

- What is the experience of professional support for these carers during this time?

- What is their experience of other forms of support?

- What are the unmet needs of carers looking after cardiac surgery patients?

3.3 Research Paradigms

Marshall and Rossman (2006) define a paradigm as an interpretative framework - a basic set of beliefs that guides action. For the researcher a paradigm is a perspective taken towards data - an analytical stance which facilitates the gathering and ordering of data in such a way that the processes of data collection and the structure in which data is presented are integrated. Saks and Allsop (2007) offer a definition of the paradigm specific to the area of healthcare research, suggesting that the researcher's paradigmatic positioning relates to his/her understanding of reality and the nature of knowledge in this field of enquiry.

Denzin and Lincoln (2005) offer a functional account of the paradigm, highlighting specific issues the researcher must consider in formulating an approach to data collection and analysis. They identify the three principles of a paradigm as ontology (knowing what the nature of reality is), epistemology (knowing what the nature of knowledge is) and method (knowing how to gain knowledge of the world). In terms of this definition the researcher approaches the world with a set of ideas, or framework (theory, ontology), that specifies a set of questions (epistemology) which the researcher examines in specific ways (methodology) in the course of which process data can be collected (Denzin & Lincoln, 2005).

Defining a specific paradigm involves asking what the researcher conceives as the nature and essence of things in the social world, or in other words, what the researcher's ontological position or perspective is (Mason, 2006). As mentioned, in this study the researcher's aim is to explore the experience of carers of cardiac surgery patients in the three months following hospital discharge. A key to this aim was to enquire into the perspectives of the carers themselves. The researcher

considered that this objective was best approached by asking such carers to 'tell their own stories' – ie to document what happened during their lives in this period. The outcome of such an enquiry should be an understanding for the researcher of reality from the carer's perspective; in other words the participant's ontological position with regard to a very specific circumstance (caring for a relative in the three months following discharge after cardiac surgery), contributes to a broader ontological position – that of the researcher – regarding the general focus of the study.

The second element in a general definition of the paradigm is epistemology (Denzin & Lincoln, 2005). The epistemology of a paradigm pertains to the researcher's theory of knowledge, and should concern the principles and rules by which the researcher decides whether social phenomena can be known, how they can be known, and how such knowledge can be demonstrated (Mason, 2006). This involves adducing complex questions about the nature of evidence and knowledge from ostensibly simplistic questions about how such evidence can be collected. The researcher may use deductive methods, (for instance by testing hypotheses), as a way of generating knowledge. Knowledge developed by such an approach takes the form of a theory. In the current study this approach was considered unsuitable, since it was not the researcher's aim to produce a theory. This is an instructive example of the way in which consideration of epistemological issues facilitates the choice of an appropriate data collection approach - illuminating the relationship between epistemology and method. A further illustration of this relationship is afforded by the current researcher's experience during the literature review. While exploring a range of studies, it became evident that the majority of relevant research has been conducted using a cross-sectional

design as a means of understanding a range of carers' experiences. In the current study, the researcher was concerned to elicit information regarding the experience of carers over time. This could not be achieved using a cross-sectional design because such an approach involves studying groups of participants at the same instant. This reflection prompted consideration of the possible merits of a longitudinal qualitative study - ie a study in which the researcher performs repeated conversations or observations at designated points during a specific period of the participants' lives (the time span involved may be anywhere from a few months to a lifetime). Such an approach allows the researcher to view the <u>development</u> of the participants' experience – providing high quality information about continuity and/or discontinuity of participant experience, and allowing for the tracking of individual patterns of change, as well as trends of development within a group. It may thus be seen how the process of conducting a literature review provoked an important debate in the researcher's thoughts concerning ways in which the nature of the knowledge required in order to answer the research questions must contribute to key aspects of project design.

Research plays a vital role in society. It is the means by which discoveries are made, ideas are confirmed or refuted, events controlled or predicted and theory developed or refined. These functions contribute to the development of knowledge (Polit & Beck, 2003). Perspectives on the nature of knowledge are a key area of consideration for the researcher; they fall into two subsidiary paradigms - positivistic and naturalistic. The positivist approach involves the use of measurement designed to test assumptions about the nature of phenomena being studied, and is commonly carried out by quantitative design. For example, if the researchers want to know whether a particular nursing intervention is good for

heart disease patients, they can recruit two groups of such patients. One group receives the intervention and the other group continues to be treated by another standard nursing procedure. Outcomes in both groups are measured. The result may give some indication of the effectiveness of the nursing intervention in question for heart disease patients in general. This example shows us the positivist paradigm as a measure of the cause-and-effect relationship between participant experience and elements under investigation in the research project. Crucially, it is also an example of an approach which may succeed when the researcher is both socially and psychologically detached from the participants.

In contrast, the naturalistic approach assumes that knowledge is maximized when the distance between the researcher and the participants in the study is minimized. In research conducted with this emphasis the 'voice' and individual perspectives of those under study become crucial to understanding the phenomenon of interest; subjective interactions are the primary means of gaining access to that phenomenon. The findings from a naturalistic inquiry are a product of interaction between the researcher and the participants. Research design influenced by the naturalistic paradigm commonly features ethnography, grounded theory, or phenomenology (Morse & Field, 1996; Silverman, 2004). The account given above of this researcher's reflections and response to the literature review have cast some light on the decision to favour the naturalistic paradigm; there follows a more detailed account of the issues involved in this decision, and the researcher's consideration of those issues.

3.3.1 Quantitative research

Quantitative research can be defined as a means for testing objective theories by examining the relationships amongst variables. These variables are measured, typically using instruments, so that numerical data can be generated, and analysed via statistical procedures (Creswell, 2009). Such studies entail a deductive approach to the relationship between theory and research; the investigation originates in an hypothesis which is deduced from a theory; the study design sets out to test and verify the hypothesis, resulting in the production of numbers (Bryman, 2004). Quantitative researchers are therefore concerned to derive findings which can be generalized and replicated (Creswell, 2008) – findings whose interpretation contributes to a view of social reality as an external, objective phenomenon (Bryman, 2008). In the current study, the aim is to explore the personal experience of carers – a focus impossible to quantify by number, level or degree without yielding anything more than a superficial understanding of the participants. If quantitative research methods were employed in this study, it might be pertinent to establish whether the experiences of the carers in question were 'good' or not – a finding expressed only by a simple 'yes' or 'no'. The outcomes by which an hypothesis might be verified (and/or variables related to the phenomenon under investigation) would thus be overtly simplistic, precluding the possibility of the sort of in-depth data required to understand the subtleties and dynamics of individual human experience.

Nonetheless, a number of studies into research areas close to that of the current project have employed quantitative design (Halm et al., 2006; Halm et al., 2007). In these studies researchers investigated care-giver burden for carers of cardiac surgery patients, using the Care-giving Burden Scale (CBS). The scale assesses

direct, instrumental, and interpersonal caregiver tasks, with two separate 5-point Likert scales: 15 caregiver tasks are rated for time spent (objective burden) and level of difficulty (subjective burden). The studies show that carer burden for relatives of post-operative cardiac patients failed to diminish within a year of discharge. The efficacy of CBS as a measurement of caregiver burden can, however, be questioned; Hoenig and Hamilton (1966) assert that subjective burden refers to the individual's <u>own</u> assessment of his/her impairments and the extent to which he/she perceives the caregiving situation as burdensome. The implication of Hoenig and Hamilton's observation seems to be that objective assessment of subjective burden is impossible, and any attempt to make one is liable to be misleading. In spite of this, as already mentioned, the literature review revealed a preponderance of quantitative investigations into the issue of caregiver burden; (Halm et al., 2006; Halm et al., 2007; Rantanen et al., 2004). This is perhaps surprising since the majority of carers in these studies were relatives of the cared-for person, without training or previous experience – a particular category of caregiver for whom there is no existing research, and whose subjective experience might therefore be considered of more than passing interest to the authors of the studies. Rantanen et al. (2004) designed a questionnaire to elicit data regarding the support needs of carers and cardiac surgery patients. The findings report levels of need for support amongst carers and patients – social support from the network of friends and acquaintances, as well as professional support from nurses – which they feel are simply not being recognised or met. However, the specific experiences on which the carers' discontentment was founded are not reported, making it difficult to identify precisely how the perceived void of support might be redressed. Likewise, in Rantanen et al.'s study, notions of support were derived exclusively from the perspective of healthcare

professionals, as opposed to the carers themselves. The general consequence of these oversights in research methodology is a notion of carer need and support which is restricted and one sided, and therefore unlikely to be fully applicable to the carers themselves. Consideration of the limitations in these studies has caused this researcher to reflect that there is a category of carers who have had little or no opportunity to express their views about their experiences or gain any personal insight into their roles. This is a key issue; lacking proper understanding of their experiences, it is unlikely that carers will request or be in receipt of the help they require; interpretation of their experiences, limited to a professional perspective, lacks intuitive understanding of carers' situations and context. To intervene effectively in this area requires knowledge rooted in the personal paradigms of carers - perspectives developed through expedience. Only if carers are given the opportunity to describe their experiences will it be possible to identify these essential structures.   It is this researcher's belief that an authentic impression of subjective caregiver burden is possible only via the personal narratives of the participants – a type of data unavailable through quantitative research. In light of such considerations it was decided that a quantitative research design would be unsuitable as a means of addressing the research questions in the current study; any numerical assessment of caregiver situation would be unlikely to convey what was valuable and important about the participant's experiences.

In order to address this limitation in data, a qualitative design based upon carefully formulated research questions, would be more appropriate, facilitating understanding of the issues affecting carers' lives and of their need of support from professionals and others. Mason (1996) is supportive of this notion; he refers

to the naturalistic paradigm, suggesting that knowledge is socially constructed and reality is ultimately subjective; experience cannot be quantified - it can only be described (Mason 1996). Through qualitative research, knowledge about carers' experiences can be assimilated and projected from their own perspective and thus may be better understood as a document of subjective human thought and feeling. Any assessment of carer need based upon such methodology is likely to be more valid, and the manner and means of addressing those needs consequently more effective.

3.3.2 Qualitative research

Qualitative research refers to the study of the nature of reality. Its key principle is the belief that reality is the sum of individual experience, and is therefore not objectively measurable. Individuals construct their reality by associating meaning with certain events or actions (Bryman, 2008); qualitative research seeks to elicit those individually formulated meanings by questioning participants' responses to those events and actions in their lives which form the empirical basis of the study. The qualitative researcher favours approaches such as interviewing and observation, preserving data in the form of field notes, taped conversations and transcripts (Marshall and Rossman, 2006). She may interview participants in their homes and observe their reactions as they speak, seeking to establish an understanding of participants' lives, their experiences, and the subjective meanings rooted in those experiences. Subsequently, through analysis of the data gathered, the researcher hopes to offer some account for the process of decision making and action which characterises the participants' conduct.

Qualitative research begins with a fundamental experiential phenomenon and asks questions about the nature of that phenomenon. Where the quantitative researcher might seek to establish how <u>much</u> of a particular type of experience has been gained, the qualitative researcher asks 'what is the experience <u>like</u>?' looking for an answer to this question from the perspective of the participants. Inquiry into the nature of the experience leads naturally to a question as to how and why the nature of the experience varies in different circumstances. Kären et al. (2004) designed a qualitative research study investigating the experiences of spouses of coronary heart disease patients during the rehabilitation phase. They sought particularly to understand the views of participants regarding the expedience and/or desirability of lifestyle changes in their altered domestic situations – the degree to which participants supported change. As such their study underlines the suitability of qualitative methodology where the researcher is interested in the changeability of experience. Kären et al reported five different views of the spouses' roles in response to the variables of lifestyle change. It might be argued that, on their own, these findings are too narrow; 'support' for lifestyle change may include the views of others beside the patient's spouse. The true relevance of such a finding is dependent upon its generalizability - a quality for which a quantitative inquiry might be appropriate. This offers us an incidental insight into the possible validity of a mixed methods approach.

A further defining characteristic of qualitative research is the inductive approach; the researcher gathers qualitative data (for instance, the evidence of conversations with the carers) as a means of identifying and highlighting the way participants interpret their social world and the context of their experiences. Inevitably, the results of qualitative research tend to be in the form of words rather

than quantification or numbers (Silverman, 2010). The researcher apprehends participants and their individual viewpoints by encouraging and analysing original conversations, texts or narratives. Effectively, such an approach brings what might otherwise be unspoken into a comprehensible public domain – this is the essence of what might be referred to as 'induction', perhaps (in the case of the current study) establishing how circumstances and support may be improved for carers.

Qualitative research studies people in their natural settings, interacts with them in their own language, and adopts a multi-method approach to understanding their lived experiences (Mason, 2006). It is possible by these means to reflect what reality is like for these individuals both in terms of the statements they make and the behaviour they demonstrate in relevant environments, exploring both elements of their response (verbal and behavioural) individually, as well as exploring the relationship between verbal and behavioural data. In the current study, the aim is to uncover the experience of carers looking after cardiac surgery patients following hospital discharge. The experiences which comprise these carers' lives are complex, subjective and embedded in specific social and historical contexts. Qualitative research highlights the influence of those social and historical factors - the contribution they make to the complexity of the participants' subjective experiences - not by studying isolated elements of the social and historical context, but by permitting their influence, as it is manifest in the words, facial expressions and actions of the participants, to occupy a position of central significance in the data. The importance of this level of sophistication in data may be illustrated by reference to a number of studies. Davies (2000), for example, undertook a survey study to examine carers' perceptions of recovery following cardiac surgery one

week and six weeks after hospital discharge. The survey showed higher levels of positivity and optimism amongst carers at a point immediately following discharge, and six weeks later, compared with pessimism and negativity after a week. Although the finding is useful, it offers no account of why carers were happier at those points. What is missing is <u>detail</u> of specific events and the participants' reactions to them at those stages. Information regarding what happened at those points would itself alone add considerable value to the findings; still greater value and usefulness in the findings might be added by evidence regarding participants' conscious and subconscious reactions to those happenings. Psychological and emotional data of this finesse is only achievable with a qualitative research design.

3.4 Research Design

Pope and Mays (2000) assert that it is important to employ the appropriate research design - one which is linked to the theoretical perspective of the study, and which provides a conceptual framework which both supports, and is supported by methods of data collection, enabling analysis of the social world and the research process. The research design should demonstrate to the reader that the research project is well planned and that the researcher is competent to undertake the research, capable of applying the approaches identified and sufficiently interested to sustain the effort necessary for the successful completion of the study (Marshall and Rossman, 1999, p24). How do researchers maintain the flexibility of research design necessary in order that the research can 'unfold, cascade, roll and emerge' (Lincoln & Cuba, 1985, p210), and yet demonstrate a plan that is logical, concise and capable of meeting practicable criteria?

In this study, it is the researcher's intention to give a voice to carers regarding their everyday experiences and feelings, and examine the processes and the context of their support needs in a depth and detail that cannot be achieved using quantitative research methods. The criteria for study, and the broad approach were thus self evident from the outset. However, qualitative research designs and approaches vary depending on their philosophical underpinnings; in order to identify a method with the flexibility advocated by Lincoln and Guba (1985), and so ensure the practicability of the project's aims, three different qualitative approaches have been considered.

3.4.1 Ethnography

Ethnography is a basic form of social research (Baillie, 1995); it comprises the study of a group of people or a culture. An ethnographic researcher may observe, describe, document, analyse and interpret the general customs and beliefs of a particular group of people at a particular time (Leininger, 1985). . Culture, above all, is central to ethnographic research (Laugharne, 1995). For that reason the analysis of cultural difference is also of key importance, since it often only by entertaining comparison between cultures that each becomes clear in its own right, by virtue of its difference. Clarity and detail are of fundamental importance in such a study, for which reason the ethnographic anthropologist will often conduct his/her study by living with the participants, entering into their lives and customs, rather than studying the individual as cultural exemplar in isolation. An ethnographic approach was considered unsuitable for the current study, in which family carers were to be the focus, since it would have involved the researcher taking up residence in the homes of the participants – an approach which, albeit

potentially advantageous in certain respects, would have been both physically and financially impracticable.

3.4.2 Grounded Theory

Grounded theory was introduced by Glaser and Strauss in their book *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967). The basic approach vindicated in this book has developed and diversified over the past 40 years: Strauss, with Corbin, introduced a greater flexibility into the method, encouraging the researcher to think creatively (Strauss & Corbin 1990; Strauss & Corbin 1998); they emphasised that the techniques and procedures contained within their version of grounded theory were not intended to be applied religiously, but to provide researchers with a set of tools which would facilitate a confident approach to analysis.

In the version of Grounded Theory which has evolved in the four decades since its inception, the researcher does not approach research with the intention of validating or modifying a preconceived theoretical standpoint. It is more common that the researcher will be prompted to focus on a situation in which he/she perceives some theoretical inadequacy or lack. Procedure for data collection (often by interview) and analysis is designed and undertaken with the intention of addressing this void, and theory is developed as a result. Theory is thus literally 'grounded' in the research process – the ongoing verification and evolution of theory directly responsive to the analysis of evidence. Data collection, data analysis and the development of theory stand in joint relationship with each other.

In this study, the researcher aims to explore the experience of caring for relatives of cardiac surgery patients in the period following hospital discharge. A grounded theory approach might prove beneficial to this aim insofar as the arena for study is the informal social setting of the home, and grounded theory offers a systematic means of apprehending the social world. However, the intended outcome of grounded theory, as the title suggests, is the generation of theory; in the current study the researcher is not seeking to formulate theory but to establish an understanding of the lived experience of individuals based in the essential meaning participants attach to their own experience. Thus, grounded theory does not fit the study aim and cannot answer the research questions in this sense.

3.4.3 Phenomenology

The etymological derivation of the word 'Phenomenology' is a conflation of two Greek terms - 'phaenomenon' meaning appearance and 'logos' meaning reason. According to Spiegelberg (Spiegelberg, 1976) the phenomenologist attempts to describe the essential features or structures of a given experience or any experience in general. Roche expands on this basic definition adding that the experience or experiences under exploration include the researcher's own and those of others (Roche, 1973). The expansion is important, because it emphasises the notion that description of experience not only reveals facts about the world (which in the broadest account comprises an aggregate of phenomena) but also sheds light upon the act of consciousness in which phenomena are perceived, and therefore upon the nature of consciousness itself. Husserl (1931) gives us perhaps the most subtle and detailed account of this dichotomy:

> Natural knowledge begins with experience (*Erfahrung*) and
>
> remains within experience. In the theoretical position which we

call 'natural' standpoint, the total field of possible research is indicated by a single word: that is, the 'world'. The sciences proper to this original standpoint are accordingly in their collective unity sciences of the world, and so long as this standpoint is the only dominant one, the concept 'true being', 'real being', i.e. real empirical (*reales*) Being and – since all that is real comes to self-concentration in the form of a cosmic unity – 'being in the world' are meanings that coincide. (Husserl, 1931, p. 51)

From the viewpoint of Husserl (1931), phenomenology is simultaneously a method for understanding the individual's nature and the way the material of experience manifests to our consciousness. Roche (1973) paraphrases this notion suggesting that the aim of phenomenology is to describe experience in order directly to disclose facts about the world, and at the same time to unfold facts about consciousness which facilitate our understanding of the way human beings apprehend the world.

Phenomenological research design has been adopted in studies of health care and nursing for a long time, but it divides broadly into two forms, both of which have been closely considered in formulating the research approach for the current study: research based in Husserl's phenomenology, and research based in Heidegger's hermeneutic phenomenology. Ultimately, a Husserlian approach was deemed more suitable for the current study. In order to clarify the thinking behind this decision, some similarities and differences between these two phenomenological approaches will be discussed.

3.4.3.1 Hermeneutic (interpretive) phenomenological approach

According to Heidegger, phenomenology, as a preliminary to ontology, must be hermeneutic (Heidegger, 1962). 'Hermeneutic' in its strictest sense denotes the development and study of theories embracing interpretation and understanding of narratives. In terms of Heidegger's philosophy it refers to an understanding and interpretation of human existence – 'narratives' thereof comprising a process of being in the world, and being with others. Heidegger's major work 'Being and Time' (Researcher's copy issued1962), was first published in 1927, and was intended as his introduction to a study of the concept of being. It was greatly influenced by the works of Edmund Husserl – in whose ideas Heidegger identified an emphasis on ontological enquiry – a view of the individual in terms of his/her ability to understand things. Heidegger's book concerned itself with human *being* as an autonomous notion, and with the temporal and historical nature of human being. His phenomenology is thus based in an existentialist perspective, exploring the relationship between human thought and human existence (Lopez and Willis, 2004). It is in this way that his phenomenology may be described as hermeneutic, since the relationship between thought and existence is apprehended in the exploration and interpretation of the temporal narratives which comprise individual and collective human existence. For Heidegger people are 'in and of the world' (Reed, 1994); he interprets human existence as comprising a temporal structure - a constant projection towards the future and a constant re-assessment of the past. Within the parameters of this dynamic he identifies two separate but interlinked questions which together comprise the core of ontological inquiry: 'how do people come to understand things?' and 'what does it mean to be a person?' (Leonard, 1999). For Heidegger understanding what it means to be a person is synonymous with understanding the other phenomena of existence. In other words, to analyse

the human condition is to analyse the conditions in which human understanding takes place (Gadamer, 1976).

The significance of Heidegger's phenomenology for the researcher obtains in his conviction that to search the meaning of the lived experience is not to reformulate another's experience in analysable form, but rather to develop the power to grasp one's own possibilities for being in the world (Johnson, 2000). If the researcher wants to understand the human world as it impinges upon her own consciousness she needs to investigate the relationships between herself and other people, and between herself and the other phenomena of existence – apprehending and understanding the context of the events in which she is involved. If the researcher seeks to understand the human world as it impinges upon the actions and consciousness of others, (her participants) she must seek not only to investigate the relationships and events in which they (the participants) are involved, but establish and deepen that understanding by relating the experiences of participants to her own. Although the researcher may have a prior understanding of the human world, she must disclose this prior knowledge – to herself and to others – revising and consolidating it, to make what is implicit explicit. This means that a phenomenon is understood in an act of re-synthesis – or 'co-constitution' - as the sum of the perceptions of both the participants who experienced it and the researcher whose previous experience reflects it (Flood, 2010; Hamill and Sinclair, 2010). For example, if the researcher wants to understand the experience of caring as it is conceived by relatives of cardiac surgery patients, she needs to go to those carers and explore the experience with them. The researcher must combine her own experience and the carers' experiences of everyday phenomena

to apprehend their experiences with genuine empathy and understanding, rather than with mere theoretical interest.

The basic premise in the above example is the lived experience of caring as constituted in the perceptions of the relatives of cardiac patients, and a rudimentary speculative understanding of this lived experience as constituted in putative levels of the researcher's prior knowledge. The researcher, for example, may understand in a general way that the experience of caring is burdensome. She may wish to elevate that level of understanding from generalism to specificity, and seek the testimony of carers in order to begin this process. On the basis of an initial meeting, and subsequent further meetings, the researcher seeks to expand the rudimentary understanding. This is the process by which superficial knowledge and understanding are enhanced - whereby those deeper and subtler levels of apprehension which underlie superficial knowledge (the implicit) become explicit. For the researcher, for the participants and for the readers of the study, the lived experience is illuminated, and ultimately, it is hoped that understanding and appreciation of the lived experience will contribute to the enrichment of other peoples' existence in the world.

Although the hermeneutical phenomenological approach offers a vehicle for understanding the lived experience of people, it places overt emphasis on the importance of prior understanding of the phenomenon under investigation (Koch, 1999). With regard to the specific focus of research in the current study, prior understanding must inevitably issue from existing studies. The researcher's critique of existing literature has demonstrated that to date such studies have been primarily concerned to report the viewpoint of the health care profession. This

researcher's primary aim is to establish an understanding of the lived experience of her participants - relatives caring for cardiac surgery patients in the interval following discharge from hospital. It is true that, without some adequate prior definition of this phenomenon, the basic validity of the study is brought into question, but against this it must be argued that if, as a matter of expedience, such prior understanding is heavily dependent upon the findings of professionally centred research studies (as in the case of the current study it must inevitably be), there is a significant risk of bias – both in the nature of the evidence gathered, and its interpretation in analysis. Bias towards the perspective of the health care profession fundamentally contradicts the most basic premise of the current study, viz, to understand the lived experience of caring, from the carer's perspective. Any such study is likely only to reinforce the professional's view of carers, potentially devaluing the truth of the experiences described by them, although it is that truth which is accounted of most potential value to the current study. On this basis, it is considered that the hermeneutic phenomenological approach is not appropriate for this study.

3.4.3.1 Husserlian (descriptive) phenomenological approach

Edmund Husserl was a German thinker whose writings, published in the early decades of the twentieth century, have earned him a reputation as the father of phenomenology (Moran, 2006), and have influenced a succession of subsequent philosophers, such as Heidegger (1889-1976), Spiegelberg, Gadama and Merleau-Ponty (1908-1962). He began his academic career as a mathematician, defending his doctoral dissertation in Vienna in 1882. It was at this time that he

came under the influence of Franz Brentano, attending a series of lectures in the city, in consequence of which he began to consider several fundamental problems in epistemology and the theory of science. Brentano was a prominent psychologist and philosopher of the ninetheenth century - a seminal figure in the early history of the phenomenological school. He it was who established the idea of a phenomenological psychology, advocating the notion that psychology should be based on empirical grounds (Cohen, 1987). As a mathematician Husserl was accustomed to dealing with the relations and operations of phenomena (numbers, algebraic properties, idealised geometric forms) whose conceptual essence is of equal, or greater moment than their material existence. This may go some way towards explaining the impression made upon Husserl by Brentano, who seemed to be offering him an opportunity to realise and explore the provenance of numbers (and by implication, of similar abstract phenomena) in a concrete dimension. Although, as Husserl's own phenomenological ideas became more refined and elaborate, he ultimately sought to distance himself from Brentano's psychologism, one should not underestimate the influence Brentano had on the formation of Husserl's philosophy. A key concept he inherited from Brentano was the concept of intentionality (Roche, 1973). This concept refers to the notion of mental phenomena as distinct from physical phenomena; ie inasmuch as a mental phenomenon is <u>about</u> something (a belief is a belief <u>in</u> something, a desire is a desire <u>for</u> something) it may be distinguished from a physical phenomenon, which possess no intentionality. This concept went on to form the basis of Husserl's philosophy, established with the publication of his first major work, Logical Investigations (1900-1901), which is considered to be the founding text of phenomenology (Schultz, 1967).

The fundamental notion for an understanding of Husserl's phenomenology is the distinction between meaning and object, and the perspective into which our understanding of human consciousness is thrown by this distinction. Husserl's inclination is to accord equal, or greater, status to the mental representation of an object as a discrete phenomenon, than to its material manifestation. In the years following the publication of Logical Investigations, he sought to elaborate on this belief, suggesting increasingly sophisticated definitions for the nature of the object. He contended that while objects have a basic material existence, they are more important to us as phenomena constituted by the act of thought. He sought to discriminate between the assumptions about a given object which comprise the phenomenon from a 'natural standpoint' (ie the object as dependent in 'external reality') and those which comprise the 'intentional inexistence', accorded by the act of intentional perception. He developed the notion of 'bracketing', whereby those aspects, or assumptions which emanate from our empirical prejudice concerning the object as a constituent of external material reality, must be set aside, or transcended, if we are to perceive the 'essence' of phenomena (Husserl, 1931).

In the late period of his philosophical development, Husserl increasingly acknowledges the influence of Cartesianism; he evokes the quality of 'inter-subjectivity', stating that the essential meaning of an object emerges from human communication about the object (ie intentionality becomes the sum of a collective conscious), and that this constitutes an autonomous objective reality entirely separate from objective meaning as defined in natural science. While Heidegger's phenomenology focuses on the lived experience as opposed to the abstract consciousness, Husserl contended that whatever an individual knows about the

world, whatever we know about the objective truth, begins with and is based in subjective consciousness (Husserl, 1931).

In order to elucidate the significance of Husserl's phenomenology to the researcher, it is important to examine each of the above mentioned elements of his thinking in relation to the research process in general and to the specific conduct of the current study. Husserl tells us that the experience of the individual must remain with the person who experienced it and as it is given (Husserl, 1931); a paraphrase of this statement is to suggest the importance of maintaining respect for the experience of the individual, in terms of the value and interpretation the individual attaches to it. When the researcher asks 'what….?' there is implied an exploratory and open-minded approach to the belief an individual or group of individuals may adduce from the interpretation of their own experiences. The questioner, the researcher, accords that individual, or group of individuals the respect of attaching meaning to their belief. Thus, in the case of the current study, in asking carers about the experience of looking after a relative following cardiac surgery, the researcher is offering her participants the opportunity to describe the changes which took place in their lives with the advent of this responsibility – attaching importance, by the act of inquiry, to those events, and to the way in which the participants coped with them.

In Husserlian phenomenology, there is an attempt to understand the problem of how objects and events appear to an individual's consciousness, based on the fundamental proposition that nothing can be spoken or seen if it does not come through individual subjective experience. (Giorgi & Giorgi, 2003). Specifically, Husserl was concerned to apprehend phenomena in their 'essence' (Paley, 1997;

Flood, 2010) – that is, devoid of all assumptions which derive in the definition of phenomena as elements of material external reality, or as partaking of any pre-existing value system. The key to apprehension of phenomenological essence is an act of 'reduction'. Reduction requires that the researcher transcend all preconception, all theorisation and categorisation regarding a given phenomenon – even generally accepted beliefs concerning what we call "real" or "not real" (Max van Manen, 2002). The importance of phenomenological essence is related to the idea that the <u>experience</u> of an event may be considered as real as the event itself, or indeed may have greater relevance as a mental event than as a concrete empirical occurrence. The practical significance of this notion, for the researcher, is a salutary reminder to put all presupposition aside in the recording and assimilation of experience, to be alive to the essential <u>meaningfulness</u> in evidential data. For instance, the researcher does not ask 'How do carers learn to look after their relatives?' but 'What is the nature of the experience of looking after relatives following cardiac surgery?' The sought after outcome in this case is not objective information with regard to the caring situation, but an understanding of the subjective experience of care-giving. This understanding should be guided by the assimilation and penetration of material that relates directly to the subject being considered in the process of the research. The researcher may use interviews, field-notes or diaries to record research data - media which admit time and space for the individual participant to express his or her thoughts and feelings, and which therefore give primacy to the subjective meaning of the evidence gathered. When participants express themselves in words, they communicate intentional meanings present in their consciousness. When the nature of the lived experience awakens a person to the meaning of his or her experience, he or she gains a fuller understanding of what it means for them to be human. The more

deeply a person understands her own or others' human experience, the more knowledge of global dimensions of life she gains. For the researcher, to become privy to these subjective understandings may facilitate the deep exploration of the phenomenon under study more effectively and answer the research questions directly (Giorgi, 1989). For instance, if, in the current study, with the benefit of interview, a carer is recorded as saying said 'I did not know what to do. I felt I was hurting him', we are able to understand by these words, not only the material situation to which the words allude, but the participant's emotions in that situation – sensations of helplessness, anxiety and uncertainty. It is in such ways that descriptive phenomenology directs our attention to the understanding of meaning rather than the observation of behaviour (Lopez and Willis, 2004). Where quantitative research might concentrate on the numerable elements of human experience or behaviour (concrete positivistic 'objects', as defined by Husserl), a qualitative phenomenological inquiry focuses on the meanings attached to experience – specifically, from a Husserlian standpoint, those meanings mediated by the participants - permitting readers 'to see the deeper significance or structure of the lived experience being described' (Koch,1999). If we are enabled to understand the meaning, for participants, of behaviour or experience, there is a greater possibility that we may be able to act usefully in the interests of participants and those like them on the basis of our findings.

It is in the pursuit of the purity of apprehension referred to by Koch (the pursuit of 'essential' meaning) that Husserl's concept of 'bracketing' – ie of laying aside all but the fundamental invariant properties of any phenomenon - is most pertinent and most useful to the researcher. In the act of reduction, or bracketing, the researcher must be alert both to the danger of presupposition, and also to the

potential presence of essential phenomenological significance in the evidence gathered, and in her interpretation of it. Bracketing is also important in underlining the researcher's attitude to theory, helping her to examine how preconceived intellectual interpretation may gloss or obscure the experiential reality upon which it must ultimately be based. Theories often purport to explain phenomena that are not fully apprehended or understood in a lived, concrete sense; a key motivating factor behind the current study has been this researcher's desire to address a marked imbalance in existing research into care-giving, between authentic phenomenological veracity, and theory-based supposition. In adopting a descriptive phenomenological methodology, the researcher should approach the act of inquiry free from preconceived theory, and from any intention to evolve theory from research; she must approach those individuals whose experience interests or concerns her, and seek to understand and express the phenomenological essence of their experiences. In her role as an intermediary between the experiences of the participants and the apprehension and understanding of those experiences by others, she offers herself as an agency or channel for intersubjectivity, proposing an objective meaning to those experiences, a meaning which has value for others. Therefore, for instance, in the current study, although it will be assumed that the participants' experiences of care-giving differ in sundry respects, the researcher should focus significant concentration on the identification of invariant, or 'essential' qualities in the record of participants' experiences – such as, for instance, the incidence of stress, (the aggregate of which leads to the objective but immaterial phenomenon of 'caregiver burden') and the common elements of those means by which the levels of stress are accelerated or reduced. The experience of stress is individual and subjective; a sensitive record of that experience amongst a group of individuals in similar

situations presents us, by the operation of intersubjectivity, with a valuable objective phenomenon. So, a deeper understanding of the nature or meaning of everyday experience may be unfolded, and the suspension of the experience overcome (Giorgi & Giorgi, 2003).

In summary, Husserl's descriptive phenomenological approach has been deemed most appropriate for the current study because it is the researcher's intention to eschew all theoretical preconception or bias in approaching her research subject, to allow the record of her participants' experiences to respond to their own interpretation of the value and significance of those experiences, and to mediate between the evidence of individual care-givers, and between the body of evidence as a whole and its eventual readership, in such a way that essential objective phenomena of genuine value and usefulness may be allowed to emerge and contribute to existing knowledge in the research area.

3.4.4 The rationale for using a phenomenological approach in this study

Cohen (1987) described phenomenological intuiting as the test of all knowledge. The intuition to which Cohen referred should not be thought in any way a mystical or inexact quality (an inference from the use of the term in common parlance), but a demonstrable action embracing logical insight based on careful consideration of representative samples. The act of intuition addresses itself 'to the things' themselves, ie to phenomena, not theories. In phenomenology what is studied are phenomena, a term which denotes the appearance of things to the subjective consciousness, as opposed to noumena - the things themselves (Cohen, 1987). This, above all is the crucial aspect of phenomenology which fits it to the aims of the current study. The researcher wants to understand 'the meaning' of caring for

relatives who have undergone cardiac surgery; she wants to understand the carers' 'experience' of professional support in this situation, and their 'experience' of other forms of support. In other words the researcher is not in pursuit of facts for their own sake, but information insofar as it refers to the experiences of carers and the meanings they attach to those experiences. This objective is best served by a phenomenological approach since, as Cohen reminds us, the concern of phenomenology is with individuals and their views. The individuals are consulted and trusted (Cohen, 1987).

Moreover, the fact that the current study is concerned with the issue of care-giving in the home further confirms the appropriateness of the phenomenological approach to the study aims. Streubert and Carpenter point out the importance, in phenomenology, of the investigation of the 'life-world' - the incorporation of the life-world into the evidence-gathering process (Streubert & Carpenter, 1999). Cohen reinforces this notion, confirming the importance of the fact that the individual is studied in their natural context, not in contrived situations, and the importance to the researcher of reflecting in the evidence the natural disposition of the participants, the everyday un-reflected attitude of naïve belief most likely to be forthcoming in a familiar and unthreatening setting (Cohen, 1987). This research perspective and the study of events as lived experiences serve as the foundation for a phenomenological inquiry (Oiler, 1982). Ultimately, the researcher in the current study is seeking to establish meanings based on the subjective interpretative reactions of participants to experiences they have undergone in the context of their own life-world; phenomenology, focuses on those kinds of meanings – meanings which are inseparable from the experient in whose mind they develop and from the context in which they are generated, and which lead to

intersubjective general ideas of practical importance. The research questions of the current study may be most fully and effectively addressed by this approach.

3.5 Research Methods

In this study, a qualitative phenomenological approach design was undertaken. Data collection was to be managed through three weekly diaries and two semi-structured interviews. As phenomenology has evolved in nursing research, the traditional data collection strategy has been the qualitative in-depth interview (Lopez and Willis, 2004). The output of the interview is a narrative account by the participants of their experiences related to the topic of study. However, in the current study, the researcher elected to use diaries as well as interviews to collect data over a three month period. This is shown in Figure 2.

Figure 1: Data Collection process

```
┌─────────────────────────────────────────────────────┐
│                                                       │
│                      Phase I                          │
│                                                       │
│   keep a weekly diary for the first three weeks       │
│                 post discharge                        │
│                                                       │
└─────────────────────────────────────────────────────┘
                          ↓
┌─────────────────────────────────────────────────────┐
│                                                       │
│                      Phase II                         │
│                                                       │
│            Individual Interview at week 6             │
│                                                       │
└─────────────────────────────────────────────────────┘
                          ↓
┌─────────────────────────────────────────────────────┐
│                                                       │
│                     Phase III                         │
│                                                       │
│           Individual Interview at week 12             │
│                                                       │
└─────────────────────────────────────────────────────┘
                          ↓
```
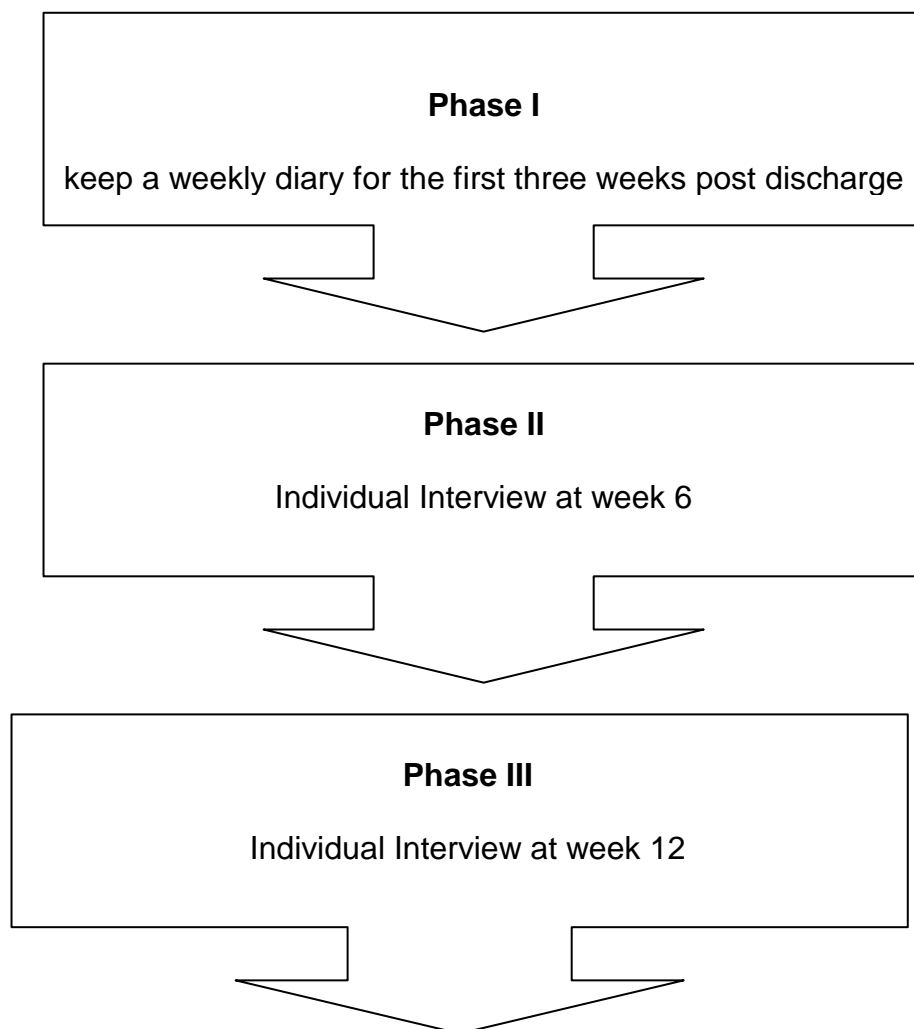
Diaries were decided upon (Phase I) as a means of enabling the researcher to to grasp the immediate quotidian experience of carers in the early discharge period, as represented in a written narrative. Three weeks after the submission of the diaries, at week 6, the researcher interviewed the participants (Phase II), following this up with a secondary interview at week 12 (Phase III). Interview responses comprise a narrative account of the lived, or subjective, experiences of the participants. The methods described are consistent with the naturalistic paradigm, eliciting types of data which enable the researcher to engage with and reflect upon subjective meanings and the nature of socially embedded individual experiences. The result of such engagement is the revelation (as opposed to the generation) of themes, and the discovery of the essence of the participant's life-world; the use of diaries and interviews facilitated the passive and co-operative engagement with the participant's world and experiences which made this possible. The following paragraphs discuss details of how the researcher designed diaries and interview schedules as well as how data was collected.

3.5.1 Diary

Diaries and journals have been variously deployed across the ages – as a simple record of what happened over the course of a day, as a confessional, as a form of therapy permitting people to disclose deep reflections on their spirituality, marriage, family relationships, and so on. The advantage of using a diary as a data collection method is that it produces rich data in which participants can unfold a series of events and perceptions relevant to specific actions and their reactions rather than relying on recall of past events (Richardson, 1994; Bolger et al., 2003). Bradburn et al. (1987) state that recall of past experiences involves active reconstruction which may introduce inaccuracies. Because of the shortcomings of retrospective

recall, it is important for the researcher to employ alternative measurement strategies. The diary, by limiting recall and capturing experience close to the time of its occurrence, is generally regarded as one of the most reliable sources of accurate data.

Diaries are self-reporting instruments used regularly (often daily) as a means of examining ongoing experiences; they offer the opportunity to investigate social processes within everyday situations, simultaneously recognising the importance of the contexts in which these processes unfold. They can be viewed as a useful means of capturing the everyday life experiences which fill most of our working time and occupy the vast majority of our conscious attention (Bolger et al., 2003). Reading the diaries collected at the end of Phase I in the current study, events, issues or experiences participants had been through became evident, and the researcher was able to reflect that the invitation to participants to keep a diary had fulfilled a useful social and psychological purpose. Menand (2007) states that:

> *diarizing is a natural, healthy thing, a sign of vigor and purpose, a*
> *statement, about life, that we care, and that non-diarizing or, worse,*
> *failed diarizing is a confession of moral inertia, an acknowledgment,*
> *even, of the ultimate pointlessness of one's being in the world.*
> *(Menand, the New Yorker,*
> http://www.newyorker.com/arts/critics/atlarge/2007/12/10/071210cra
> t_atlarge_menand)

Taylor and Taylor seem to concur both with the researcher's and Menand's judgement, describing the diary as follows:

> *'A diary is like a drink' wrote the Scottish Poet…… Others have*
> *kept their books (diaries) only in special times – over the course*
> *of a trip, or during a crisis. Some have used them to record*
> *journeys of the soul, plan the art of the future, confess the sins of*

the flesh, lecture the world from beyond the grave. And some of them, prisoners' and invalids', have used them not so much to record lives as create them, their diaries being the only world in which they fully lived. (Taylor & Taylor, pp.ix, 2000)

Diaries have for many years been a powerful tool for studying various human phenomena, including those associated with healthcare, such as physical symptoms (Richardson, 1994), behaviour changes (Vannier & O'Sullivan, 2008), and mental health (Alloy et al. 1997). Information from diaries has helped researchers understand and clarify the issues related to these health areas. One of the crucial benefits of using the diary as a method is that it permits the examination of reported events and experiences in their natural context (a benefit specifically exploited in the current study), providing information complementary to that obtainable by more traditional designs (Clayton & Thorne, 1994; Bolger et al., 2003). Another benefit is that it by minimizing the time elapsed between an experience and the account of that experience, the diary may reduce the likelihood of retrospection, admitting the possibility of more spontaneous and frank responses to experience.

In the current study, it was assumed that the participants would be very much preoccupied with the business of caring, particularly in the first three weeks after discharge, when the scope, intensity, and strangeness of new responsibilities would be most challenging. In light of this likelihood it was considered a matter of priority for the researcher to employ a method of data collection simultaneously capable of yielding data of depth and sensitivity while representing the smallest disruption into the participants' day. The medium of the diary proved ideal in this regard.

In order to maximise the effectiveness of the diary for this purpose it was necessary to think very carefully about its design. As such it was a clearly vital to focus on the research questions which represent the core aims of the study, and consider the ways in which the diary should address them. A poorly designed study diary may involve considerable effort but yield little useful information. Bolger et al. (2003, p581) suggest three principles which should be taken into consideration to achieve research goals when the medium of the diary is involved in research design:

- Building a relationship to obtain the person's information

- Observing intrapersonal changes over time, as well as individual differences in such changes

- Understanding the intrapersonal changes and individual differences in these changes over time (Bolger et al., 2003, p581)

Such considerations played an important part in the formulation of guidance notes and advice regarding the purpose of the diary and the most helpful and beneficial way to use it. These were given to participants at the outset of the study.

.

Wheeler and Reis refer us to three specific diary designs employed as a means of data collection in research studies (Wheeler & Reis 1991). The diary designed to be used at timed intervals is the longest established format, based on the familiar daily diary. It requires participants to record events and report on their experiences at regular, predetermined intervals. Most commonly individuals who keep diaries favour a specific time – often the end of the day – at which they make entries for the preceding period, reviewing and reflecting upon their experiences. The shortcoming of this design is the length of period the diarist is required recall,

and thus the length of time it is likely to take to make the entry – a commitment some individuals (not least tired carers) might be reluctant to make.

A second design is the health diary. Health diaries have been employed for three purposes – as a principle data source for levels of well-being, incapcitation, medicinal intake etc; as a means of reporting and comparing levels of debility or well-being for retrospective and prospective data, and as a simple aide memoire for the reporting of health events in later interviews. The challenge of this design is that it places a very heavy reporting burden on the participant – with regard to the amount of data required, its possible complexity, and the necessary frequency of required entries.

The third design is the event record; this is the most distinct design strategy, requiring participants to provide a self-report each time a specified event occurs. This design enables the assessment of specific occurrences and attendant factors related to them, such as a headache and its severity. Data of this nature may not always be captured by fixed or random interval assessment (Clayton & Thorne, 1994; Wheeler & Reis 1991). The drawback of such a design is related to the possible partiality of the evidence recorded, for instance as a consequence of participants recording events they consider to be most impressive or otherwise significant. A further disadvantage of diaries in general is that the researcher is unable to respond to the offering of information at the time of its inclusion – for instance by probing for further information, as might be possible in an interview (Richardson, 1994). To overcome this problem, the researcher may need to triangulate evidence collection, deploying other means of collecting data to corroborate findings.

In the current study, the researcher chose a time interval diary as most suitable to the naturalistic paradigm, (whose aim is to understand participants' experiences within their own context). Interview is the commonest approach in fulfilling the requirements of the naturalistic paradigm, but it was assumed that the participants might be too busy in the early stage of caring post discharge for interview to be either a practicable or fair imposition. The time interval decided upon was a week; the reason for choosing a weekly diary was in order to minimise pressure and levels of disruption for participants.

3.5.1.1 Diary Design

Bolger et al. (2003) suggest that the researcher must choose whether to have participants report relevant events immediately after their occurrence or to allow participants to postpone responding at inopportune moments. In the current study, the researcher was interested to obtain a broad range of information contributing to an understanding of the participants' experiences in the three weeks following discharge, but with the proviso that the requirement of providing information should not interfere overtly in the day to day management of their daily lives. It was therefore decided to provide each participant with a set of semi-structured questions based upon the main research questions, in order to guide them as to the preferred areas of information and the level of detail sought. It was hoped by this means to reassure participants, and minimise the amount of time required to make entries by avoiding the inclusion of redundant material. The researcher recognised that a weekly, rather than daily, time interval might militate against levels of accurate recall, but was reassured by the consideration that the repetitive

nature of the tasks and responsibilities for each new carer would most likely reduce this risk.

A document was prepared designated as a user guideline; this showed the participant how to record in his/her diary. A diary pack was then prepared comprising the user guideline, three weekly diaries and three self-addressed stamped envelopes. Each of the three weeks was distinguished by a different colour further facilitating ease of use: week 1 was yellow, week 2 was blue and week three was pink.

Creswell (2009) states that qualitative researchers collect data by examining documents, observing, or interviewing participants. The diary was designed in such a way as to represent a conflation of these approaches – a semi-formal document whose information content is guided in the same way that content may be guided in interview, ie by semi-structured questions encouraging an open and personal response. There were a number of issues to which it was thought necessary to direct participants - ie what tasks they were undertaking; how these differed from the usual chores; what help they received and from whom, and (possibly most importantly) how they felt about their situation. The original diaries questions were as follows:

Diary Questions

- Would you please think back to the day your husband or wife was discharged from hospital and write down what things you had to do which you would not normally do?
- What were the different things that you did during that whole week when your husband or wife was discharged from hospital?

- How did you feel about those changes during that week? Can you explain why you felt that way?

- What things did you find especially difficult during that week? How did you deal with them?

- Did anyone help you with any of these things? Who did help you when you needed it? How often did that happen? Was there any help you needed but did not receive?

- Did you get help from any professionals during this time? How did that work out? Was there help you needed but no professional gave it? Can you describe that here?

- Can you please give me your opinion of what sort of support would have helped you best during this time?

The diary was constructed in booklet form, with open formatted leaves allowing participants space to write as much or as little as they wished. Extra blank sheets were included for comments from the carers about any issues they thought important to raise during the period. In order to test the overall diary design, a small pilot stage was planned and run shortly before the three week period.

Originally identical questions were to be asked for each of the three weeks, but after the pilot this approach was modified so that identical questions appeared in the first two weeks, and modified questions in the third. In week one and week two participants were asked to record what happened during the week, including daily tasks, routine assistance and so on (Appendix VI & VII). The third diary asked the participants to reflect on their experiences over the entire three week period (Appendix VIII). This allowed the researcher to investigate the individual changes for each participant over time.

3.5.1.2 Diary Piloting

Prior to the main study, most researchers carry out pilot studies to test the feasibility of the data collection methods and to develop relevant questions (Oppenheim, 1992). Pilot studies have been recognized as providing a significant contribution to quantitative and qualitative studies. In the current study, the aim of the pilot was to assess the degree to which the diary questions elicited answers in line with the requirements of the main research questions. As a more straightforward alternative to sampling the pilot participants, the researcher distributed information to neighbours and colleagues with experience of caring for a relative. One of the researcher's colleagues whose husband was about to undergo a minor surgical procedure, offered to assist in testing the diary questions in the three weeks following her husband's procedure. This provided a specific opportunity for the researcher to review and revise the appropriateness of the diary questions for carers looking after a relative in the immediate aftermath of hospital discharge. The diary pack was distributed by the researcher and informed consent obtained. The results of the pilot suggested that revision was required – a suggestion particularly influenced by advice from the above-mentioned colleague who recommended that the phrasing of the diary questions should be more straightforward. The researcher discussed this proposition with the supervisory team and made appropriate changes. This made the questions simpler and responses easier to record for the participants. Figure 2 shows the revised diary questions.

Figure 2 Shows the revised Diary Questions of Week 1

Diary Questions (Week 1)

1. Think about this week; this is the week that xxx came home from hospital. Please write about the things you are doing for him/her.
2. Which of these things do you not normally do for him/ her?
3. How do you feel about these changes this week?
4. Why do you feel this way?
5. What things did you find especially difficult during this week? How did you deal with these matters?
6. Did anyone help you with any of these problems?
7. Who gave help when you needed it, and how often did that happen?
8. Was there any help you needed which wasn't forthcoming?
9. Can you describe the help you got from nurses or doctors during this week?
10. How did they know you needed help?
11. Was there any professional help you needed which wasn't forthcoming? Can you tell me about it?
12. Please write about any other support that would have been particularly helpful this week.

During week 2 of the pilot the above-mentioned participant returned her diary expressing concern that questions between week 1 and week 2 were similar. The researcher explained that the duplication of questions between weeks 1 and 2 reflected her supposition that the range of activities dominating the participants' lives during that period would be broadly the same. The participant contested this, suggesting there would be changes in the nature of activities every week. These comments were taken into consideration and refinements made in the form of slight amendments to a few of the questions. The revised version is presented in Figure 2.

Figure 3 Shows the revised Diary Questions of Week 2

Diary Questions (Week 2)

1. What were the things that you don't normally do for xxx? How did you deal with them?
2. How do you feel about these changes this week?
3. Why did you feel that way?
4. Did anyone help you with any of these things?
5. Who helped you when you needed it and how often did that happen?
6. Was there any help you needed which wasn't forthcoming?
7. Can you describe the help you got from nurses or doctors during this week? How did they know you needed help?
8. Was there any professional help you needed which wasn't forthcoming? Can you tell me about it?
9. Please tell me about any other support which would have been particularly helpful this week.

During week 3, the participant returned her diary and explained that her husband's condition had improved since the first two weeks, meaning that her level of responsibility was reduced. Consequently she felt that a number of questions in the diary might no longer be suitable. The week 3 questions were subsequently considerably altered, on the assumption that a similar degree of improvement would be manifest in the cardiac patients as in the pilot sample. The general emphasis of the questions was shifted from straightforward recall towards participant reflection. The final version of week 3 diary questions was presented as follows.

Figure 4 Shows the original design of Week 3 Diary Questions

Diary Questions (Week 3)

1. Can you describe how you feel during this week and why?
2. On the basis of all you have written in your diaries during the past two weeks, can you explain what the word 'support' means to you?
3. As a relative or friend, what information would you like to have now that would have helped you, but which you have not mentioned before?

3.5.1.3   Limitations of diary design

Burns and Grove (2009) describe the pilot study as a small-sample preliminary study conducted prior to the main research in order to establish the feasibility of the study in general and the data collection methodology, or, where appropriate to improve the design of the research. As described in the previous section, one such test was employed in the current study before the diary design was finalised, specifically to trial the suitability of the questions. Given that use of the diary precluded the possibility of observation or discussion of any of the points made by participants, the researcher decided to narrow the range of questions - for instance requiring that participants refer to only a limited number of weekly activities, such as washing and shopping. Another issue raised in the pilot was that the design of the diary necessitated a consistent level of participant commitment if valid and reliable data was to be forthcoming (some pilot participants left questions unanswered). The issue of question length was also considered, but in the end it was decided to leave the questions at their original length. The burden of repeated queries and responses places substantial demands on the participants; considering this, some researchers will design diary questions which are short and take only a few minutes to complete. However, this can limit diary studies to a somewhat shallow level of data, something, which in the case of a study employing a descriptive phenomenological approach is counter-productive.

3.5.2 Interviews

An interview is a conversation which can connect researcher and participant, and/or diminish the distance between them (Johnson, 2000). Kvale (1996) defines the qualitative research interview as a method of data collection which fulfils the need for both factual and meaningful experiential information, enabling the

phenomenon under study to be more fully unfolded and deeply explored. Kvale and Brinkmann (2009) suggest that 'meaning' as such is established insofar as the researcher is able to identify and describe the central themes in the life world of the subjects, acquiring an understanding of their experiences, and of the story behind them. The great advantage of the interview in this regard is the opportunity it provides for the researcher to follow up points made by participants, either in the course of the interview, or in other formats, such as questionnaires (McNamara, 1999). Bell (2006) describes this virtue in more detail, referring to the 'adaptability' of the interview, explaining that an experienced and skilful interviewer will follow up ideas with probing secondary questions to investigate feelings and deepen understanding of the events related, thus providing a level of disclosure unlikely to be forthcoming in written responses. A brief overview of the various interview types available will demonstrate the potential for this level of data in each, and provide an explanation of the interview format adopted in the current study.

The interview format falls into three broad types - Structured, Semi-structured, and Unstructured. The following table summarises the three different types of interview and the questions characteristic of each format:

Table 5 I-Tec Typology of interviews

Type	Form	Response	Use	Questions
Structured	Most common format is open-ended survey questions; short answers; often include interviewer directions on specific probes and when to use them	Highly controlled and specific; limited detail; most easily comparable since each person interviewed has been exposed to exact same group of questions	easily integrated into surveys; effective with large study populations; generally easiest type of interviewing to "train up" staff to conduct	Over the last month, in what locations did you buy drugs?
Semi-structured	'Interview guide' can guide the interview all questions written down; script includes interviewer instructions	Controlled; more detailed; comparable responses; little room for exploration beyond interview script	With adequate training and practice, can be used successfully with less experienced interviewers; easier to compare answers	Can you tell me about the first time you and your partner talked about using condoms? [Prompt: Who first suggested condoms? What did you/he say? How did you/he react?]
Unstructured	Other than a topic no interview guide, the interview control by the interviewer	Less controlled; exploratory and flexible; informants are encouraged to tell their stories	Quality of data depends on interviewer's skill; generates a large amount of rich, detailed data; very effective for uncovering new information	Can you tell me about your first boyfriend?

Source : I-TEC (2008) Qualitative Interviews. USA: Washington

The aim of a structured interview is to ask questions with fixed choices, posed in a logical and standard manner (Britten, 1995) - for instance, through questionnaire and follow up. The advantage of this approach is that such interviews are more time-efficient than semi or unstructured alternatives. Given the restricted nature of possible responses, for the structured interview to be effective it is important that the researcher develop the questions carefully. Even so, structured interviews are best used when a lot of information about the topic is already known (Bryman, 2008). The limitation of this technique is the comparatively 'closed' nature of the responses available to the researcher, and the overall inflexibility of the approach. The structured interview does not permit the interviewer to pursue topics or issues that may arise spontaneously, or fall outside the parameters of the prepared questions. Structured interviews also reduce the extent to which individual circumstances or differences can be explored.

Semi-structured interviews are generally organised around a set of predetermined but open-ended questions (Mason, 2006), with other questions emerging from the dialogue between the interviewer and interviewee. The interviewer usually works with an interview guide, which includes probing and non-probing questions, and contains prompts (as opposed to fixed questions) allowing for a degree of flexibility. Kvale and Brinkmann (2009) explain that the interview guide allows an interviewer the relative spontaneity necessary to follow new leads, while at the same time demonstrating that the researcher is prepared and has the situation under control. The interviewer will need to switch skilfully between different types of questions in order to clarify responses or encourage elaboration if a participant seems to provide contradictory information. Semi-structured interviews are very useful tools for obtaining specific details about a topic that has already been explored but is

not fully clarified. This technique also works well in situations in which time must be efficiently used.

The term 'unstructured' is to a certain extent misleading, since no interview is completely devoid of framework and direction. If it were, it would be a serious challenge to ensure that the data gathered satisfied the requirements of the overall research questions. Unstructured interview is the term used to describe a form of controlled intercommunication intended to allow participants to express themselves freely with minimal restriction imposed by the interviewer, in order to elicit the maximum possible information about a particular topic (Kvale,1996). The unstructured interview is useful for the exploration of new or partially familiar topics and ideas. Unstructured interviews may involve informal discussion, meetings or conversations. The interviewer customarily explains the topic before the interview starts and proposes a few premeditated directions as a means of steering the discussion. During the interview, this level of partial control is maintained, the interviewer guiding the flow of information by probing the informant for more detail while making sure the discussion doesn't veer too far off topic. Because of its interactive nature, unstructured interviewing often depends on the ability and experience of the interviewer. For this reason, practising before the interview or selecting interviewers with demonstrated experience and skills is important (Bloom-DiCicco & Crabtree, 2006).

In the current study, a semi-structured interview design was employed to collect data. This is consonant with the common practise in naturalistically based research, for which interview is generally held to be the optimum format for gathering information. Interview is of course a feasible approach in positivistic

research, but is more likely to be structured and directed towards the derivation of quantitatively oriented findings - specific questions with a fixed range of possible responses (Bryman, 2008). Such data would be unlikely to provide the depth of experiential understanding the researcher sought in the current study. The semi-structured interview was favoured because it permitted the development of dialogue between researcher and participant which was considered crucial if any true penetration of the participants' ideas and emotions was to be achieved. At the same time, it was felt that the existence of a structure would provide the reassurance of control both for the researcher and the participants in their exploration of issues and experiences which might conceivably be sensitive and difficult. An additional benefit of the semi-structured interview is that it not only provides the opportunity for face-to-face interaction between researcher and participant, but allows sufficient flexibility in the course of that exchange for the researcher to observe and record any modulations of facial expression and body posture which might occur in the course of the interview. Such observations furnish a rich complement to verbal data, providing a subtle and significant interpretative context to the words spoken. It was the researcher's feeling that many of her participants might encounter difficulty articulating thoughts and feelings about the issues of caring - particularly since this responsibility and its concomitant levels of stress were likely to be new and strange to the majority of them. The semi-structured interview seemed in this regard to offer the most reassuring format for the participants, while at the same time providing a means of apprehending their experiences on a deeper level.

In order to apprehend the full richness and breadth of participant response, each interview was tape-recorded, and supplemented by written notes. The latter, in

particular, allowed the researcher to acknowledge and reflect upon those elements of interaction which cannot be adduced from the audible exchange.

3.5.2.1   Interview Design

The design of the interview involved considerable thought and preparation. The project was constructed as a means of uncovering the participants' experiences of caring for their relatives and to investigating changes in those experiences over time. Therefore it was decided that the interviews would be conducted at week 6 and week12 post discharge. Literature suggested that the recovery period following discharge would be two to three months (BHF, 2008); the interview windows were selected to reflect participant experience and disposition at the mid-point and end-point of this period. An interview guide was developed to support the participants in the interview process. It comprised twenty-two questions. These were formulated in order to encourage participant responses in three general areas of inquiry:

- What did the carer do when the patient was discharged?
- What is the day to day experience of caring; how does it feel?
- How has the carer managed things during this time?

 The original interview guide is shown in the figure 4.

Figure 5 Shows the original Semi-structured Interview Guide

Semi-structured Interview Guide

1. I see from your diaries that you have been doing ****** and ****** and ******* and ****** with ****** Can we take each activity in turn and talk about your experience of doing these things and the kind of support that you had?

2. You said in the diaries that you were doing****** and that you felt***** can you explain this further?

3. Why is this question unanswered in the diary?

4. How is ***** since he/she got out of hospital?

5. When did ***** get out of hospital?

6. How did *****get home?

7. Were you involved in the discussions about his /her discharge?

8. Can you tell me about the things you have been doing at home when **** was discharged from hospital?

9. How did you manage with these things?

10. I do not quite understand about ****, can you explain it further?

11. Did you get much help?

12. If yes, from whom and how was it?

13. If no, what do you think about that?

14. Where do you anticipate your support should come from?* Why?

15. What is your experience of professional support?*

16. How do you think your support needs can be best met? During our talk you've said that ***** helps you and that this has been a good/insufficient source of support. Can you explain your opinion of this support? What support do you think would have been better and why?

17. In your conversation you mention…….. Why?

18. What do you mean by ……….?

19. Can you explain what you mean by….?

20. I'm not sure that I understood you when you said……Can you say it again?

21. Can you tell me about what help you've received and how that help is offered?

22. In your conversation, you mention that you have been worried; what was the cause of your worry at this time?

Since the larger design of data collection comprised two sections – the diary phase and the interview phase – it was considered appropriate that the interview guide contain two sections: the first section clarified questions which arose from the diaries, the second section asked the participants to offer insight into their experiences during the first 6 weeks after discharge. These were interspersed with non-specific probe questions such as 'can you explain it further?' 'what do you mean by this?' in order to encourage clearer articulation or a deeper level of disclosure on key points. Each interview was planned to be recorded by digital voice recorder. If participants were unwilling to be recorded, note-taking would be substituted. Each interview would last 60 to 90 minutes. It was assumed that participants would be willing to share their experience; the researcher used open-ended questions in the course of the interview as a means of encouraging participants to do so. The interview guide was initially piloted; following this it was used to collect data in Phase 2 and Phase 3 of the study.

3.5.2.2   Interview Piloting

Bryman (2008) suggests that piloting an interview is an important means of enhancing the researcher's confidence.   Improving the shape and flow of questions, identifying and maximising opportunities for natural conversation are important considerations towards this end. It is also important, as Bryman (2008) goes on to point out, that the researcher assures him/herself as to the adequacy of instructions for the interviews. This element of data collection is more likely to be successful if the participant, as well as the researcher, is confident and secure as to the form and purpose of the interview procedure. In the current study, a small pilot of interview data collection was conducted in order to test the effectiveness of the interview guide and allow the researcher to rehearse her interview skills. The

researcher distributed information about the research to colleagues. Three colleagues with first-time experience of caring for post-operative patients volunteered to join the pilot. This series of interviews was carried out in a quiet room at the university. The participants were all female spouses. Prior to the commencement of the interview, the study was introduced and its topic clarified. The experience of the pilot provided a useful general idea as to the shape and tenor of the interaction, and how best to sustain and conclude it. The most conspicuous finding from the pilot was the realistion that the planned structure of the interview was too rigorous and dogmatic. This deficiency was accordingly rectified. The revised interview guide is shown as follows:

Figure 6 Shows the revised Semi-structured Interview Guide

Semi-structure Interview Guide

I have read the diary you completed and returned to me; there are some points I would like to clarify:

1. In your diary, you said that you……… Can you explain this further?
2. In your diary on week….., you said ……. What makes you think this?
3. In week three in your diary you wrote ………What did you mean by this?
4. In week...in your diary, you mentioned that……How do you know that?

Thank you very much. I feel clearer about the information you have given in your diary. Your diary was really helpful for my research. Now I would like to ask some more in-depth questions about your opinion of support needs. You can talk about anything you want to with me.

1. In the light of what you have said before, what are your feelings about the caring experience now?
2. In comparison with the first three weeks, what are your feelings now?
3. Some probing questions I can ask during the interview:

   Can you give me more detail about this?

   What do you mean by that?

   Please explain this further.

   How do you know this?

   Why do you feel this way?
4. Is there anything else you would like to say which you have not so far mentioned?

`

3.5.2.3   Limitations of the interview

A well planned and flexible interview should enable the interviewer to obtain descriptions of the interviewee's life world, and interpret the meaning of the described phenomena (Kvale and Brinkmann 2009). In the current study, this presented a particular challenge, because the interviewer hails from a different culture. Much of the success of a semi-structured interview depends upon the

132

interviewer's ability to react spontaneously and intuitively to naturalistic expression, embracing a range of cultural inflexions and usages, as well as culturally specific non-verbal semiotics. Particular difficulties faced in the pilot were the participant's use of dialect words, such as 'goonie' for 'nightie'. The solution to this problem was for the researcher to make a specific request that participants use as little slang as possible. This, with the addition of clarifying questions, such as 'What do you mean by that?' 'Can you explain this further?' proved a sufficient strategy to facilitate clear communication.

Prior to the interview, it is also essential for the researcher to develop a broad overview of the entire investigation, establishing a foundation from which the more flexible conversational level of interaction may develop (Kvale and Brinkmann 2009). This was very clearly brought out in the course of the pilot; it was pointed out that the researcher's natural apprehension prompted her to rely too heavily on the interview guide, resulting in a somewhat stilted and hesitant exchange. Other valuable pointers to emerge from the pilot included advice to the researcher from her supervisory team to be sensitive to the domestic and social environment of her participants. It was suggested this would enable her to understand and accommodate any preconceptions or apprehension interviewees might feel as to the nature of the conversation between themselves and the researcher.

3.6 Main study

3.6.1 Sampling

Choosing a study sample is an important step in the research project. It is, of course, impossible to study a whole population, and is therefore important to

consider the most practicable means of representing that population in the group of participants who take place in the study. In order to achieve a genuine representation it is necessary first to understand what is meant by the term 'population'. Saks and Allsop (2007) suggest that 'population', in terms of a research study denotes a target group of interest to the proposed investigation. Bryman (2008) offers a similar definition, describing a group which comprises those 'universe units' from which a research sample is to be selected. The term 'units' in this definition refers to the fact that the sample may not necessarily be composed of individuals – the researcher may want to sample from a 'universe' of general unitary groups such as nations, cities or regions.

Sampling is an inevitable step in any research study. Whatever method is used to collect data, decisions will always have to be made about who and where to collect data from - decisions which will have a fundamental effect on the quality and usefulness of findings (Polit et al., 2001). It is therefore no surprise to find that many research texts devote much space to the minutiae of sampling techniques, and the various types of sample which may be included in the research study. In the broadest terms, sampling falls into one of two types – probability sampling and non-probability sampling. Within the range of procedures embraced by these definitions sampling may be more specifically identified by the degree to which the composition of the group selected for the sample is likely to contain a fully representative cross-section of the research population. This is partially related to the degree of purposive intervention on the part of the selector in the selection process.

A probability sample is selected in such a way as to be fully representative of the

research population (Bryman, 2008). Such samples are generated by random or stratified selection (Burns and Grove, 2009); both of these approaches guarantee that each unit in the population stands an equal chance of being represented. Probability samples may be said to provide valid or credible results insofar as they reflect the broad range of characteristics in the population from which they are selected. In purely random sampling there is no purposive intervention at all in the process of selection. It is arguable that where such a selection strategy is employed, there is always a chance, albeit remote – that a particular subgroup within the population may be over-represented - a likelihood greater where smaller samples are involved. For this reason purely random sampling is more appropriate in research studies which involve large samples; the larger the sample, the less chance there is of one or another element of the research population dominating. Stratified sampling is distinguished from purely random sampling inasmuch as there is purposive intent on the part of the selector to ensure elements of the population which are of importance to the research study are fairly represented; before sampling, the research population is divided into levelled categories, or 'strata' of importance for the study. Following this the population within each stratum is randomly sampled (Saks and Allsop, 2007). Stratified sampling might therefore be appropriate in cases in which samples are small, but are nonetheless intended to be fully representative of the population.

These two sampling strategies are regarded as the most suitable for quantitative research design because quantitative research is more often concerned with testing hypotheses – a practice in which objectivity is of paramount importance. It is thus necessary in any such research that the participants who are featured in the study comprise the most broadly representative sample of the research

population. A representative sample is more likely to be the outcome when probability selection is employed.

Bryman (2008) defines non-probability sampling very simply as a form of selection that is not random. A more accurate definition might be that non-probability sampling is a form of sampling which, either by accident or design, is non-representative. The approach in general is divided into two specific categories – Convenience (accidental) sampling and Purposive (designed) sampling proper. Convenience sampling falls into the non-probability category inasmuch as it may yield samples which are unrepresentative in the extreme. This is in consequence of the fact that selection is dictated simply by the accessibility of the sample (Marshall 1996); the sample is literally taken from units which are 'conveniently' to hand. It could be argued that this approach is in some ways more 'random' than stratified sampling, since there is no element of purposive intervention on the part of the researcher. However, unlike stratified and random sampling convenience sampling risks generating poor quality data. This tends to suggest that where the equalising effect of randomly selected high numbers is impracticable and/or inappropriate for the study, some degree of purposive intervention is desirable in the sampling process if data is to have integrity.

The most extreme example of conscious intervention in the composition of the sample is Purposive sampling. Bryman (2008) defines a purposive sample as a non-representative subset of some larger population, constructed to serve a very specific need or purpose. Manson (2006) emphasises that the particular virtue of the purposive sample is for the generation of information rich cases, facilitating in-depth study. The quality of information, and the size and specialised, nature of the sample are factors directly answerable to the deliberated purpose of the study.

There is a strong argument in favour of purposive sampling in qualitative research. Lincoln and Guba (1985) remind us that in qualitative research the study design is emergent rather than preordained - determined by the context in which research is conducted and based on the researcher's construction. Purposive selection deliberately limits the scope of participants - both in terms of demographic range and size - favouring quality over quantity (Todres, 2005). This make it highly suitable for qualitative research (particularly in harness with grounded theory); the limited sample size enables a closer more intuitive focus on the evidence generated, and thus a more sensitive response to the emerging categories of experience characteristic of grounded theory qualitative research. Whereas positivistic quantitative study tends to search for objective results, drawing evidence from randomly selected samples; naturalistic research sets out in pursuit of complex subjective understandings, for which small selective samples are most appropriate and useful. Such samples lend themselves to the apprehension and deeper understanding of experiential data – the humanistic 'why' and 'how' questions characteristic of qualitiative inquiry (Byrne, 2001). The phenomenon under investigation in the current study is the experience of caring; there would be limited logic in seeking evidence of this phenomenon from individuals who have had no involvement in caring; further, it represents a sensible refinement of research design to seek a sample amongst those whose experience is most complete (Holloway, 2005).

3.6.1 Sample selection

For the selection of a sample, the researcher formulated inclusion and exclusion based around the necessity of securing participants with experience of caring for

relatives in the period following discharge after cardiac surgery, with the specific aim of discovering new meanings and describing previously unexplored areas of carer experience,. Ten participants were recruited from a Teaching Hospital in Scotland. Although the sample size was small, it was considered necessary to apprise all participants as to the nature and aims of the study to encourage the development of rich data. The sample selection and criteria are described below.

3.6.1.1 Inclusion Criteria

1. Participants who are aged 18 years old and over and are the significant other of the patient;

2. Participants who live with or visit the patient at least once a day, during the first three months following cardiac surgery;

3. Participants who live within the Lothian area.

3.6.1.2 Exclusion criteria

1. Participants who are aged under18 and are not the significant other of the patient;

2. Participants who live outside the Edinburgh and Lothian area;

3. Participants who did not visit the patient at least once a day, during the first three months following cardiac surgery.

Following an unsuccessful attempt to recruit participants from a leading Scottish medical charity, and discussions with the Supervisory Team, the recruitment setting was changed to a clinic centre at a teaching hospital in Edinburgh. Ethical approval was sought from the School Committee (Appendix IX) and from Lothian Research Ethics Committee (Appendix IX) and was obtained. Bryman (2009)

described some of the reasons for the production of a representative sample and these include:, the availability of the participants during the time of the study and the researcher's judgement about how friendly the people concerned are likely to be or by how comfortable the participants might feel about being interviewed as well as how the researcher feels about interviewing participants of the same or opposite sex. Therefore it is important that the researcher provides detailed information in the research information pack and to give the participants time to think and reduce anxiety about being interviewed. The second attempt to recruit participants was carried out in the hospital clinic. This recruitment attempt was very successful. At this time the researcher joined the clinic meeting with the carers and patients together. This meeting provided a chance for the researcher to meet the carers and to be involved with the process that the carers and patients were going through. While the patients were being examined, the researcher had time to meet the carers face-to-face and to explain the purpose of the study to them.   Ten participants volunteered to join the study. These participants were recruited between November 2005 and July 2006. Eight of the participants were female spouses and were aged 55 - 75. One participant was a sister (45) and one a male spouse (75). On reflection, it might have been better to tighten the inclusion criteria to only have included female spouses since the majority of people having cardiac surgery are men. Although the sister and a male spouse fitted in the inclusion criteria, it may have been better if the researcher had made all the participants female spouses. This might reduce potential bias because it would from the view with the same gender. One of the important things in sampling is to select a group which would be cohesive with respect of the data. In reporting or integrating the experiences of these carers, the attempt was not to have the sister or the male's experience overshadow that of the other participants' experiences.

Although their experiences would be different, this has to be acknowledged in the interpretation and reporting of the data.

Detailed demographic information about participants will be given in Chapter 4 where their stories are presented. Holloway and Wheeler (2002) suggest that a degree of demographic variation within the sample may enhance the researcher's apprehension of the structure and dynamic of phenomena related to the lived experience of participants. Thus, the two ostensibly anomalous participants described above were welcomed as a means of enriching data. Thirty-three diaries were completed, and twenty interviews were conducted between July 2006 and June 2007.

3.6.2 Phase I Data Collection

In the current study, weekly diaries were used to collect the data in the first three weeks. This decision was made because it was assumed that the carers would be very busy during this time. While it was clearly important to achieve an understanding of experience immediately following hospital discharge, it was equally important to cause minimum interruption to the participants; a likely undercurrent in this data would be related to levels of stress, and the researcher reflected that any unwitting contribution on her part to the raising of those levels would not only be generally inconsiderate, but might also compromise the integrity of the data gathered in this period.

Bell (2006) suggests that in a small sample qualitative study it is important to contact and meet up with participants in order that the purpose of data collection

can be explained fully. Accordingly, when the patients and their relatives were called to a clinic meeting, prior to surgery, the researcher made a point of attending. The purpose of the meeting was to explain the surgery procedures. Following the meeting, the patients were taken for their pre-op examinations in atrium, while the family members remained in the room. At this point, having joined the meeting at the outset, the researcher distributed the research information pack to the family members. The pack included documentation covering informed consent, research information and the contact details of the researcher. The researcher explained the contents of the pack, following which each relative was asked to provide contact details and informed that they would be contacted a week hence. It was hoped that by this time potential participants would have arrived at a decision regarding their willingness to take part in the study.   A week later the researcher phoned each potential participant and asked for their decision. If the carer agreed to join the study, he or she was asked to fill in the informed consent document.   This comprises the individual's agreement to participate, in clear appreciation and understanding of the facts of the study, their implications and possible future consequences (Marshall and Rossman, 2006).   Having completed the form the participants were asked to return it to the researcher using the stamped and self-addressed envelopes supplied in the research information pack.

A week prior to the patients' operations, relatives who had agreed to participate were sent a diary pack. This included three diaries, each of a different colour, three stamped addressed envelopes and instructions for the use of the diaries. The diary was divided by colour to enable participants to distinguish more easily between the separate weekly sections. The instructions made it clear that participants were not obliged to make daily entries, but were free to record any day

within the week. Most participants made summative entries at the weekend, although one chose to keep a daily record of her experiences. Participants were reassured that the researcher was available to contact should they encounter any problems in using the diary. At the beginning of week 2 and week 3 the researcher telephoned any participants who had not returned their diaries. At the end of week 3 all the diary evidence was transcribed verbatim by the researcher. The original copies were locked in a safe place.

3.6.3 Phase 2 Data Collection

Phase 2 data collection started at 6 weeks after discharge. The first interview was timed to be held during the sixth week because it was hoped by this stage that the patient's condition would be improving, allowing participants more time to reflect on their experiences. Rubin and Rubin (2005) describe the interview as an opportunity to obtain participants' interpretations of their experiences and an understanding of their life-world. In order to maximise this opportunity, it is important to apprehend and analyse the setting and context of those experiences. This is particularly valuable if the researcher wishes to develop a 'feel' for the life-world of the participants. Experiential data, even of the most rich and personal nature, is likely to carry less impact if it is delivered in the neutral setting of a college or hospital interview room – and it is a key element of the phenomenological approach that the researcher's understanding of her participants' experiences must be informed by her own experience of the setting in which those events unfold, and thus of her own essential perceptual phenomena as they arise from that setting. Therefore it was decided that 2nd phase interviews should, (if possible agreeable to the participants) be conducted in the interviewees' homes. To this end once the diaries had been returned and the evidence

transcribed, at week 5, the researcher phoned each of the participants. The purpose of this call was to acknowledge the contribution of each individual, remind them that the interview would be conducted in a week, and discuss a suitable time and place for the interview. Bearing in mind the importance of understanding the domestic context, and the likelihood that participants may be more relaxed and forthcoming in the familiar setting of home than in a neutral space, the researcher made a point of offering each participant the opportunity of conducting the interview at home. All preferred this option. The researcher also took the opportunity to inquire after their progress in caring for their relatives. A number of participants were settled and coping well, some were still struggling with the patient's wound. This information was useful in helping the researcher to anticipate the disposition of each participant, and modify her attitude where necessary.

On the day of interview, the researcher made a point of arriving punctually. All participants were happy to meet the researcher, offering tea and biscuits prior to and during the interview. Such social nuances in the behaviour of participants are a valuable element of qualitative data, indicating not only the participants' attitude to the research process, but enhancing the overall impression of their disposition at a specific stage in the care-giving journey. Before the interview started, the researcher provided a copy of diaries for each participant to read and asked if any data was missing from their pages. All participants confirmed that the diaries were accurate and complete.

As a prelude to the main body of the interview the researcher took the opportunity to broach questions arising from the diary evidence. For example, one participant

had neglected to provide an answer to diary question 6 – an issue which was quickly cleared up. After setting up the voice recorder the researcher used the semi-structured guide to question the participant about their experience of caring over the preceding 6 weeks. The interviewees were encouraged to recall their memories, and to explore the nature and implications of stories during this time, offering evidence which they had not given in the diaries. Participants were happy to describe the events which had taken place in their lives, adding information about their thoughts and feelings in response to those events.   The researcher was gratified and encouraged by the friendliness of the participants, and their readiness to respond to her requests for clarification and further explanation. The following example features a typical exchange between researcher (R) and participant (P):

P: I helped my husband in the bathroom and he sat in the bath bridge.

R: Bath bridge...?

P: I showed you. It's in the bathroom.

R: Ok. Thank you very much.

Interviews lasted between 45-90 minutes. Each interview was recorded by a digital voice recorder and transcribed verbatim. Participants were reminded at the close of the interview that the next interview would be in 6 weeks.

Overall the Phase 2 interviews were a positive and useful experience. The only issue of any concern related to one case in which a particular participant seemed restricted and ill at ease as a result of the presence of the patient at the interview. The situation came about as a result of the participant requesting the patient's presence, in order that the researcher could see the patient's post-operative scar. Having offered this demonstration the patient seemed inclined to remain in the

room; it was only when he went upstairs to smoke that the participant revealed her discomfort at his continuing presence, suggesting that she felt somewhat constrained in her ability to talk freely. As a consequence of this incident, the researcher decided that it would be important to offer the participant the opportunity to be interviewed over the telephone in future, giving her the opportunity to speak without worrying abut the presence of the patient.

3.6.4 Phase 3 Data Collection

The second interview was scheduled for week 12. It was assumed that by this time the patient would have recovered, and that the caring role would be correspondingly diminished. The researcher phoned the participants at week 11 in order to arrange a specific time for the second interview. All participants declared that they were happy to share their further experiences, and welcomed the researcher to visit them a second time.

On arrival at the participant's house greetings were exchanged, and a relaxed atmosphere quickly established. Before the second interview commenced, a copy of the first interview transcript was presented, and an opportunity offered for the participant to make any amendments or elisions. All participants declared themselves happy with the transcript information as it stood. It was interesting to note the participants' reactions to the written record of their own words. A number expressed surprise and amusement at the amount they had said – a reaction suggesting that the alteration in their situation since week 6 was sufficient for them to forget how much there was to describe 6 weeks previously, or indeed perhaps how much they personally needed to talk about their situations.

The interview commenced with a request for the interviewee to describe his/her life experiences over the preceding 6 weeks. This was followed by a question asking the interviewee to express thoughts and feelings related to the entire 3 month period since the patient's discharge. The intention here was to establish a balance between factual information and reflection. It was noticeable, however, that once the interview was officially over – a point signified by the deactivation of the voice recorder – participants became markedly more relaxed and forthcoming, sharing feelings and thoughts which had not occurred to them under the slightly more pressurised circumstance of recording. The researcher took the opportunity to make a few notes at this point, having verified with the participant that it would be alright to do so. Each interview lasted between 45-90 minutes. All the interviews were transcribed verbatim; data analysis followed each interview. Any of the above-mentioned written notes, containing information not included in the recorded interview, were included in the data analysis.

Lincoln and Guba (1985) stress the importance of establishing the trustworthiness of data from qualitative research. As indicated above, integrity of Phase 2 evidence was confirmed by participant verification at the outset of Phase 3. This procedure was not available to the researcher in the aftermath of Phase 3, since there would be no subsequent opportunity to present interview transcripts from that phase to participants at a later date. It was nonetheless considered crucial to guarantee the richness and veracity of Phase 3 evidence. To this end the researcher resorted to a combination of two commonly recommended approaches - prolonged engagement with the data, and peer checking (Burns and Grove, 2005). These approaches were made possible through the regular presentation of

data to the supervisory team, and by data analysis. During this phase, the researcher also informed participants that the final report would be sent to them when the study was completed. It was considered that the combined effect of these steps would be sufficient to guarantee the trustworthiness of data (Lincoln and Guba, 1985).

3.7 Data Analysis

Data analysis is a practice in which raw data is ordered and organized so that useful information can be extracted from it (Grbich, 2007). The process of organizing and thinking about data is a key to understanding what the data does and does not contain. In qualitative naturalistic studies, the researcher is subject to the influence of her own experiences and their impact on the interpretation of data. It is therefore important for her to be aware of her preconceptions and interpretations (the 'phenomena' of her own perceptions) with regard to the participant's world, and mindful of how this may influence the way in which her understanding of that world develops during the analysis process.

It is notoriously easy to manipulate data during the analysis phase, consciously or subconsciously to push certain conclusions or theoretical possibilities. For this reason, it is important to pay attention when data is presented, and to think critically about the data and the conclusions which may be drawn from it. The aim of Husserlian phenomenology is to ground the foundations of knowledge, to understand underlying or 'hidden' meanings which attach to objects/events in the natural standpoint, and how participants make sense of these, in order to understand the essence of phenomena of interest (Koch, 1995). In research, this

'grounding' obtains through interaction between researcher and participants, and analysis of the data which proceeds from that interaction. It is through this process of analysis that the researcher may arrive at a certain level of truth, enabling her to describe the essence of phenomena (Holloway, 2005). There are three different approaches to phenomenological analysis, a discussion of which follows below.

3.7.1 Giorgi's style of analysis

Giorgi's (1985) structure of analysis focuses on describing the individual's lived experience and grasping the concepts of Husserlian phenomenology - description, bracketing, intentionality and the pursuit of essence. The method developed by Giorgi (1985) is predicated on the phenomenon in focus as a real object in time and space, regulated by causality; but the fundamental interest is in how such objects are perceived (Giorgi, 1989). In the current study, the researcher was interested in the experiences of relatives caring for cardiac surgery patients after hospital discharge. In terms of Giorgi's analysis, the carer is the object and the phenomenon the researcher seeks to understand is the situation in which the carer is involved. Giorgi's phenomenology studies variations within this structure as they are suggested by human descriptions (the evidence of participants). The method aims to effect a description of lived experience from interview data, and derive the phenomenological essence of that experience. This process, as it might be employed by the researcher in the current study, comprises the following steps:

- Reading of the entire description in order to derive a sense of the whole: material was carefully read to obtain an overview.

- Discrimination of meaning units within a psychological perspective: the interviews were read with a specific aim – ie the discrimination of meaning units with a focus on the phenomenon being researched.

- Transformation of subject's everyday expressions and expressions of their psychological insight: when all meaning units were classified they were discussed, and compared for sources of variation or agreement. Similar meaning units were grouped together and crystallised into a category. Reflection and imaginative variation were used.

- Synthesizing all the transformed meanings into a consistent statement regarding the subject's experience.

3.7.2 Van Kaam's style of analysis

Van Kaam's (1966) procedure of data analysis is based on content analysis. He advocates the classification of participants' data into categories. These categories must be a consequence of what the participants themselves are explicating. The categories thus generated are pooled, and attention is focused on the consistent re-occurence of categories, which may thus be expressed as a percentage (Valle, 1998). In terms of the current study, the process of Van Kaam's analysis would involve the following steps:

- Listening and preliminary grouping, classifying the data into categories.

- Reducing the concrete, vague and overlapping expressions of the subjects.

- Checking and eliminating elements that are not relevant to the phenomenon under study.

- Writing an hypothetical identification and description of the phenomenon being studied.

- Applying the hypothetical description to a randomly selected sample. If necessary, the hypothetical description can be revised. The revised description must be retested.

- Reviewing and revisiting previous steps until the final hypothetical description is identified.

3.7.3 Colaizzi's style of analysis

The basic tenet of Colaizzi's (1978) approach is that experience is always out in the world. He developed a style of analysis in order to address the objection that traditional natural science and experimental psychology cannot answer questions about experience. It was his intention to analyse data in such a way as to embrace human experiences as they are lived. It might be said that he was concerned to remind himself of the empirical lived object, and of the fact that the phenomenon – the 'hidden meaning', or essence, whose identification is the goal of analysis - derives in the empirical, lived object/experience. The process of Colaizzi's (1978) analysis involves the following steps:

- Reading carefully in order to get a full picture of the phenomenon.

- Coding and extracting significant statements.

- Formulating meanings from the significant statements.

- Summarizing the formulated meanings into clusters of themes.

- Describing the investigated phenomenon.

- Sharing the results with the participants.

3.7.4 Data analysis approach Chosen

In the approaches recommended by each of the three above-mentioned researchers (Giorgi, 1985; Van Kaam, 1966; Colaizzi, 1978) there are certain common elements. For example, original data is separated into units, units are transformed into meanings, meanings are combined to generate an overall description of the experience. There are, however, significant differences: Giorgi (1985) focuses on expressing psychological insights derived in the participants' experiences, whereas Colaizzi's focus is broader, aiming to define the phenomenological essence of an experience, while allowing that the essence may comprise other elements related to the wider empirical source and nature of experience. In the current study, it was the researcher's intention to discover the lived experience of caring – an experience in which social context as well as psychological context, is important. This consideration disposed the researcher to favour Colaizzi's analytical method over Giorgi's. Likewise, Van Kaam's emphasis on percentage recurrence of experiential categories, seemed to the researcher to represent a quasi-quantitative tendency at odds with the naturalistic basis of the current study. Ultimately, while each data analysis approach has its philosophical background, Colaizzi's (1978) emphasis on returning to 'things themselves' and on the process of deriving essential 'meanings' from lived experiences commended his approach as most suitable to the aims of the current study.   In order to understand and describe the phenomena of most interest and importance to this study, it was necessary for the researcher to go 'out into the world', placing herself in the physical and social setting of the participants' life-world. It therefore seemed sensible to select a data analysis approach embracing all aspects of lived experience.   The means by which this approach was fulfilled in the current study are detailed below.

3.7.4.1 Reading carefully in order to get a full picture of the phenomenon

Colaizzi (1978) advocated that the researcher should read and listen to the participant's narratives to acquire a feeling for them. Each diary was typed and read at least 8 times; the interview recordings were listened to at least 10 times, typed and, again, read at least 8 times. The researcher compared and contrasted each participant's diary and interview transcripts. This helped to distinguish how their experiences changed over time. During this time, all thoughts, feelings and ideas were written in a diary to assist with the reflection process.

3.7.4.2 Coding and extracting significant statements

Following the first step of data analysis, attempts were made to identify and highlight the participant's experience. Colaizzi (1978) suggests coding and extracting each transcript with significant sentences or phrases in order to draw more sense from the data. During this step, it was important to identify the relation of each sentence to the participant's story. In doing this, the researcher was obliged to pay the closest attention to what was being said; not only did the researcher code the sentence or phrase, she also wrote down what the sentence meant. Through each coding (Figure 7), the researcher discovered what events had befallen a particular participant and became acquainted with their habitual lexicon. For example, it was evident that one particular participant referred to 'stockings' both in the diary and in interview. This suggested a specific issue of importance to relatives caring for cardiac surgery patients (Figure 8). Diary and interview transcripts contained the same or nearly the same phrase, thus

repetitions of these phrases could be eliminated. The following example on Table 9 provides an idea of how the researcher coded. Following each coding, the researcher wrote down her opinion of the sentences she had already eliminated.

Figure 7 Coding of diary transcript

Diary from participant 3
I had to rig up a hoist using a belt and a piece of nylon rope which I attached to the end of the bed. The hoist lowered him into bed and allowed him to pull himself up.
*I put his surgical **stockings** on each morning, gave him his medicines.*

Interview from participant 3
We didn't. When we left the hospital they said make an appointment to see your doctor in a week's time - *that's all we were told but his legs were bleeding and every time I took the **stocking** off it would open it up again.* So, as I say, we went to the doctor after a week and she said oh, I'll go and make an appointment for the nurse to dress it. You'll get an appointment in a week's time so for two weeks he was going to have this open wound. So however, the district nurse phoned to see when she could come I said could she come right away because somebody has to look at my husband's leg. Oh, she said, I'll get a nurse then cause she did and the next day there was a nurse in here. I just felt the first week we just had none.

It was unclear if the discharge letter had been sent to the GP

The carer left hospital without any information to how to care for her husband who had a bleeding leg.
Did the carer know how to put stockings on?

Figure 8 Significant statement Coding

Diary from participant 1
Jack was discharged from the (hospital) on 30th August 2006. We arrived in our flat just after 12 noon.
(1) *Called at J's GP's surgery to deliver letter from hospital* and
(2) To ensure that district nurse called next day
(3) Phoned friends/relatives to inform them that we were back

Interview from participant 3
We didn't even see a doctor before we left the hospital. We were waiting to see a doctor to get a letter to take to our own doctor and we were sitting and sitting and eventually *a nurse said you'll not see a doctor until about 8 o'clock tonight. I'll just send the letter by email to your doctor so we just assumed that all the information would be sent to our doctor.*

No, the hospital was going to send the letter. *We were supposed to take it to the doctor.*

There were some problems between hospital and community. Whose responsibility would be delivering the letter during discharge?
Did they have proper discussion with carers before the patient was discharged?

There might be a gap between hospital and community when the patient was discharged

Because it is important to involve the participants during this stage, the researcher took the transcripts of the diaries to the first interview and asked participants to check for missing data. Similarly, the researcher took the transcripts of the Phase 2 interview to the Phase 3 interview in Week 12 and asked the participants to check it for missing data. It was also made clear to participants that they were welcome to make retrospective amendments or additions to the existing data from diaries and interview. All participants declared themselves satisfied with the veracity and depth of data. This feedback demonstrated that what was written and said in the diaries and interviews was a true representation of their experiences.

3.7.4.3 Formulating meanings from significant statements

In this step Colaizzi (1978) emphasises that the researcher, while acknowledging and recording the ostensible significance of evidential statements and phrases, should seek to adduce 'hidden' or underlying meanings. This represents a shift of emphasis in the researcher's response and interpretation, from what participants say to what they mean – an intention to understand what participants want to express. Figure 9 offers a general example of this process:

Figure 9 Shows the formulation of meanings

Diary from participant 6
I have put up a bed in the living room to save her from having to go up and down stairs as our toilet is down stairs and only a short walk from the living room.
I am helping her to wash and dress.
I am doing the cooking and cleaning and have learnt how to work the washing machine, hanging out washing and using the iron.
In general making her as comfortable as possible.
Doing the shopping.

The carer took ***more responsibilities***, for example, more household chores, washing, cooking, shopping, personal care of the patient

Hidden meaning of the participant's statement

No deeper 'hidden' relevance can be adduced which does not proceed from the original significance of evidential statements; but it is the goal in this element of data analysis to interrogate original data for unstated meanings. For example, one particular participant in the current study wrote 'call at Jack's GP's surgery to deliver letter from hospital' (Hannah, Diary 1), the meaning of which the researcher formulated as 'Jack's wife wanted to make sure that she could get support from health care professionals during the recovery period'. In this example, the contextual meaning, albeit not explicitly stated, is implicit in the original data; the researcher must respect the ostensible, or surface level of the original data, and at the same time transcend it. During this time, the researcher also kept a reflective diary in which she was at pains to remind herself to lay aside, or 'bracket', preconceptions and respond only to concepts generated in the course of data analysis. The reflective diary also contributed significantly in helping the researcher to understand and relate to participants – a potential suggested by Holloway & Wheeler (1996). Figure 10 provides an example of sentences from the researcher's reflective diary, indicating the way in which this document related to the process of interaction and analysis.

Figure 10 Sentences from Reflective dairy

12/11/2006
I found that the participant was very worried. When she said ' I always go and check him… that he was alright, he sometimes felt annoyed.' ' I just wanted to make sure that he was ok.' Although the above sentence showed that the participant was worried, it also showed that their relationship was influenced by the disease during this time.

This was related to psychological strain

This was related to psychological strain during my data analysis

This was related to the relationship change

3.7.4.4 Summarize the formulated meanings into clusters of themes

Having extracted formulated meanings, the researcher was in a postion to arrange these meanings into clusters of themes (Colaizzi, 1978). For this study, 228 formulated meanings were arranged into 6 themes and 11 sub-themes. Themes and sub-themes are shown in Table 6. The researcher referred these themes back to data contained in participants' diaries and interview transcripts. This enabled the researcher to verify the accuracy of extracted meanings and subsequent themes against original data – guarding against the danger of overt improvisation of meanings and themes in the process of analysis.

Table 6 shows the overarching themes, themes and sub-themes derived from the experience of carers

Overarching Themes
- Changing nature of relationship
- Reassurance
- Being there

Themes
- Walking in the dark
- Getting on with it
- Looking forward to the future

Sub-themes
- Nursing the patient
- Playing multiple roles
- Finding a balance
- No yardstick for knowing
- Hospital to community care gap
- Psychological and physical tiredness
- Continuing of care
- Still playing multiples roles
- Continuing support
- More honest now
- Being back to normal life

3.7.4.5 Describing the investigated phenomenon

At this stage Colaizzi (1978) recommends that the researcher integrate results of analysis into an exhaustive description of the investigated phenomenon, including in that description the processes which comprise previous steps of analysis, and the meanings derived from them. In the current study, the results are thus presented in chapters 4 and 5; the themes and sub-themes as well as the essence of participant experience are revealed. During this stage in the process of analysis, the researcher brought her themes and sub-themes to the supervisors for

validation. Their feedback indicated that the researcher had drawn a picture of the participants' experiences. This is the picture presented in chapter 5 - a rich description followed by an explanation. A more detailed audit trail showing the links between the raw data and how Figure 11 emerged is given in the appendix X.

3.7.4.6 Share the results with the participants.

Colaizzi (1978) suggests that the final step of data analysis should be to share findings with the participants. This helps to ensure the trustworthiness of the study, and that findings represent as accurately and meaningfully as possible the experiences of the participants. Streubert and Carpenter (1999) suggest refinements to this approach, proposing that the researcher return to each participant in turn and ask if the exhaustive description reflects his or her experience. Although no interview was conducted at this point in the study, the researcher endeavoured to satisfy this concluding element of the data analysis process by sending a copy of the final result to all participants and asking for their feedback. The participants agreed and confirmed that the findings were authentic and genuinely reflective of their true experiences as carers to their relatives following hospital discharge.

3.8 Ethical Issues

In any research which involves human subjects, there must be safeguards for their protection. The possibilities of injury range from social harm through disclosure of sensitive information to the emotional and psychological damage which may result

from inquiry into sensitive personal issues (Cormack, 2000).   In any form of research it is important for the researcher to be aware of these dangers. If the researcher is conscious of an ethical issue, arrangements must be made to reduce such a risk. A simple but nonetheless essential consideration is the researcher's obligation to ensure that all potential participants are in receipt of full and accurate information regarding the purpose, content and parameters of the prospective study, and are given sufficient time to reflect on the likely outcome and ramifications of agreeing to take part, and to consult before arriving at such a decision.   The principles of such ethical issues are discussed in the following section.

3.8.1 Principles

Researchers must observe certain basic ethical principles when conducting a study. These should be addressed at the planning stage and regularly revisited throughout the course of the project. These principles include respect for autonomy, beneficence and justice, and non-maleficence (Streubert & Carpenter, 2007; Polit & Beck, 2004).   There follows an account of the way in which these principles were observed in the current study.

3.8.2 Respect for Autonomy

A fundamental principle in research is respect for the autonomy of the participant. Autonomy literally means self rule, it can be defined as the deliberate governance of one's own actions and decisions, and is specifically defined by Gillon (1994) as a special attribute of all moral agents. Respect for autonomy comprises a moral obligation to value and uphold the autonomy of others insofar as such respect is

compatible with equal respect for the autonomy of all potentially affected (Gillon, 1994; Streubert & Carpenter, 2007). In qualitative research, for example, the researcher is obliged to be aware of any aspects of the research process which might jeopardise the right to self-governance of participants. It is the researcher's duty to safeguard participants against emotional, psychological or moral discomfiture, for instance by terminating an interview which seems to be causing distress to the participant, and/or providing follow-up counselling or referrals for participants who may have suffered such harm as a consequence of this or any other element of the research process (Streubert &Carpenter, 1999). Prior to the research process proper, it is vital that the researcher obtain the consent of participants to contribute to the study. Such consent must be informed by full knowledge of all aspects of the project – enabling the prospective participant to reflect on the potential of any such aspect to cause inconvenience or harm. In the current study, the researcher provided a full explanation of the study to potential participants during the recruitment phase, and reassured them as to their right to withdraw from the process at any point. It was made clear to every participant that he/she was at liberty to determine both the duration and degree of participation without recrimination or other negative consequences. Thus, for example, a participant was free to cease making entries in the research diary at any point. Following the three weekly diaries, the researcher contacted participants to establish whether or not they were willing to be included in the next phase of research. For those who agreed to continue, the Phase 2 interview was mooted and a location for interview agreed. The right of the participant to select this venue was emphasised.   The researcher was careful to secure each participant's agreement to being voice recorded, and for the content of diaries and recorded interviews to be transcribed. The right of the participant to refuse voice recording

was established, and the suggestion made that any participant who vouchsafed refusal might be transcribed on the day.

3.8.3 Beneficence

Another foundational principle in research is that of beneficence. The researcher's duty of beneficence embraces an obligation wherever possible and practicable, to act in a way which benefits the participant (Streubert & Carpenter, 2007). This includes, for example, the stipulation that participants must at all times be treated with respect and dignity. In the current study, participants were assured that although they would not benefit specifically during the period of the project, their contribution might be of benefit to future others in similar situations, by virtue of the potential for improving the awareness and practices of healthcare professionals through the contribution to knowledge of the study.

3.8.4 Confidentiality

It is important for the researcher to understand that involvement in a study should not place participants at a disadvantage or expose them to any kind of unwanted attention (Streubert &Carpenter, 2007). A key aspect of the researcher's obligation to her participants must therefore be a guarantee of confidentiality; this represents a commitment to ensure that any information participants offer is accessible only to those whom they have authorized in the act of informed consent (Bryman, 2008).   In the current study, the anonymity of the participants was protected as follows:

1. Any information that could identify participants or their setting was removed.

2. A pseudonym was used for each participant and each patient. Participants and patients were informed of their pseudonym and given the opportunity to change it.

3. All information recorded in the course of the study was stored in a locked filing cabinet, protected by passwords, and was not shared with anyone (all demographic information was stored separately).

These steps were explained to, and agreed by, all participants as a guarantee of confidentiality throughout the research process.

3.8.5 Non-maleficence

In the course of a research study it is possible that participants may suffer physical, psychological and/or social harm (Polit & Beck, 2006, Burns & Grove, 2009). A commitment to non-maleficence represents the researcher's guarantee that she will at all times endeavour to minimise all types of harm or discomfort to the participants. In the current study various approaches were formulated to facilitate this commitment:

The researcher made a full explanation of the nature, purposes and likely structure of the study at the outset; this was considered important as a means of reassuring potential participants and reducing the possibility of anxiety regarding their own and their relative's well-being.

Information regarding sources of psychological and emotional support was made available to participants at the outset of the study, including contact details for the local GP, district nurse, consultant and support staff of the Chest, Heart and Stroke Society, and the Cardiac Liaison Nurse Team; this was considered an appropriate precaution against the likelihood of participant depression or anxiety.

Participants were also reassured that they were free to withdraw from the study at any time without any explanation.

Due consideration was given to the possibility that a participant's relative might not survive the surgical procedure (Weaver, 2007). In light of this consideration, agreement was secured from the Liaison Sister to inform the research team of any such circumstance, and arrangements put in place whereby a letter would be written by the researcher expressing sympathy and appreciation of the participant's willingness to take part in the study, and absolving them from any further involvement.

Similarly, in the eventuality of a participant's relative not surviving the post-operative period (Weaver, 2007), an agreement was secured from the Cardiac Rehabilitation Coordinator to contact the research team, and arrangements made for a letter of sympathy to be written by the researcher. At the same time assurances would be made to the participant and other relatives and friends of the patient regarding their freedom to withdraw from the study should they so wish.

These steps were carefully considered in light of the researcher's obligation to minimise all potential harm to participants in the course of the study.

3.9 Ethical Approval

Ethical approval was initially obtained from the Faculty of Research Ethics and Governance Committee, Edinburgh Napier University (Appendix VIIII). It was hoped this would prove sufficient because at that time a research sample was being sought from Chest Heart and Stroke, Scotland. As no such participants volunteered to take part, it was decided after six months to adopt an alternative recruitment strategy. Participants were then sought through a teaching hospital in Scotland. In consequence of this procedural change, Ethical Approval was applied

for from Lothian Local Research Ethics, and obtained. At the same time Research Governance Agreement was granted by Lothian NHS (Appendix VI).

3.10 Access

In order to assess the feasibility of a study, it is important first to consider a range of settings likely to provide suitable participants (Streubert & Carpenter, 2007). Once a potential setting has been identified it is necessary to become acquainted with that location (Burns and Grove, 2009). In order to do this the researcher must seek permission to gain access to the proposed setting. Holloway and Wheeler (1996) describe access as 'the process by which the researcher observes the situation, talks to members in their natural setting, reads the necessary documents and interviews potential participants' (p.30). In the current study, the researcher first identified two hospitals in Scotland delivering major heart disease care. The researcher initiated access procedures by communicating with, and introducing herself to, the Cardiac Liasion Team. The Cardiac Liasion Team's function is to manage and administer the list of cardiac surgery procedures in Scotland. Through this initial communication, the researcher learned that the Cardiac Liasion Team is based at a Teaching Hospital in Edinburgh, and therefore chose this hospital as the proposed setting.

Power to grant or to deny access to a hospital site is important as a means of safeguarding potential participants. It is customary, as Holloway and Wheeler (2002) point out, for there to be gatekeepers whose function is to grant or withhold access. In the current study, in order to meet with members of the Cardiac Liaison Nurse Team it was necessary for the researcher to negotiate with gatekeepers, eventually obtaining access by permission of the Head of Service. Having been

granted access the researcher was shown the relevant areas of the hospital. A Liaison Nurse kindly explained the operative and follow-up care procedure within the hospital, and subsequently introduced the researcher to the Rehabilitation Team. Thus the researcher gained a clear idea of how cardiac patients were cared for while in hospital, and of the arrangements made for post-operative care at home, as laid out in the information guide for carers.

3.11 Reflectivity

For a novice researcher, it is important to reflect during the research process, especially if, as is the case in the current study, English is not the researcher's first language. In order to facilitate the reflexive process the researcher elected to keep a reflective diary. In the pages of the diary three topics were discussed: 'bracketing is logically not possible', 'relationship between the researcher and the participants' and 'problems of how one culture sees another'. The details of those discussions are given below.

3.11.1 Bracketing is logically not possible

A key aspect for the conduct of a research study based on Husserlian phenomenology is the process of bracketing – otherwise referred to as phenomenological reduction (Husserl, 1931). It is the process by which the researcher liberates her thinking from all empirical preconception and prejudice in order more fully to apprehend the essence of a phenomenon. Hamill and Sinclair summarise a researcher's guide to the process in eight steps:

- Writing down your knowledge about the topic before its start

- Delaying the literature review until after data collection (checking the literature review for traces of themes generated through data collection need not be undertaken where there is no evidence of such cross-contamination)

- Keeping a reflective diary

- Checking the trustworthiness of the study

- Peer checking and feedback

- Participant feedback

- Supervisory review of the interview schedule and transcript (Hamill &Sinclair, 2010, p.21). As generalised advisory points towards bracketing these steps are clear; in the case of the current study however, they have been employed with an emphasis on establishing the trustworthiness of data. It is possible, therefore to suggest that the establishment of data integrity and the process of bracketing are to a significant extent synonymous. However, it is this researcher's belief that the overlap between these processes is not complete. The following discussion is an illustration of this point.

The fact that the researcher hails from a different culture, does not speak English as a first language, and arrived at the start of the research process as a relative stranger to the Scottish healthcare system, suggests that she was in possession of certain advantages with regard to the process of phenomenological bracketing, since she was naturally less burdened by native preconceptions than might be the case with a British researcher. In spite of these ostensible advantages, it soon became clear to the researcher that her experience as a nurse – and particularly the experience of caring for her own mother – represented a significant obstacle to

the intellectual and psychological purism recommended by Husserl. The researcher found it impossible to separate the emotional influence of her nursing background from her response to participants in the study. This is not an unheard of circumstance; Paley (1997) argues that it is impossible for nurses to achieve or maintain the fundamental neutrality required in phenomenological reduction, by virtue of their necessary physical and emotional commitment as professional caregivers. It therefore became a matter of importance for the researcher to ensure that, in spite of the aforementioned obstacles to phenomenological reduction proper, the outcomes of the study should be impartial – the researcher's intellectual and psychological disposition free and flexible. Marshall and Rossman (2006) emphasises that the challenge for the qualitative researcher is to demonstrate that personal interest will not bias the study. As already suggested, in the current study this was in part guaranteed by those measures taken to ensure the integrity of data. But if impartiality is to be assured it must be shown that the area in which data validation and bracketing do <u>not</u> overlap can be satisfactorily redressed. It is this researcher's belief that full qualitative integrity is available via the process of reflexivity as represented in the maintenance of a reflective diary. A simple example of the way in which reflection may not only counterbalance potential bias, but indeed validate the researcher's empathic involvement with her participants may be demonstrated as follows:

In some interviews, the researcher found herself resorting to a certain amount of previous knowledge and experience in the process of questioning, and in guiding and encouraging participant responses. For instance, in one particular interview, she asked the participant 'Do you feel stressful during this time?' effectively anticipating an emotional disposition in the participant on the basis of her own prior

experience in a similar caring situation. The researcher subsequently recorded this instance in her reflective diary, both as a means of averting a similar occurrence in interview, and as a reminder to examine the significance of this factor as it affects the process of phenomenological reduction. It was the researcher's belief that such retrospective examination of a subtle and fundamental aspect of the research process would not only serve to ensure her ongoing commitment to impartiality in data collection, but might also give rise to a general reflection of value – a contribution to knowledge regarding the challenge of impartial qualitative research for researchers with a history of involvement in the field of study.

3.11.2 Relationship between the researcher and participants

Although qualitative research methodology has been popularly used for healthcare professionals in the health care research, the majority of literature seems more concerned with role of research in healthcare, and the rigour and value of findings (Lincoln & Guba, 1985; Lincoln & Guba, 2005; Marshall & Rossman, 2006), than with the difficulties for the researcher in relation to participants. For this researcher it seems that there is an area of uncertainty regarding the potential difficulties inherent in the relationship which develops between researcher and participant in a qualitative healthcare study. This was brought home by a particular instance in the course of the current study. At the conclusion of an interview with a particular participant the researcher switched off the voice recorder. At this point the participant seemed to relax, and became tearful when the researcher inquired as to the results of her husband's oncology appointment. She explained her emotional state in these words: 'We don't know the final result yet, we have another appointment on Wednesday.' In response to this information and to the clear evidence of the participant's emotional upset, the researcher

172

sought to comfort her, putting an arm around the participant's shoulders. This gesture was offered in full knowledge of the strict impartiality which should govern the researcher's gestures and conduct, and the necessity of attempting to bracket all emotional and intellectual predispositions in the course of a phenomenological study. The researcher felt that these considerations came into conflict with spontaneous sympathy, and the impulse to offer a natural gesture of human compassion. There is some recognition of this issue in existing literature; Gribch (2007) suggests that the emotional position of the researcher is a crucial matter because every researcher is inevitably subject to the influence of their own life experiences. The incident was recorded in the researcher's reflective diary and certain conclusions were mediated: the researcher accepted that it would be unethical to return to the participant and inquire further into the outcome of her partner's oncological investigation, on the grounds that this might cause further upset, or place the researcher in a position of obligation to offer comfort she is unqualified to give. The researcher reflected further, in a more general vein, on the likelihood that the qualitative investigator may be exposed to such difficult and spurious interactional issues – concluding that this was a reflection which should be highlighted for future qualitative studies. Finally, certain practical advisory guidelines were considered and formulated against the eventuality of such a recurrence. They are as follows:

- Discuss the situation with your supervisor and colleagues

- Keep a reflective diary

- When analysing data, stop analysis and free your mind to think about other things.

These guidelines were considered useful, both as self-administered advice to the researcher in question, and future researchers in qualitative studies.

3.11.3 Problem of one culture seeing another culture

The first few weeks after hospital discharge is a critical time of adjustment for carers and a time of disruption in family roles and routines. Although carers feel stressful in the interval immediately following discharge, the situation improves over the course of the three month period. For the majority of carers life reverts to a level of approximate normality. The researcher's experience of similar healthcare situations in her home country of Taiwan suggests a quite different outcome. Carers in Taiwan stay with the patient in hospital for a longer time, assisting hospital staff with the care of their relative.   As a consequence of this they are better prepared for the sort of situations they are likely to encounter when their relative returns home.   Routines assimilated during the extended hospitalisation period tend to be perpetuated in the home environment and the carer-patient relationship benefits in general by this extension and continuity.   Although the social care system is poorly developed in Taiwan, there is less of a waiting list for medical attention than there is in the UK. This means that if problems develop in the care situation once the patient has returned home, the resultant need of hospital treatment can be more precipitately met.

Although research into caring remains a neglected area in Taiwan, it is hoped that the meeting of two cultures, as represented by the information gathered and the knowledge gained through the current study, may make a useful contribution to improvements in home healthcare in the researcher's native country.

3.12 Summary

In this chapter, the researcher's understanding of, and engagement with the Husserlian phenomenological approach has been addressed; in addition the use of weekly diaries and interviews as a means of qualitative data collection is explained. An account of the researcher's decision to employ Colaizzi's (1978) data analysis method is offered; the researcher's commitment to the Ethical Principle throughout the process of data collection and analysis is also rehearsed. The chapter concludes with an account of the researcher's rationale in maintaining a reflective diary, with a digest of the reflections contained therein and the conclusions which arise from them.

Chapter 4

Chapter 4 Life History of the Participants

4.1 Introduction

In this chapter short life histories of each of the ten participants will be presented. This will provide the reader with a broader and more sympathetic context to the research findings.

4.1.1 Participant 1: Hannah Barton

The Bartons lived in a third-floor flat on the outskirts of the city, a 40 minute bus journey from the city centre. They had been married for 35 years. Hannah was 70 years old and her husband, Joey, 72. The couple had one daughter from this marriage who lived close by. An elder daughter from Joey's first marriage lived further away and so could not give much assistance during her father's illness.

Although Hannah described herself as an outgoing person, her husband was more self-contained, and they lead a quiet life together.   There was no television in the house; the couple liked to listen to the radio and share opinions on matters of mutual interest. Joey occasionally helped Hannah with the household chores, but in general regarded his role as one of decision-maker in the administration of their daily lives.

Two events in Hannah's earlier life had informed her attitude to illness: when she was young, her mother suffered a circulatory disorder which necessitated a significant level of care; in addition, when Hannah was in her 40s, she herself suffered a serious accident and was in hospital for two months. As a result of these two situations, Hannah was no stranger to the realities of caring for a family

member, and developed a pragmatic attitude to the notions of physical deterioration and mortality.

For the majority of his adult life Joey enjoyed generally good health. However, in the period preceding this study he had begun to complain of lethargy and depression. This necessitated a trip to the couple's G.P., the upshot of which was a diagnosis of a serious heart condition necessitating triple bypass surgery. Not unnaturally, this was a huge shock to them both, and left Hannah wondering how she would cope.

Hannah accompanied Joey to the pre-operative day, and while she waited for his tests to be completed, met and talked with a number of other people in situations similar to her own. This, she said, was helpful in enabling her to come to terms with the implications of her husband's condition and treatment.

4.1.2 Participant 2: Jenny Neil

Jenny was a 48 year old woman, who looked after her 37year old sister (Nicola) following heart surgery. She was married with a son and a daughter. Jenny and her husband lived in a house near the seaside, about an hour's drive from her sister's home.

Jenny lead a busy life, working four days a week as an administrator at the university and sometimes helping to look after her grandchild. As the eldest of four siblings, she also supported her own parents, visiting them most weekends.

When Jenny was in her 30s, her sister, Nicola, was diagnosed with Hodgkin's disease. During that time Jenny gave lots of practical and moral support, and the two sisters became very close. Jenny said that now she sometimes thinks of Nicola as another child rather than as a sister, (though there are only 10 years between them). Not surprisingly, her 'real daughter' gets a little upset when her mother gets their names mixed up.

Nicola was divorced and had two daughters, both attending boarding school. One of them had a learning disability. When Nicola was in the IT Unit the older daughter wanted to visit but her mother refused to allow it.

During Nicola's recuperation, her father developed a chest infection. At the same time, Jenny's daughter, who was pregnant, was suffering from morning sickness, and Jenny herself discovered she had breast lump. Jenny felt too concerned with the needs of others to do anything about her own treatment until the demands of the family became less. Because of the delay in her treatment, the research interviews were postponed twice. All through this difficult time Jenny's husband was extremely supportive.

4.1.3 Participant 3: Irene Watson

Irene was a 73 year old woman in her second marriage, and worked as School Dinner Lady. She described herself as an outgoing person. She had one son by her previous marriage. Her current husband, Victor, was aged 70. The couple lived in a bungalow five minutes' walking distance from the bus station. Her first husband, Robert, a heavy smoker, died of cancer. Victor was also a long-time

smoker and continued to smoke throughout the period of his surgery and recuperation. Prior to their marriage, Irene insisted that she would only marry Victor on the agreement that he promised to give up smoking, explaining that she did not want to be left a second time. He made this promise, but failed to keep it. This was the cause of a number of arguments between them.

A few years ago, when Victor was diagnosed with cancer, Irene again tried to persuade him to stop smoking, without success. Fortunately, the cancer was cured. Recently Victor suffered from chest pains and was diagnosed with heart disease.   Irene felt sure this was because of his smoking.

4.1.4 Participant 4: Penny Nicol

Penny was a 68 year old married lady. Her husband, Michael, was the same age as her. Penny and Michael owned a big house in one of the city's wealthy suburbs. They had son and a daughter, both of whom lived far away. As a couple they shared the household chores, and were active Church members.

Penny formerly worked as a university librarian, and when she retired, took up voluntary work designing websites. The demands of this work came to a peak at Festival time, and coincided with her husband's illness. This caused her enormous stress.

A few years prior to her husband's illness, Penny's cousin was operated on for cancer, a procedure which subsequently necessitated PEG feeding. At the time of

her husband's illness, the condition of Penny's cousin became terminal and she was admitted to long-term care. As next of kin, Penny was obliged to cope with her cousin's death, and manage the subsequent winding up of her affairs. This also meant that the second interview was postponed.

4.1.5 Participant 5: Maggie Young

Maggie was a 62 year old woman married to a man of the same age, Joe. The couple lived in a bungalow with their cat Smoky. Two daughters and a son lived nearby.

Maggie had worked in a small hospital as a night care assistant, but changed her job to become a part-time chartered accountant in order to give her more time to help look after her grandchildren. Joe ran his own company and worked long hours.

A few years prior to the current study Maggie was diagnosed with Hodgkin's disease and breast cancer. She was treated successfully. Since that time, she and her family hade taken out private health insurance, chiefly for the reassurance of being able to obtain prompt medical attention. Maggie appreciated the level of support she received while undergoing treatment, and subsequently became a volunteer in the breast cancer unit at the hospital in order to share the benefit of her experience with others.

4.1.6 Participant 6: Jack Taylor

Jack and his wife Mary had been married for 46 years; both were 68. They lived in a house on the outskirts of the city, a fifty minute bus journey from the centre. Two and a half years before the current study Mary suffered a mild stroke from which she never fully recovered. Before then neither Jack nor Mary had suffered with illness: Mary was always more domestically inclined than Jack, taking responsibility for the bulk of household chores; Jack enjoyed sport, and attended a local bowling club every week; both enjoyed spending summers in a holiday home they owned. The couple had two daughters and two sons, all of whom lived nearby. Both Jack and Mary enjoyed helping out with their grandchildren on occasions and spending time with them. One granddaughter helped with shopping when Mary became ill.

When Jack was young, his father was killed in the Second World War and he had to become independent. As manager of a mine he learned to organise his work and routine. When Mary became ill, Jack sold their holiday home because they were no longer able to use it. This was a great sadness to him.

4.1.7 Participant 7: Lillian Frame

The Frames were an elderly couple, Lillian 71 and Paul 85. They owned a bungalow, with a large supermarket and a bus stop conveniently situated nearby. They had two children, a daughter in America, and a son who lived locally. Before the children were born Lillian enjoyed a career as a civil servant, but she quitted the job to look after them. In later years Lillian remained an energetic person, particularly as a member of a walking club – a hobby she pursued with a close

female friend, Maria. Shortly before the current study Maria died, leaving Lillian feeling frustrated and housebound. This situation was worsened by the fact that Paul was diagnosed with heart disease eight years previously. Before that time he had been a willing helper with household chores, but the condition caused him to slow down and become apathetic. This attitude resulted in arguments between Paul and Lillian.

4.1.8 Participant 8: Sheena Hunter

The Hunters, Sheena and Dennis, were a 73 year old couple living in sheltered accommodation an hour's bus journey from the city centre. Sheena and Dennis met when they were five. They went to the same school, married at 19, and had been together for over 50 years. They had two daughters and one son who all lived nearby.

For the majority of their wedded life Dennis enjoyed good health, but shortly before the current study he began to experience problems with walking. A consultation with their doctor revealed that Dennis was suffering from hardening of the arteries. Dennis underwent thoracic surgery. Two days after his discharge he was readmitted and had further surgery. He remained in hospital for another five weeks. During this time, it was discovered that he had liver cancer. Sheena felt upset as the doctor could not find the original site of the cancer. She postponed the second interview because the couple were tired from repeated journeys to the hospital and back. At the time of the second interview, she was still waiting for an appointment with the Oncologist .

4.1.9 Participant 9: Anne MacRae

The MacRaes lived in a 3-bedroom flat a 25 minute bus journey from the city centre. Anne was 71 years old and her husband, Philip, 80. They had been married for 50 years and had a son who lived approximately an hour's drive away and a daughter who lived in the English Midlands.

Anne spent many years working as a nursing sister. As a result of this background she was able to turn to a number of professional friends for advice and support when Philip became ill.

Philip's younger brother Edmund had suffered from the same disease as Philip, and underwent the same operation. Eighteen months after surgery he collapsed and died while walking along the beach in front of his house. This turn of events caused Anne to become extremely anxious about Philip's well-being, and lead to a great deal of worry during the period of his recuperation.

4.1.10 Participant 10: Millie Mochi

Millie, 57, and her husband Tony, 53, had been married for 3 years, but never had children. Tony's family lived in Italy, Millie's in England. The lack of relatives nearby had made the couple very close. They enjoyed their lives together, sharing the daily round of domestic chores, with the exception of the cooking which was Tony's domain.

Before marriage Millie trained to be a nurse, but never pursued this career. At the time of the interview she was working in the job centre.

When Tony's illness was first investigated the doctors feared that surgery would be impossible, a suggestion which inevitably caused Millie considerable depression and anxiety. Ultimately the surgeon decided that an operation was

possible, but warned Tony and Millie that it would be more risky than usual.   The couple nonetheless decided to go ahead with the procedure.   The date of the operation was their 31st anniversary.

Chapter 5

Chapter 5 Findings

5.1 Introduction

In this chapter, findings arising from analysis and interpretation of data provided by the 10 participants will be presented. Data is drawn from the participant diaries, kept up over the first 3 weeks after discharge, and interviews conducted over a 3 month period. Findings will be displayed in the form of themes and sub-themes which emerged from the phenomenological analysis.

It became clear from their accounts that the carers considered the experience of caring for their relatives as being like a journey. This journey consisted of three phases; each theme demonstrates a particular phase of the journey. During Phase One of the journey they referred to the notion of 'walking in the dark'. Within this theme six sub-themes were identified: 'nursing the patient', 'playing multiple roles', 'finding the balance', 'no yardstick for knowing', 'hospital to community care gap', and 'psychological and physical tiredness'. All of these arose either from the diaries or from interview 1, which took place at a week 6.

The theme for Phase 2 is 'getting on with it'. It is divided into three sub-themes: 'continuing care', 'still playing multiple roles' and 'continuing support'. These emerged from analyses of both Interview 1 and Interview 2 (undertaken at week 12).

The theme for Phase 3 of the journey is 'looking forward to the future'. This has two sub-themes: 'more honest now' and 'being back to normal life'. These came from Interview 2 (at week 12.)

These three phases reveal the progress and development of the journey over time. However, it is important to point out that for each participant the journey was an individual experience; changes which, as they are represented in the sequence

of phases, seem generic, inevitably took place at different times for different participants. This explains why, from one participant to the next, similar experiences may be illuminated by data drawn from weeks 3, 6 or 12 of the data collection period.

Notwithstanding this, there are three overarching themes: 'the changing nature of relationships', 'reassurance' and 'being there'. These three overarching themes were evident in each phase of the journey for all the participants, and were not episodic but rather continuous throughout the journey. The data in which these themes arose occurs in the diaries, and both interviews. However, these overarching themes will be presented first in this chapter.

The final section of this chapter will show that the essence of the caring journey may be interpreted as process of transformation and return in which carers move from being a person to being a carer to being a person once more. Figure 1: shows the three Phases, the Themes and Sub-themes and their relationships.

Figure 11 The essence of carer's experience of caring

Changing nature of relationship

Reassurance

Being there

Walking in the dark

- Nursing the patient
- Playing multiple roles
- Finding a balance
- No yardstick for knowing
- Hospital to community care gap
- Psychological and physical tiredness

Getting on with it

- Continuing care
- Still playing multiples roles
- Continuing support

Looking forward to the future

- More honest now
- Being back to normal life

Phase 1

Phase 2

Phase 3

Three Month Period

Recuperationn

The essence of the experience of caring: person – to carer – to person

Overarching Themes

5.2 Changing nature of relationships

There are three overarching themes which continue throughout the caring journey. The 'changing nature of the relationship' is the first of these. It refers to the overturning of a basic assumption held by all participants - that their relationship would not be altered.

As one husband in the sample pointed out:

> *Well, because I've been doing everything. I've been more like a carer who's become no[t] [a] man and wife [but] carer and somebody. It's made a big difference there, as well, yes. (Jack, interview 1, p4)*

Inevitably when one's husband, wife or sister develops symptoms of a grave nature necessitating hospital investigation and major surgery, expedient changes will be forced upon the family carer. Perhaps the most important feeling expressed by these carers was one of fear at the newness of the situation they were confronted with:

> *Researcher: How did you describe your whole experience during that time?*
>
> *Maggie: Scary.*
>
> *Researcher: Scary?*
>
> *Maggie: Scary to be truthful. You never ever know what's involved until you're in it yourself, you know. (Maggie, interview 2, p8)*

> *Right, because when my husband was, when he had the operation, the surgeon said, obviously they tell you all the risks of the operation and I was frightened that my husband*

> *wouldn't survive the operation. I was frightened that he*
> *wouldn't come home. (Millie, interview 1, p 2)*

This last quotation indicates how anxiety for the carer at the newness of the situation is compounded by basic fear regarding the potentially life threatening nature of their relative's illness. It also underlines the changing nature of the relationship between the couple, from man and wife – a relationship in which the balance of need is more or less equal - to carer and patient, where the need of one partner is greater, and the other subserves it. A different example of relationship change was provided a carer who described how she viewed the altered emotional and psychological situation between herself and with her sister:

> *I see her as an extra child. She's like an extra daughter to*
> *me in a way. I mean she's only five years younger but you*
> *know I feel responsible for her. (Jenny, interview 1, p10)*

So for these two and all the other participants there was a relationship change whereby one partner was obliged to adopt a paternalistic disposition towards the other whose physical needs were suddenly greater and more complex than previously – a situation which prevails for the duration of the journey. As another of these participants put it 'I am like a mother hen' *(Hannah, interview 1, p8)*

It is important to note that although the changes described in the extracts above occurred at the start of the journey, the experience of the participants is that change is continuous throughout the course of the journey. This is why the changing relationship is interpreted as an overarching theme.

> *The first time he went out on his own he went round to post*
> *a letter at the post box which is just out on the road and I*
> *was watching on both windows you know to see if he was*

alright. Then when he started to go for a walk by himself,
and I still do this. (Anne, interview 1, p4)

A further aspect in the dynamic of relationship change was identified at that point in the relationship when the carer's relative began to recover a degree of good health and independence. It was at this point that the inequality created by the relative's illness, between need in the one partner and an obligation to care in the other, began to be redressed. As Hannah said:

> *I feel what we need to do and he does as well is that we*
> *really ought to get away somewhere together and get our*
> *relationship back onto a more normal footing with not so*
> *much me looking after Joey but as an equal partnership.*
> *(Hannah, interview 2, p5)*

One relationship amongst those included in the research sample stood apart from this pattern – this was the relationship between Jenny and her sister Nicola. As we have seen, after her Nicola's diagnosis, Jenny thought of her as being 'an extra child'. The initial change in this case was Jenny's transformation from a sister to a carer, but there could not then be a 'return to normal' because a further illness – Jenny's breast cancer - intruded into the journey, causing the carer to become the 'patient'.

> *But she certainly was a wonderful support over Christmas.*
> *And she did come and pick me up and take me to*
> *chemotherapy one time, which was lovely to have her there.*
> *And that was fun but I would have managed fine, I would*
> *have managed fine if she hadn't been there. I don't know if I*
> *would have managed Christmas without her - we probably*
> *would but she made it fun. But I am so used to supporting*

> *her you see I think it's quite difficult to accept the role reversal. (Jenny, interview 2, p 8)*

It is clear from this extract that further change for Jenny took the form of a reversal, whereby she moved from being the partner in control to the partner in need, yet it seems that Nicola was a good carer and actually made some of the second journey 'fun'. Since this is the only example of a carer whose position changed from caring to being cared for, we do not know if this experience would be duplicated in similar cases. Perhaps it is important to comment that for Jenny and Nicola, their relationship, though altered, was perhaps less drastically changed than for married partners. It can also be seen that from Jenny's perspective the changing nature of the relationship from carer to being the cared-for-person was not an easy transition to make, obliging her to accept a role in which she seemed uncomfortable. However we do not have any evidence as to how Nicola felt about the reversal because of course she was not included in the sample.

From the foregoing evidence it can be seen that changes to the relationships themselves altered over time. However, although comments were made suggesting that most of the carers' relationships had returned to normal at the end of their journey, there is no evidence that the relationships actually returned to exactly the same status as before.

5.3 Reassurance

The second overarching theme is 'reassurance'. It refers to a form of support necessary to the family carer throughout the duration of the caring journey, although its importance may vary in degree depending upon the particular phase

of the journey in question. The specific type of reassurance needed may also reflect the individual nature of the caring experience. For example, carers might need more reassurance from healthcare professionals in the initial Phase of the journey, more support from family and friends during the middle Phase, and need encouragement from the cared-for-person during the final Phase.

Irene gave details of how she required reassurance on a specific topic in Phase 1.

> ***I felt I was hurting him when I put his stockings on because I didn't know how to do it without hurting him I needed reassurance. (Irene, Diary 1, p1)***

This sort of reassurance could be derived only from the advice given by healthcare professionals. In the main such reassurance could only be sought from and provided by professionals of different sorts such as GPs, nurses or health visitors – although there is one case in the sample where such reassurance was available from relatives and friends who had such experience;

> ***I have very eminent doctors in my family who are working in the rest of the world and I have a very eminent surgeon who lives in the [Place's name]. And it is through my family support that I learned more about how to deal with a patient coming out of hospital. (Penny, interview 1, p4)***

The comfort and security carers derived from such reassurance reduced their worries, which of course made their lives more bearable.

Some carers complained of a lack of communication between the hospital and the community healthcare provision, whereby the carer's relative was discharged on a Friday, leaving the carer bereft of that essential preliminary support and reassurance over the weekend;

> ***If I could have had a visit on the Saturday morning after my husband came home that would have been fine. I didn't***

get that and I appreciate there is difficulties at the weekend so I don't know what you do in that case. You are not allowed to be ill at the weekends nowadays. But I think perhaps during that first week you should have at least two visits from the doctor. I think from a reassurance point of view, yes I think. (Anne, interview 1, p7)

Anne's experience was not an isolated incident; there were several occasions on which family carers felt let down at the point of discharge – deprived of reassurance and support at perhaps the most difficult and vulnerable stage in the journey;

They gave me none. They discharged Michael and the district nursing service was furious on the following day because he should have been discharged with seven days' worth of dressings for the district nurses to begin treating him. (Penny, Interview 1, p 5)

Penny's account highlights the fact that it is not only moral and technical support the family carer needs at this stage, but simple material support as well. Other carers spoke about the need of assistance and guidance with such tasks as bathing the patient, helping him/her into support stockings, and dressing wounds;

I felt I was hurting him when I put his stockings on because I didn't know how to do it without hurting him I needed reassurance. (Irene, Diary 1, p1)

Oh very, very... I was frightened to move him in case it pulled something. That was the worst because I think I felt that I would hurt him and you know do him some damage. I think I would like to have had some sort of lessons from the nurses to say this is what you do. (Millie, interview 1, p5)

Although these seemed basic tasks, they represented new and challenging duties for the family carer, who often wanted no more than to know that they were doing the right things, or that the symptoms their relative was experiencing were normal. It is interesting to note that despite Anne's background in nursing, she nonetheless craved reassurance from healthcare professionals. The majority of the carers expressed their appreciation of the support they received from health visitors, district nurses and the rehabilitation nurse;

> *And then the health visitor, she's through the doctor as well and she was coming in every week so I thought that we got great service as far as that, you know, great help and if I was worried, if I was wanting to check on something I would phone up the health visitor and she would advise me or say "I'll pop in..." or something like that, you know. (Lillian, interview 1, p7)*

> *I can't praise the district nursing service too highly. Without them and their cheerful, practical help I wouldn't have survived. (Penny, Diary 2, p4)*

> *I would say "am I doing the right thing?" "Should I be doing this?" "Is this the right thing?" And she would look at it and say "yes, yes, that's fine you're doing very well" and made me feel stronger and more confident because she spoke like that. (Hannah, interview 2, p1)*

A number of carers, while acknowledging that the nurses were helpful, still looked for reassurance from the GPs with specific regard to symptom management;

> *They[Hospital staff] gave me a letter and I was told at the practice well there's no point now because there will be no doctor here till Monday so you might as well just hold onto that letter and the doctor will come. Now no one came until Tuesday. Yes, it was the Tuesday before anyone came which meant that I was all weekend with him at the worst*

part.

Well, the most worrying part because he was just out of hospital and suddenly you have got the whole responsibility. You know you feel if someone professional comes and sees him and sounds and then listens to his heart and does his blood pressure you feel reassured, that it's alright, you know. (Anne, interview 1, p 2)

However, help and reassurance from the family Doctor was not always forthcoming. For some carers, a phone call or a visit to the practice was necessary to elicit such help, but this course of action was generally not pursued until a situation arose which the carer perceived as a crisis.

Joey experienced weakness and sweatiness during the week. I phoned doctor and he visited us; he checked Joey's blood pressure, sounded chest and discussed these symptoms and their meaning. (Hannah, Diary 1, p3)

One participant – Jack, husband of Mary – having submitted the discharge letter to the Health-centre, automatically assumed that GP involvement would follow, and was ultimately disappointed at the level of coercion necessary to secure this assistance:

Never seen any doctors, had problem's getting prescription set up even after handing in the letter from the hospital. Had to go to the surgery and request to see a doctor to get a prescription for antibiotics which had run out. (Jack, Diary 1, p 2)

Of course it cannot be assumed that the GP will have been given any more information than the simple fact of Mary's discharge, but this would only reflect poor communication within the practice. Further evidence from this participant suggests that this was not the only issue carers might have with the local practice;

A doctor came in sat down and asked why he was here. I had to tell him we had not sent for him we thought this was a visit to check my wife was all right, we got him to check blood pressure which was low but ok, he then left. (Jack, Diary 1, p 2)

Here then we have a carer with two specific issues about the local health provision; in both extracts there seems to have been a lack of clear communication in the health centre, whereby the GP is at first unaware of the carer's needs, and then mistakenly believes that a visit has been requested from him. In this second instance we see that the participant is also unhappy with the visiting GP's bedside manner. Both instances underline the importance of sensitive provision of reassurance by the local health services.

During Phase 2 of the journey carers also said that they had gained reassurance from their friends. Family and friends with a medical or nursing background were especially helpful, being able to reassure carers that they were doing the right things. Anne said:

Well, I have a very good friend who was a nursing friend and her husband is a doctor - retired and yes, I speak to them and if anything worries me about my husband I'll say to this friend, who is the retired doctor, [.....] I have people like that I can speak to them about it and I speak to them most days, they were very, very good when my husband was in, they were on the phone every day and still are just to see how things are so yes I have, I can speak to them and can ask advice from them about it which is good. (Anne, interview 1, p7)

It is interesting to note how valuable the reported 'daily' contact and reassurance offered was. This was a luxury enjoyed by only one other of the participants, Penny. In Penny's case contact was much less frequent, but this nonetheless seemed to fulfil her needs. Interestingly, it was Penny who instigated this contact,

rather than these 'helpers'. This difference suggests how differences in the attitude and outlook of the carer may affect the level of support and reassurance they obtain.

In the final Phase of the journey carers gained reassurance, in addition, from the patients themselves – specifically, from the perceived improvement in their relative's condition following surgery. For example, Jenny gave details of her experience.

> ***She was a very red colour but her colour is clear now and she's got so much more energy.***
> ***Maybe a tiny bit but compared to before I mean it really has been a wonderful operation, a wonderful operation. (Jenny, interview 1, p6)***

The remaining aspect of reassurance that was shown by the data was that sought by the extended family. Although these additional family members may have perceived in general that their relative's condition was improved, given that they had successfully undergone surgery and been discharged, they continually sought reassurance concerning the daily incremental improvement from the carers:

> ***I found this with my daughters and the son who doesn't live in Edinburgh. It was me they were looking to for reassurance as well. "How is daddy, how's dad?" And I was saying "He's not doing too badly, he's doing this, he's doing that and you've not to worry, it's quite normal, he'll be alright..." So, in that way I was supporting them perhaps. (Hannah, interview 2, p 8)***

This aspect of reassurance was common to all participants, and consistent throughout the course of the journey, so that carers who themselves were seeking reassurance were the conduit of reassurance to the extended family.

5.4 Being there for each other

The third overarching theme is also seen throughout the carer's journey, but unlike the other two, alters little over time. All the participants were closely related before their respective journeys began either by marriage or because they were siblings. In an ideal world, marriage is built on the concept of sharing a life together, a fundamental element of which is a commitment to being 'there for each other' in sickness and health. In the case of the sibling, there is generally a familial bond of loyalty which involves an habitual degree of interest in the lives of fellow siblings. However, there is qualitative difference in the type of interest which obtains between siblings as compared to that between married couples; the sibling bond is not chosen, whereas the bond between marriage partners is the product of a consciously made commitment. For this reason it is important to be aware of the extent to which the bond between siblings is affected by subsequent commitments to a marriage partner and children. In the case of Jenny and her sister Nicola, it is clear that the original loyalty Jenny felt towards her sister continued alongside the later commitments to her husband and her children.

The majority of participants were married and all living together – a commitment which, in the face of a diagnosis in one or the other partner, acquires a new and heightened aspect - 'being there' takes on a different quality. Maggie explained:

> *That's right I mean my time was for him and whatever it*
> *took really, because he would obviously do*
> *[the same thing for me] - Well he was the same for me*
> *(Maggie, interview 1, p9)*

This Maggie experienced breast cancer five years before her husband, Joe's diagnosis, and consequently had the model of Joe's unswerving commitment to

her during that time on which to base her own endeavours as a carer.   When the tables were turned, as Maggie explains, she was prepared to 'do everything'.

> *You know, he couldn't do anything. He couldn't put his hands down to pick up something, even turning a page – he never read a paper – if he did it was … but as you do a thing that's second nature to you … you just say well this is my life just now so everything else is cast aside. (Maggie, interview 1, p8)*

Several participants referred to the acts of care as being 'second nature'; it is possible to suggest that there is an implicit distinction between an act performed because it is 'second nature' and a similar act which derives in the loyalty and tenderness of the marriage bond.   However when we look more closely at the nature of the caring referred to in these cases, it becomes clear that the term 'second nature' simply refers to acts performed without thought, such as are typical in a marriage.   Throughout the research data there were numerous examples of participants couples taking care of their partners to an extraordinary degree, so that for example if 'the patient' was up in the night then so was the carer:

> *I think because he was slow and the worst was at night he couldn't sleep at night so every two hours I was waking up and I was very tired but I don't think it, I suppose it did change but I expected to look after My husband and he expected me to look after him so it's just what we expected. (Millie, interview 1, p5)*

However there was one participant, Lillian, who acted differently. She and her husband Paul apparently lived their lives very independently, even following Paul's illness. An extract from the interview with Lillian makes this clear:

> *Yes, the first week I don't think, well the only thing I did the first week while he was home. I go line dancing. I do that and I would leave like after lunch, I would give him his lunch and I would go away to that and if I leave him he would be fine. And come back he was ok. (Lillian, interview 1, p4)*

This carer took a much more detached view of what 'being there' for her partner signified than was the case with any of the other participants. The couple slept on different floors – a fact which, in light of Lillian's statement that she was 'a sound sleeper' *(Lillian, interview 1, p4)*, suggests that she was undisturbed by any needs Paul might have experienced in the night. It seems reasonable to suggest that this is an example of not 'being there', certainly not consistently or continuously.

As already mentioned, Jenny and her sister Nicola had remained close, despite the development in their adult lives of other relationships. Indeed the pair were if anything brought closer by the alteration in Nicola's situation brought about by the combined effects of her divorce and her diagnosis with Hodgkin's Disease – two events which happened in a relatively short space. Had Nicola's marriage not collapsed, it seems unlikely that Jenny would have needed to be 'there' to the same degree as she was. Jenny articulates this situation explicitly;

> *Because she's had nobody else to turn to. I'm the nearest to a husband I suppose for support. I'm the person that she would turn to first. If she has a bad day she's more likely to phone me than anybody else. I am not the same because I've got my husband but I do think that we are very close now. Particularly having both gone through the chemotherapy and…(Jenny, interview 2, p3)*

Although the commitment to care was a reality for all participants, all do not

express that commitment as lucidly as Jenny. It is possible that the reality of a life-threatening condition makes such emotions easier to speak about, or indeed that the gravity of the condition makes it necessary for the carer to articulate his/her feelings as a form of release. The sincerity of the sisters commitment to one another may be seen in the fact that although they remained on different sides of the country, Jenny was prepared to 'take time off work and to look after her' *(Jenny, interview 1, p9).* It is perhaps also the case that the relationship between the sisters was facilitated by the fact that Nicola was a very organised individual who had clearly thought out what would be required to manage her journey. In addition, as well as having her sister as a carer, she employed someone to come in and take care of her when Jenny had to return to work. Both of these considerations may conceivably have reduced the level of pressure on the relationship which might otherwise be brought to bear by the burden of caring. The fact that the carer/cared-for person relationship was reversed in this case without any adverse effect is further testimony to the genuine commitment each felt for the other. Jenny explains her feelings with respect to this role reversal:

> *Yes, well it does feel strange. I'm used to being the supporter not the supported. It was very good of her but I can manage on my own now.* **(Jenny, interview 2, p3)**

Along with most of the other participants, Jenny and her sister Nicola became closer following adversity. But the important element of all these stories is that there was a strong reciprocal nature to these relationships, and in most cases the assurance that your family will be there for you.

These overarching themes prevailed throughout the carers' journey, altering over time, although not consistently. The reality of having experienced this journey seems to be that although life might eventually 'return to normal', the effects described in the overarching themes may also leave lasting legacies. Irene articulated this possibility succinctly it when she said, 'I think he appreciates me more' *(Irene, interview 1, p 19)*. A significant element of this legacy may well be that any subsequent illness could be faced with greater equanimity.

5.5 Walking in the dark

In this Phase (Phase 1) of the caring journey the majority of data was derived from weekly diaries kept by the carers during the first three weeks following discharge. There is also some information which emerged from Interview 1, conducted in the sixth week after discharge.

'Walking in the dark' was the most obvious theme revealed by the carers in Phase 1 of their journey. As we have already seen the effects of being discharged from hospital following acute surgery has enormous implications for carers even if they have some health care background and this is accentuated for those who do not have such experience. Carers were 'thrown in at the deep end' with little preparation for what was about to happen to them. As Penny explained:

> *The steep learning curve imposed by the necessity to deal with unforeseen factors was very difficult. In reality, it was a totally new way of living our life, with drastically different priorities. This arrived before I could prepare for it and I had no 'road map' to navigate into or through it. (Penny, Diary 2, p2)*

The feeling of being without direction (of having no 'road map') to which Penny refers is the predominant characteristic of 'walking in the dark' which so many of the participants described. The phrase alludes to a state of not knowing what to expect, not understanding the implications of various actions, and of having insufficient time to set up support systems. As described under the previous theme 'reassurance', the inadequacy of input from health professionals was a contributory factor to this feeling.

Many participants explained that the caring journey began for them with the perception of their relative as a patient – a perception which originated with hospital visits, and persisted after the relative was discharged. In consequence of this altered perspective, participants felt it incumbent upon them to pick up where hospital staff had left off, accepting responsibility for helping their relative with a wide range of activities of daily living. As Millie put it;

> **Shower and help him dress, make his meals and drinks, keep him company. Give him his medication; help him in the night to change his position and pillows (Millie, Diary 1, p1)**

Millie's list illustrates the impact of the changed situation on her perception of herself and her role in relation to her relative.

A number of the tasks carers were confronted with necessitated detailed specialist knowledge, and it became obvious that they required help from health care professionals. Irene's experience illustrates this:

> **We didn't. When we left the hospital they said make an appointment to see your doctor in a week's time - that's all we were told but his legs were bleeding and every time I took the stocking off it would open it up again. So, as I say, we went**

to the doctor after a week and she said "Oh, I'll go and make an appointment for the nurse to dress it. You'll get an appointment in a week's time..." So for two weeks he was going to have this open wound. (Irene, interview 1, p1)

At discharge, the hospital staff gave instruction that a discharge letter should be given to the GP. Most carers regarded this as being reasonable since they lived close to their Health Centres, but were uncertain what would result from the delivery of the letter. Some assumed that it would lead to GP visits, and the automatic issuing of necessary prescriptions. However from the data it became clear that these expectations were not met. This may have stemmed from the fact that carers did not communicate directly with the GP but with reception staff who did not convey the entire message:

I also found it difficult when I had to go to the doctor surgery 3 times before his medication was ready, plus they did not prescribe the correct dosage so I had to go back. I found that very stressful. (Millie, Diary 1, p1)

I don't know. But what happened was I had a lot of bother getting her prescription thing sorted out. I had got a letter from the hospital. One to hand into the doctor and one for us to keep. And I handed the one into the doctor. Went up days after it and nothing had been done about it so this other doctor came out and spoke to me and I gave him my sheet of paper. (Jack, interview 1, p9)

This experience illustrates the sense of frustration and loneliness which carers felt confronted with the responsibility of providing round the clock care without suitable professional support.

This seems to have been the case for the majority of participants, although there is one, Lillian, whose evidence, suggests a different experience. Lillian seemed to be rather detached from her husband, and less affected by his illness than many other participants were in their equivalent situations. She explained that she did not have much to say about her situation because she found it "quite good", that she "hadn't any problem in looking after him." and there was "nothing to worry about". The only task Lillian mentioned was "putting his stockings on and taking them off" *(Lillian, interview 1, p1)*. Her husband even went to rehabilitation classes alone. However, although Lillian did not complain of 'walking in the dark', she did experience negative effects as a result of her changed situation; she reported that:

> *"he became a menace; because he was getting so much better*
> *he was sort of doing the things he wanted and we argued a lot"*
> *(Lillian, interview 1, p1).*

Before her husband's illness the couple lived very independent lives - Lillian spent a lot of time going out with a friend while her husband stayed at home. It is possible that the arguments which arose between them were a result of the enforced sharing of space to which both were unaccustomed.

In general terms, 'walking in the dark' refers to the lack of knowledge and understanding which characterised the carers at the start of their journey. Eight sub-themes explain in further detail the specific aspects of this overarching theme, and will now be dealt with in turn.

5.5.1 Nursing the patient

One of the most significant aspects of 'walking in the dark' is embraced by the sub-theme 'nursing the patient'. This sub-theme centres around the concerns of participants regarding basic practical aspects of caring with which they were confronted at the start of the caring journey. Millie makes a specific comparison between these challenges and the duties of nursing:

> *When he first came home the first two or three weeks it was*
> *like nursing a patient. Yes he wasn't well enough to cope by*
> *himself. It was like being a nurse, yes. (Millie, interview 2, p2)*

The implication of Millie's statement is that the extent of her husband's weakness obliged her to behave less like a wife than a health-care professional, and it seems clear from her evidence that had not anticipated the burden that would be placed upon her. The role involved a variety of tasks centred mainly on the activities of daily living, for example toileting, bathing, dressing and, for some, feeding their relative 'patient'. For some participants, the major problem they faced was the task of helping the 'patient' to find a comfortable position in their bed, or to get out of it. Irene showed ingenuity, fashioning a make-shift hoist to help her husband, which both made her task easier, and enabled her husband to help himself:

> *I had to rig up a hoist using a belt and a piece of nylon rope*
> *which I attached to the end of the bed. The hoist lowered him*
> *into bed and allowed him to pull himself up. (Irene, Diary 1, p1)*

Irene's example underlines the lack of professional help and advice which was typical in many cases. She, like many of the participants, was obliged to deploy her own problem solving and decision making skills to identify an ingenious way of overcoming the shortfall in professional assistance. The degree of thought and

ingenuity which was necessary to help her husband in this instance incidentally indicates the level of assessment which might have been carried out before discharge, and once again points to a lack of communication between the professionals in the hospital and those in the community.

The lack of ready medical assistance coupled with the fact that the home environment is naturally less appropriately equipped for health-care purposes lead to a degree of anxiety amongst many participants. A statement from Hannah demonstrates this:

:

> *…it is quite scary, four days after a big operation being the one that's in control. I'm not a nurse so you just had to do your best. (Hannah, interview 1, p 5)*

A diary entry from Sheena articulates more explicitly the correlation between the necessity of attending to unaccustomed duties and increased levels of stress. She reports that she had to do "absolutely everything" for Dennis, and continues:

> *…he is very weak after going through a further operation to clear his lungs and having a rib re-sectioned. He is also in a lot of pain and very breathless.*
> *Taking him to the toilet-washing-dressing and helping him from bed to chair, also encouraging him to eat and drink. Also supervising his medication.*
> *I have been a bit uptight being re-raised [having to get up] several times during the night.   (Sheena, Diary 1, P1)*

As well as the relatively straightforward activities involved in keeping relatives comfortable and ensuring a peaceful environment for their recovery, some carers also had also to look after surgical wounds - a completely new experience, made more daunting by the fear of infection resulting from their lack of expertise:

> *Penny: And I couldn't cope with that because to me a wound that is 48 hours just closed is not sufficiently healed to go home to a home situation.*
>
> *Researcher: Why, why do you think about that?*
>
> *Penny: Why do I think about that? Because of infections and because of the fact that I have no medical training to deal with changing of dressings and to do with keeping everything as hygienic as possible. (Penny, interview 1, p4)*

Another participant, Irene, offers an even more extreme example of the sort of 'nursing' responsibility carers were confronted with:

> *His leg was all blood*
>
> *I had to wash them every day. I don't know - whether they didn't realise how bad the leg was I don't know. But the first week was horrendous - continually having a bleeding leg. (Irene, interview 1, p19)*

Irene's example underlines the stress for carers of not knowing correct procedures, exacerbated by uncertainty as to where they should turn for guidance. This sub-theme deepens our understanding of what it meant for these carers to 'walk in the dark'.

Perhaps the most alarming example of this aspect of nursing in the first part of the caring journey came from Sheena. Her husband Dennis had undergone surgery and been discharged in the usual time frame of 7 days post operation. However, two days after discharge Dennis collapsed:

No, he only was home for two days and then he collapsed and they had to take him back in as an emergency. You know he got out on Sunday and by the Tuesday he was really, really ill. (Sheena, interview1, p1)

Sheena phoned their GP and asked him to make a visit because she knew that things were not right. The GP was so concerned he took bloods, and subsequently had Dennis readmitted to the hospital, where he stayed for another 6 weeks. It is fortunate Sheena had the common sense and courage to refer the matter of her husband's relapse, and it brings into sharp relief that fact that Health-care professionals are relying upon family carers to make judgements for which they are unlikely to be equipped.

A clear sense emerges from the examples cited that the participants felt inadequately prepared for their new roles as carers. There seems to be a conflict for the professionals between considerations of what is best for the patients and their relatives, and the pressure to meet targets set by Health Boards and Governments to shorten waiting times and maintaining the through-put of patients. Public perception of Health-care professionals may, in this instance, be negatively affected by a degree of understandable ignorance regarding the way hospitals are commonly managed and how this has altered over time. Discontentment amongst the participants and their relatives specifically is likely to be heightened by the fact that most of them are old enough to remember a time when patients were retained and cared for in hospital for more lengthy periods following surgery.

Two of the participants, Lillian and Anne, described situations in which they felt the level of responsibility was manageable, requiring them to act merely as family carers rather than as unofficial nurses:

I don't really have an awful lot to say because I found it quite good. Paul wasn't any problem…. The only thing I helped him with was his stockings. (Lillian, interview1, p1)

Anne's husband, Philip, had no wound because it had healed during his post-operational stay in hospital, so he was in better shape than some of the others in the group. Lillian's and Paul's situation was somewhat different in that they were connected to a General Practice with a cardiac exercise group which the Paul attended before surgery, so the Practice was geared up to care for him more directly than any of the others when he returned to the community. In this case, the Health Visitor came to see them two days after discharge, and subsequently provided them with support on a weekly basis. In addition Lillian had the assurance of knowing she could call for help from the Practice at any time if it was needed, although in fact she never had cause to do so.

5.5.2 Play multiple roles

During Phase 1 all the carers played multiple roles - gatekeeper, housekeeper, cook, nurse, and link with the outside world - .when they looked after their loved ones. Jack, the one male carer, found the sudden multiplicity of responsibilities particularly alien, but he was not alone in discovering that the multi-faceted burden of the family carer was a challenge. All participants were obliged to accept that, since there was no one else to carry out these roles, the responsibility fell to them. Penny recounts her experience in the diary she kept for the first three weeks after her husband's discharge:

Learning how to recognise and accept the fact that I must learn a new role: that of patient care in all its forms - nursing (albeit in a

necessarily amateur way), housemaid, companion on walks, exercise supervisor, meal planner, cook, cleaner, shopper, medicine checker etc… (Penny, Diary1, p6)

Acting as a link with the outside world assumed particular importance, as Hannah eloquently related:

Acting as a link between Joey and outside world important as is consoling him to the fact that although his operation was successful he must have realistic expectations as to what he can accomplish physically at such an early date. (Hannah, Diary1, p1)

Hannah showed her awareness of the need to dissuade her husband from entertaining unrealistic expectations regarding his physical capabilities, while reassuring him that the world was continuing to function as before, and that he would be able to resume an active role in that world when he was fully recuperated. This degree of paternalistic solicitude can become excessive or entrenched; although it is appropriate for this Phase of the journey it is a role which the carer must ultimately relinquish. The carer's ability to judge the appropriate level and duration of their input is perhaps more severely tested at this stage than any other, reminding us again of the overarching theme of 'walking in the dark'.

as the role of gatekeeper refers to the carer's responsibility for assessing the relative fitness of their loved one for receiving visitors and telephone calls, or dealing with the stress of attending to bills and other correspondence. Maggie described her experience:

You know every day we had visitors, which you do get, you know people are just concerned but if you had somebody for

> *maybe an hour I used to say to him you should just leave and go and lie down. But he didn't like to do that. (Maggie, interview 1, p7)*

Hannah's interpretation of the gatekeeper role was interesting, in that she was keen to encourage Joey to take the initiative with visitors and leave the room when he was tired of their company, rather than relying upon her to ask to bring the visit to an end.

Another role that all the carers adopted was to ensure that the provision of professional medical support. There was an expectation that such support would come from the GP, District Nurse and Health Visitors or friends who had a professional healthcare background.

Hannah tells of exactly how she went about setting up this support:

> *Joey was discharged from the hospital on 30th August 2006.*
> *We arrived in our flat just after 12 noon.*
> *(1) Called at J's GP's surgery to deliver letter from hospital*
> *(2) To ensure that district nurse called next day*
> *(3) Phoned friends/relatives to inform them that we were back (Hannah, Diary 1, P1)*

Support from Healthcare Professionals was important to obtain prescriptions for medicines and dressings, and also for advice and reassurance. Support from friends and family, particularly in the early days of the journey, subsidised a more mundane level of provision, for example by trips to the supermarket or the chemist, or through helping out with domestic chores. Some carers were notably efficient in their organisation of this type of support setting, creating rotas of allotted errands for various family members and friends.

In the case of the sisters Jenny and Nicola, Nicola (originally the

'patient') demonstrated great acumen attending to arrangements for her own care. Jenny describes this in her diary:

> *In between Nicola's discharge we have run a family rota and Nicola either employed a lovely New Zealand girl (who happened to be a physiotherapist too) to help run her home and get through her recuperation. (Jenny, Diary 2, p1)*

Most participants set about creating a personal timetable as a means of negotiating the various needs and demands of each day. A diary entry from Jack makes specific reference to this procedure:

> 1. *get into a routine of getting her up in the morning and help her get ready and then have breakfast, and take tablets on time.*
> 2. *make sure clean clothes lard out and dirty washing put in washer*
> 3. *plan meals, may have to go to local shop to buy a few items, make shopping list with My wife's help for main trip to supermarket. (Jack, Diary 2, p1)*

This sort of approach enabled carers to obtain a positive and lucid state of mind in advance of the many tasks incumbent upon them. Interestingly Hannah pointed out that writing a daily diary had in fact contributed to her self-organisation:

> *Yes that's right. We have kept this diary. Maybe that's a point to make. You will forget things within five minutes if you're upset a bit so keep writing them down and keep a diary so you know what's going on. (Hannah, interview 1, p19)*

Although at this early stage of the journey there were problematic aspects of the participants' situations which they had little power to improve, self organisation provided a relatively straightforward means for reducing the perception of 'walking

in the dark'.   Another such approach involved participants' attention to levels of cleanliness and order. This was a particularly significant consideration for carers whose relatives had un-healed wounds, and were thus at risk of infection. Penny's attitude is typical:

> *I had to do things like cleaning my bathroom all the time. Usually once a day which I don't normally do once a day. I had to have the place as clean as possible. (Penny, interview 1, p.15)*

It is clear from Penny's evidence that she has addressed herself to the new demands of her situation and modified her customary behaviour, increasing the frequency and level of daily cleaning in order to minimise the possibility of her husband's wound becoming infected. Every such alteration or improvement of conventional domestic procedures may be seen as a way in which participants have addressed and sought to diminish the difficulties of 'walking in the dark'.

The carers in this study were predominantly women, accustomed to the fulfilling the demands of various housekeeping duties. However, for the one male participant, adoption of the role of family carer involved taking on a range of tasks which were new to him.

> *I am doing the cooking and cleaning and have learnt how to work the washing machine, handing out washing and using the iron.(Jack, Diary1, p1)*

The fact that Jack's wife, Mary, suffered a stroke eighteen months prior to the surgery meant that his conversion to domestic responsibility was gradual rather

216

than immediate. Perhaps the most important aspect of this situation for Jack was that, seeing no real improvement in Mary's condition, he entertained no idea that their roles would revert.   For the majority of carers, although the process of transition was not as abrupt as for Jack, reversion to a conventional level of responsibility was more likely, once Phase 1 of the journey had passed, and the relative's recuperation was assured. Jack's situation is atypical; the more natural pattern for taking on new roles is one in which, during the learning process, the carer is 'walking in the dark' and learns new skills which are ultimately relinquished. New roles are necessary in Phase 1, but the necessity will diminish by Phase 2, and these new roles will have been given up by Phase 3.

5.5.3 Finding a Balance

This sub-theme addresses necessity for the carer of establishing a balance between their perceptions of the relative's capacities - often arising from a paternalistic attitude -   and the relative's expectations of themselves and their abilities. Hannah explains that such tensions developed between herself and her husband in the second week following discharge:

> *Joey's increased independence in movement is good but his feelings of frustration and attendant gloominess can be wearing. I'm still trying to find a balance in urging independence while cautioning against aiming too high with unrealistic expectations in Joey's mind. (Hannah, diary 2, p1)*

Here we understand that Hannah wants to encourage her husband to be more cheerful while accepting the necessary limitations attendant on his condition. She

217

is therefore at pains to urge optimism and a realistic attitude at the same time – even though these attitudes are in many ways opposed.

All carers understood that their relative had been through a major operation and, possibly in line with professional advices, should take things slowly and build up their strength gradually. The relatives, on the other hand, felt better, and saw their discharge as a pretext for regaining the control relinquished during hospitalisation. There was an inherent tension between these two views which it was the carer's task to negotiate.

Penny's evidence eloquently expresses the complexities of this dilemma:

I had strong feelings about what he should and should not do. He knew what he should and should not do. He insisted on doing what he wanted to do but as a homeopathic patient ingrained in me is the fact that the individual is in control of his or her own life and they must make the decisions they are comfortable with and all I can do is present the case and if he chooses not to pay attention then that is his choice and that is how it was left. In other words I actually swallowed my feelings and did not have a fight with him. (Penny, interview 1, p16)

He knew it and the worry came out in watching him all the time and being there. And he didn't really want me there but I was there and I just said to him I'm sorry but I've got to do this because I've got to be sure that you are alright. And the only way I can be sure you are alright is by being there to see it because he is very strong willed and very stubborn and when he sets his mind to doing something I can't change it. And so in my view having a fight with him was not going to gain anything. All I could do was hover and be there to make sure that if it went wrong I was there. (Penny, interview 1, p17)

This sort of experience was common to all the carers to a greater or lesser extent particularly at the beginning of the caring journey. However, it is interesting to note

218

that there was a point in the care-giving journey at which the carer began to feel their relative should be regaining independence, when maybe the relative in question had settled into a routine of being protected from overly challenging situations – a sort of domestic version of the institutionalisation which may occur in the hospital setting. At this point, the carer's role of finding a balance altered in its nature. A possible outcome of this alteration may be carer guilt, as Jack explains:

> *No, no, you're alright because I know I'm doing too much for her. You know, I'm doing things that she could get up and do. I just say, no it's alright I'll get that and things like that. I know I should be pushing her to get a bit fitter but I think I'm maybe a bit guilty towards …*

> *Well, because I should be making her do things. Or encouraging her to do things instead of me just - I quite like a walk along the front at [place] and that you know in the summer, just to go down and park the car and walk and come back again but I cannot get her to go out to do things like that. (Jack, interview 1, p 5)*

A further possible effect may be the reduction of social life for both carer and relative. Jack again:

> *Well we used to go out socialising most Saturday evenings you know for a meal and a wee bit of a bite to eat or up to our local bowling club and things like that - we've never been anywhere. (Jack, interview 1, p 1)*

> *In fact I'm quite sure up at the local bowling club they'll wonder if*

> *I'm still living or not because I was a sort of constant visitor, you know and I've never been there for what four months, something like that. (Jack, interview1, p25)*

Jack's evidence underlines how paternalism in the early part of the caring journey has implications not only for the 'patient's' freedom but also for the carer's. The degree of restriction and isolation imposed upon both individuals in such a situation may be a source of tension in their relationship, although in its early stages this tension may be manifest only as a sense of boredom or monotony. When Hannah was asked if the restriction of social opportunities lead her to feel isolated she replied:

> *No. I think we were actually a wee bit bored at times because we were not able to get out as much now. You know at the moment we've not been going to the pictures. We usually go to the pictures and go out visiting people. (Hannah, interview 1, p. 20)*

It is understandable how, for carers whose only desire is to make the situation for both their relatives and themselves as positive as possible, such negative outcomes as guilt, boredom or tension may lead to confusion as to the best way forward. Such confusion is a characteristic element of the state which may be described as 'walking in the dark'.

A possible solution to such negative emotions was provided by the example of Anne and her husband Philip, who developed a system of negotiation and compromise as a means of resolving tension between them:

> *Well, I won! No, he accepted it. If I said to him I don't think you should do that and he didn't. But he's getting*

220

there. I mean he will carry a shopping bag upstairs now. If we need some milk he'll get some milk and carry it from the paper shop along the road there. So he is doing little things and I'll let him come and clean the car with me so long as I do the heavier bits you know. (Anne, interview 1, p10)

It is worth noting that Anna and Philip had been married for 50 years, and had possibly already evolved ways of resolving the inevitable differences likely to arise in a long-standing close relationship. But it is also important to remember that Philip's wound was already healed by the time he was discharged. This reduced the necessity of his being forcibly restricted in his attempts to undertake otherwise unwise or impractical activities.

5.5.4 No yardstick for knowing

For carers, possibly the most self-evident aspect of 'walking in the dark' was their ignorance of what to expect with regard to the duties of their new role, and how best to discharge them. The sub-theme 'no yardstick for knowing' specifically refers to this sense of ignorance. As already discussed, carers often felt that their relative had become their 'patient', a patient for whom they as carers were obliged to fulfill 'multiple roles', and for whom they were obliged to define a sensible 'balance' between conflicting expectations of what the 'patient' could or should attempt on a daily basis. Confronted with this multi-faceted challenge, it comes as no surprise that participants identified the lack of information or guidance as their chief issue. Penny articulates this problem clearly:

You've got to, you're flung into it …. I had no briefing as to what to expect, really expect, not this airy, fairy, magical video. I had no yardstick for knowing what should be done.

221

> *I had no ability to know what might go wrong, to gauge whether <u>this</u> [what] might go wrong was a reality or a bridge that I couldn't cross. It is difficult to explain that, but when you are in an unknown situation….(Penny, interview 1, p22)*

It seems that the video with which Penny was provided lead her to anticipate a situation altogether more positive and straightforward than that with which she was confronted when her husband came home, and she realised how weak surgery had made him. Jack makes a similar complaint

:

> *Well, just they didn't give us enough information. You know they made out before she went in for the operation that everything was going to be great after the operation that she was going to be sort of running about, showing us a video of people doing things, swimming and walking about and everything just weeks after their operation and well it's not really the case. (Jack, interview 1, p.1)*

Although the video may well have given a measure of reassurance concerning the long term well-being of the 'patient', and therefore made living through the time of the operation easier (which was presumably the object of the British Heart Foundation in producing the video) it did not provide a realistic timescale for recuperation. Inadequate information lead to confusion in the participants, and possibly made the initial stages of caring for their relatives more confusing and disheartening than was necessary. Had the video been more accurate in its guidance, it is possible that carers might not have been so dependent upon the process of trial and error in dealing with the problems they faced. Inadequate and/or misleading information was a major reason why so many carers felt they were 'walking in the dark' in Phase 1 of their caring journey. Jack makes this point explicitly in his diary:

222

If more information about these things had been given before the operation I would have been more prepared and ready for things that happened like washing and helping her to dress, when I should start to get her to walk up stairs and how much exercise she should take, how long she would take to show benefits from the operation which I am fit enough to look after her but could have organized more help from the family to give me a break from some of the work involved. (Jack, Diary 3, p.1)

In some cases carers identified specific areas of important knowledge in which they felt inadequately provided. Irene was one such:

As I say, if his wound was starting to heal a wee bit it would open it up again. So when I couldn't get an appointment with the nurse for a week I went to the chemist and asked him so he gave me some dressings to put on but they were very bulky. The result is I couldn't get the stocking on with it and it was after that that the district nurse phoned me and I said to her look, somebody will have to do something about his leg. (Irene, interview 1, p2)

The lack of a 'yardstick' was clearly a key issue for these carers - finding themselves suddenly answerable for the wellbeing of their relatives, and faced with the responsibility of coping with problems or setbacks in their progress. All participants were adamant that they were not involved in the process of discharge planning which presumably took place between the health-care professionals and the hospital, and were thus confronted at a stroke with the decisions and responsibilities of the care-giving situation without any prior guidance.

Participants also complained that they received none of the necessary equipment – for example dressings, stockings, medicines and hoists - for the care of their relative, nor even any advice as the resources they would need:

> *R: What things did the hospital give you when he was discharged?*
>
> *Irene: Nothing.*
>
> *R: Nothing?*
>
> *Irene: Stockings. That's all they gave me, stockings. three stockings. Nothing to say how I put them on - they just gave me three stockings. And she said probably one pair would do him two or three days. They didn't even do him one day. (Irene, interview 1, p19)*

Irene was not given sufficient pairs of stockings, but more importantly she received no instruction in how to put them on. It is possible that the healthcare professionals assumed any woman would know how to fit stockings; if they did so they perhaps failed to consider the difference between putting stockings on yourself and putting them on someone else.   This oversight made Irene's task more difficult especially since it had to be repeated more often than might have been expected. This aspect of her husband's care was the most challenging aspect Irene faced in the early stages of the journey.

Several carers also complained of the health-care professionals' use of medical terminology without consideration of the fact that, for the lay-person, such terminology may be alien and confusing.   Jenny refers to this problem in her diary:

> *Medical terminology was sometimes hard to understand ie: CABGs-essential everyone understands what is being talked about. Warfarin Levels. . (Jenny, diary 3, p 1)*

Obviously healthcare professionals communicated with each other using medical terms and jargon which carers cannot be expected to understand – perhaps forgetting that, for the family carer, the world of medical terminology is a closed one.

5.5.5 Hospital to Community Care Gap

Several carers referred to a gap between hospital and community care, suggesting that their own situations would be improved if hospital and the community were to co-operate more closely over the patient's care. An example of this lack was provided by the example of Penny, whose husband was sent home with no dressings:

> *They gave me none. They discharged Michael and the district nursing service was furious on the following day because he should have been discharged with seven days' worth of dressings for the district nurses to begin treating him. (Penny, interview 1, p5)*

Penny's experience was further complicated by the fact that her husband was a diabetic:

> *He was discharged without any carry-over medication. He was discharged without any metaformin, which is essential for diabetics, and we were told that there was not one bit of metaformin in the hospital pharmacy that day. (Penny, interview 1, p5)*

This situation illustrates the dangers that can arise from 'hospital to community gap'. A lack of metaformin in a hospital pharmacy seems barely credible, and to discharge a diabetic patient without any positively irresponsible. Such a lack of communication between the hospital and the community caused inevitable misunderstandings between carers and community healthcare professionals. Some of the carers were understanding of the pressure under which hospitals must labour to release beds and enhance 'throughput'; one, however, felt her husband had been discharged too early, while another felt his wife had been treated 'like a number'.

However, there were a few cases in which better planning took place between hospital and community care, with the result that carers felt better catered for. This arose in one instance because the contact between hospital and community was made before the surgery took place. The carer in question was Lillian:

> *We contacted the doctor, who came right away checked medication. The local cardiac rehab nurse came to see Richard and myself to provide support. She was contacted by the hospital, she will be visiting once a week. (Lillian, Diary 1, p1)*

It was perhaps this level of support which disposed Lillian to feel positively towards the Health-care professionals, and to declare that for her the caring journey was not a problem. Another carer, Maggie, had the benefit of private health insurance, and the assurance that she could contact the surgeon, or other Health-care officials at any time if she had any doubt concerning medicine or treatment following the surgery:

> *We're in BUPA, yes - but the operation was private at the NHS HOSPITAL so that was my contact. Anytime I needed to speak to him. (Maggie, interview 1, p1)*

When the need arose, she took advantage of this offer, contacting the surgeon, and was given telephone numbers to call to ask for further aid from the most appropriate professionals in the community.

5.5.6 Physical and psychological strain

Phase 1 of the caring journey was not only consonant with that confusion characterised in the notion of 'walking in the dark', but by high levels of hard work and worry.   Besides looking after the patient at home, carers were obliged to handle problems which might well have been dealt with by nurses and other healthcare professionals. Penny bears witness to the physical strain of her role:

> *During that time, well there was an enormous amount of hard work to do. And in that time I had to completely refocus my life and the best way I could describe it is to be a 24 hour, 7 day a week, voluntary nurse. (Penny, interview 1, p 14)*

Physical tiredness arose from the necessity of attending to all the tasks involved in keeping the home running smoothly. Hannah gives us an insight into this routine:

> *I think the tiredness was due to the fact that I was actually doing more running up and down the stairs, doing*

everything, putting the dustbins out, I was doing all the work and that made me more tired but then I was tired as well because it was going round and round in my head, how was Joey, was he going to get better, or I was annoyed at him, you know sometimes his moodiness was affecting me. (Hannah, interview 1, p4)

In many cases tiredness was exacerbated by the fact that carers slept less, often maintaining a vigil in order to ensure the 'patient' was comfortable and safe, or worrying that the 'patient' would not be well in the morning

.

Sleeping as I just couldn't rest thinking something might happen while asleep. (Maggie, diary 1, p1)

The most difficult times have been during the night as my husband has been waking up every 2 hours. (Millie, diary 1, p1)

That took about a month to leave me. (Maggie, interview 1, p 6)

However, a further contributing factor to levels of tiredness amongst carers was the fact that many of the tasks they were involved in were new and strange to them:

R: What were the things that you don't normally do for your husband?
Sheena: Taking him to the toilet, washing, dressing and helping him from bed to chair, also encouraging him to eat and drink. Also supervising his medication. (Sheena, Diary 1, p1)

Exhaustion for the participants was not simply physical, but mental and emotional. Hannah alludes to this in her diary:

Luckily I'm fairly fit and able and I feel that any tiredness is simply because emotionally and physically this has been and continues to be a testing experience. (Hannah, Diary 2, p2)

A chief source of emotional stress was the constant anxiety carers felt about the ongoing wellbeing of their relatives. Maggie expresses this very clearly:

You're always feared, like if he was sitting here, because he usually sits here or lying in bed I always dreaded walking into the room in case something had happened. There was a very uncertainty for a wee while. (Maggie, Interview 1, p 5)

Many carers admitted that they were afraid of expressing these emotions in front of 'the patient' concerned that this might impede his or her recovery, and generally feeling responsible for maintaining a positive atmosphere in the household. The unconscious attrition of constantly worrying, and at the same time attempting to suppress that worry was a major factor in carer fatigue.

Carer anxiety was exacerbated by the fact that most were fiercely protective of their relative, fearing to lose them.   This emotion was particularly pronounced in those whose relatives had undergone a near death experience.   It is understandable that in such cases the carer felt compelled to exercise constant vigilance.   This perhaps explains the level of anxiety and watchfulness Anne recalls in the following extract:

> *To begin with I went with him. I wouldn't even let him go down stairs unless I was there. The first time he went out on his own he went round to post a letter at the post box which is just out on the road and I was watching on both windows you know to see if he was alright. Then when he started to go for a walk by himself, and I still do this. (Anne, Interview 1, p 4)*

This watchfulness did not just continue for a few days, but was more long lasting, partly because her husband's brother underwent a similar surgical procedure but sadly died after discharge:

> *Yes, now I've never ever said that to mu husband and I wouldn't. But I know when he wasn't well his brother was always on his mind but that slightly does worry me although I know it's not necessarily the same with my husband as it was with Angus but the picture is sort of the same though because he had the operation albeit he was younger than my husband he had the operation....(Anne, interview1, p6)*

This anxiety placed a great strain on her because she could not discuss it with anyone, particularly not with the person to whom she would naturally have turned. This is perhaps the most poignant aspect of 'walking in the dark' – the combined sense of enormous responsibility and isolation. Anne expresses this eloquently in her interview:

> *Well, the most worrying part because he was just out of hospital and suddenly you have got the whole responsibility. You know you feel if someone professional comes and sees him and sounds and then*

230

listens to his heart and does his blood pressure you feel reassured, that it's alright, you know. I mean I was checking his blood pressure and things like that but it still, I still found that bit a little worrying, you know that I hadn't had any medical back up at that point. (Anne, Interview 1, p 3)

Caring in Phase 1 is appropriately summed up as 'walking in the dark'; the obligation of accepting multiple roles, with scant foundation of professional advice or specialist knowledge, under pressure to strike a balance between personal anxieties and the impulses of the cared for relative brought with it not only isolation, but personal ill health, frustration and depression. Fortunately, for most participants the intensity of this burden diminished as the caring journey progressed from Phase 1 to Phase 2.

5.6 Getting on with it

This second theme, and its three attendant sub-themes, represents the development of Phase 2 of the caring journey. Some of the data used here was taken from interviews obtained 6 weeks post-discharge, but the majority is from week 12. This is because at 6 weeks some carers had progressed from 'walking in the dark' to a more controlled and methodical means of managing their caring. During this period, although some carers naturally still felt worried about their relatives, they could see progress in their state of health. Despite this, the caring journey continued for all of them – in each case unique to the carer and his/her individual circumstances, yet still characterised by certain general aspects in common. Data revealed that carers still were making efforts to manage things for

their relatives.   Jenny provides an especially good example of how participants continued to 'get on with it' despite various difficulties that may   arise within families:

> *You just do it. You just have to. You just have to get on. I had my grandson around as well a lot of the time because my daughter was in hospital and my grandson is two - he'll be three in February. Having him there was wonderful because children just make you get on. So I had him to look after as well. So, it helps. You just get on with it. (Jenny, interview 1, p4)*

Jenny's experience provides perhaps the most extreme example of 'getting on with it' of any of the participants, because of all the carers she experienced perhaps the greatest degree of difficulty incidental to the central caring burden. At the same time that her sister was discharged, her father was admitted to hospital with a chest infection, while her pregnant daughter continued to suffer with morning sickness. On top of this Jenny discovered that she herself had a lump in her breast. The number of issues Jenny found herself confronted with meant that she had little time to think of herself, and neglected to seek treatment for her breast lump. Although Jenny's difficulties were excessive, her general attitude is characteristic of the outlook of all participants in the study at this point in the caring journey.

5.6.1 Continuing the care

An important aspect of 'getting on with it' refers to the quality of perseverance with which carers continued to attend to tasks relating to the activities of daily life, and,

albeit to a lesser extent, to 'nursing' duties. Penny sheds light on the way in which

this habit of caring persists, even as the 'patient' is improving

:

> *Yes, and if I wasn't actually there I was listening the whole time. Ready to do anything that was necessary. Like bringing up a baby. When you have a baby your whole consciousness is 24 hours a day so if the baby cries in the night you automatically waken. And it was the same with Michael getting better. Anything that happened had to be paid attention to and it was the first priority. (Penny, interview 1, p 8)*

Penny's words demonstrate how, although in general there were no new tasks

undertaken in Phase 2, carers continued to devote thought and energy to the

wellbeing and improvement of their relatives. This care was both supported and

supplemented by those in the community.   This level of support and

encouragement is clearly part and parcel of 'getting on with it'.

5.6.2 Still playing multiples roles

This sub-theme does not include activities which are related to nursing; relatives

were by this stage much stronger than they were immediately after discharge, and

their wounds were nearly healed.   The participants' perception of this gradual

improvement is exemplified by a statement from Anne:

> *But he's getting there. I mean he will carry a shopping bag upstairs now. If we need some milk he'll get some milk and carry it from the paper shop along the road there. So he is doing little things and I'll let him come and clean the car with me so long as I do the heavier bits you know. (Anne, interview*

1, p 10)

However, the majority of the multiple roles adopted in Phase 1 continued to be of concern to most carers. The only participant who clearly had a different perception to this was Lillian; she quickly realised that her husband was fairly fit and well, and was happy to allow him to accept again some of the activities he had undertaken before his illness:

> *He said I'll be fine and he was fine and doing things like cutting the grass, and that he's not done for a long time. Well, he didn't cut the grass. He didn't do anything like that. (Lillian, interview 2, p1)*

Although Lillian was more than ready to allow Paul to resume his former activities, it is clear from her evidence here that there were still jobs, such as cutting the lawn, which she felt compelled to continue, albeit perhaps reluctantly. It is possible that Lillian's perception of Paul's improvement was not so much a reflection of his full recuperation, as of her resentment about the extent to which, in spite of his improvement, she was still obliged to fill in for him – an obligation which continued to infringe upon her social freedom.

5.6.3 Continuing support

The third sub-theme of 'getting on with it' is 'continuing support'. In Phase 1 most of the support carers required came from professional people (mainly doctors and nurses), however in this Phase other members of extended families and friends became more important in the provision of help:

I've got to say being in here you know having Jan the manager, she's very good too at coming to see how you are and so forth so I've never ever felt that I'm cut off or … haven't had somebody to give me some back up,… . (Sheena, interview 1, p5)

Oh yes. Like for instance I wanted a new light put up or anything like that my son in law is very, very helpful. He'll come and do it without any problem. I don't need to worry about it at all, you know. (Sheena, interview 1, p7)

Often, the occasion for such contributions of help and support is the necessity of attending to tasks which, although not specialised, are beyond the capacities of the carer. It probably takes some time for carers to accept that it is reasonable to seek help in order to alleviate physical and psychological tiredness. An added advantage of having other people around is that it may reduce feelings of isolation, and encourage carers to feel that a level of normality is returning. Although carers are still 'getting on with it' continuing social support may help them to adopt a more positive perspective on their relative's health, and so reduce levels of stress. Jenny made specific mention of the positive influence of having other family members around her:

Having him [Jenny's grandson] there was wonderful because children just make you get on. (Jenny, interview 1, p4)

Although what Jenny was doing was helping to look after her grandson, his company cheered her up, and perhaps reminded her of the importance of the continuity of families. This underlines the fact that such familial support may not

always be in the form of practical physical assistance, but sometimes is merely a matter of companionship.

The theme **'**getting on with it' may thus be understood as a natural development in the caring journey between discharge and recuperation. It is represented by three sub-themes - 'continuing to care' which involves 'playing multiple roles' with 'continuing support' from friends and family (rather than the professionals). It is interesting to note that the theme comprises only three sub-themes; this suggests that the dynamic of the caring journey is one of gradual simplification, towards an experience which may be explained in shorter compass.

5.7 Looking forward to the future

'Looking forward to the future' is the end of this caring journey. It comprises a positive outcome for the majority of the carers and the cared for people, and derives in data collected 12 weeks after discharge.

Carers found the progress of the patient shed a light on their lives and they looked forward to their lives together in the future. A good example of this comes from Millie, who remembered her situation during the journey:

> *I suppose because I mean it was just such a big upset in our lives because I never knew that my husband was ill. I always thought that he was really well and would go on forever and to find out that he was ill and needed, a major operation really was just awful. It was just awful and just it just changed my life and that's all that I kept thinking about all the time that my husband was ill and I didn't know how much longer he was going to be with us. I just kept thinking everyday this might be the last day that I see my husband and I suppose that,, it just affected me very badly in that way. (Millie, interview 2, p1)*

to the experience at the end of it. She went on to say:

> *It's a big difference. It was a nightmare to begin with and now it's just a nice dream.*
>
> *That's it. Yes I can see every day now that there's, you know I have a positive life. (Millie, interview 2, p 7)*

These examples show clearly the transition of Millie's life, she was told that her husband might not live long and now she could see that her husband had recovered from surgery and their lives were worth looking forward to.

5.7.1 More honest now

The first of the two sub-themes is 'being honest with each other'. By this the carers meant that they could express their feelings, what they were thinking about and discuss in greater detail and with more honesty their lives with each other. Hannah for example said:

> *I feel better in that we can discuss and clarify our emotions. We are more honest now. We are coming out and saying, at least I am saying what I think. (Hannah, interview 2, p5)*

This sort of experience was matched by Maggie's.

> *Yes, I suppose with it happening brought a lot into perspective because remember I used to say you just thought of each other always being there. Nothing was going to go wrong and it sort of brings either side of your*

> *life to a standstill and you concentrate on the middle.*
> *(Maggie, interview 2, p 3)*

In the beginning, Hannah was afraid to express her feelings as she did not want to slow down her husband's recovery. Three months later, however they discussed their feelings regarding their expectations of each other and life in the future. Thus they were 'more honest with each other'. This new honesty was common to most of these caring couples in that they could actually face their own and their partner's mortality but also how their remaining lives could expect to be conducted. This meant moreover, that their relationship improved during her husband's recovery.

Although most of those who had surgery had an uneventful progress to recuperation there was one carer, Sheena whose husband was diagnosed as having cancer during Phase 2 of the carer's journey. This was a difficult time for both of them and Sheena needed to discuss many things with her husband. She said:

> *Well just what we think would happen if anything, you know if anything did happen to him how I would cope. I mean he knows fine if I'm ill - for all I know I could go before he does but I don't have to worry in that sense about being looked after and so forth but we have spoken about different things, you know about funerals, what we would do how we would manage and so forth, well how I would manage but…(Sheena, interview 2, p4)*

This example of great honesty between these two people was particularly striking for a Chinese person for whom much of this would have been taboo. It also is notable because this couple were not thinking about recuperation but were

thinking about a much more final end to the caring journey which continued in a different way to anyone else in the group of participants.

Another example of honesty comes from Millie's husband who had a more risky operation than anyone else in the group of relatives and so this couple too discussed in more detail than others what the future might hold, and how she would manage it. She said:

> *Well, only, we talked about it a little bit but not very much. No. All he said was the day before his operation and he said to me if anything happens just live your life and enjoy it and just do what you want to do and just be happy. Just live your life and just do what you want to do and be happy. (Millie, Interview1, P12)*

Although they were honest with each other, it was distressing for the carer. This honesty, however, would have provided, and possibly still will, a very good memory that would have supported Millie during a time of bereavement. Thus this shows clearly that being honest is fundamental to looking forward to the future.

5.7.1 Being back to normal life

The sub-theme of 'being back to normal life' indicated a positive perspective for these carers and in reality it marked the end of their caring journey. Millie said:

> *I just feel very happy. And I just feel that my life is back to normal, how it used to be. You know, no different. My husband has done really, really well and it's just like it never happened. You know it's like something that, I mean I haven't forgotten about it, I don't think you can ever forget about it but our life is just returning back to normal. (Millie, interview 2, p1)*

This is an almost idyllic explanation of the end of the journey but it has to be remembered that to get there was for these carers not straightforward. The tension of having to keep positive to allow this stage to be reached is challenging and could only be reflected upon when the journey was being completed.

> *There's also the conflict between heart and head because you know things in your head but it's not always how you feel and that is one of the hardest, that's been one of the hardest things of the whole thing. The positive attitude that you had to give Cathy before the operation and you'll feel much better tomorrow other days before and during recovery but sometimes in your heart you didn't feel it you just felt what's happening here. But in your head you have to keep the positive act going. (Jenny, interview 2, p5)*

However all but one of the relatives reached the stage of recuperation on Phase 3 and so the carers were happy that their relatives were better and caring had diminished to such an extent that the only way to describe it was that 'things were back to normal'.

Normality for the couples was explained in terms of the relative being able to take up the reins of 'normal' life again. As Irene pointed out:

> *He goes out and about on his own and he's fine and the operation has made such a difference to his getting out and about you know so that's good. But we're going away next week. We're going away next week for a couple of days to Pitlochry, so that's good. He's meeting his brother, which I don't know if he would have done before but he's doing it now. (Irene, interview 2, p1)*

So not only were the relatives able to undertake their usual chores but also they contemplated taking holidays.

*Oh, we're needing a holiday yes. I think we're both needing
a holiday. (Irene, interview 2, p12)*

Thus we have a Phase which completes the journey that returns the ill person to fitness and gives the carers a feeling of 'looking forward to what can we do now and enjoying life' (*Anne, interview 2, p10*) that they have been able to contribute to this process despite it being a great deal of hard work worry and at times confusion but ultimately their lives are such that they are looking to the future with increased honesty and expectation. Their relationships certainly sounded as if they were closer than they had been before this journey began. We understand that looking to the future is explained by the two sub-themes. Because there are only two sub-themes it is clear that this Phase 3 is the simplest and most straightforward Phase of the journey which is completed with total recuperation.

There were obviously some exceptions. For these the recuperation of either of the parties in the couples had not been totally achieved. These were in the case of the man who had a diagnosis of cancer where at the end of Phase 3 he was still awaiting the oncologist's appointment to get information about the primary source of the disease. Another carer had a diagnosis of breast cancer and presumably someone else would have to start a new carer's journey. The third couple were those who argued a great deal and whose closeness did not appear to develop possibly because their honesty was incomplete which prevented their being able to look forward to the future together.

5.8 The essence of caring

After rehearsing the many aspects of understanding of the caring journey it seems important to draw attention to what that journey actually means for carers. Clearly at the start the potential carer is a person in their own right carrying out various roles within the bond of their relationship with the person who becomes ill. At the very beginning of the journey in Phase 1 it is obvious that that person becomes predominantly a carer. This of course does not mean that they stopped being persons but rather that their personal interests (did not visit friends or follow hobbies), occupations (some gave up work), and concern (all experienced great worry) was not focused upon themselves but rather on the relative. This results in taking on new roles, undertaking new tasks, needing support and trying to manage unknown situations all within a reality of worrying about death and dying, doing the right thing or hurting the 'patient'. This adoption of being a carer lasts throughout Phases 1 and 2 but during Phase 3 they return to being a person. In this last Phase there is evidence that carers are relinquishing tasks, renewing their bonds in light of their experiences and look forward to the future in terms of going on holiday and taking up their old interests and occupations. Full recuperation signals the end of the journey but it is not achieved in a moment but rather over time. Inevitably each journey is unique and so there were three examples of those (Jenny, Sheena and Lillian) who did not follow the general picture of the journey because of further illness of either the carer or the cared for person or from existing problems within the couple which made the experience sit uncomfortably in the pattern.

Chapter 6

Chapter 6 Discussion

6.1 Introduction

The purpose of this chapter is to discuss the findings of the current study. A structure for discussion will be derived by reference to the participants' frequent descriptions of the caregiving process as 'a journey'. Analysis of research data identified three Phases to the caregiving journey; the discussion will comprise three themes, each of which demonstrate and expand upon a particular Phase of the journey. Phase One of the journey is characterised by the notion of 'Walking in the Dark', Phase Two 'Getting On With It' and Phase Three 'Looking Forward to the Future'. These three Phases represent the longitudinal development of the carer's role, and of his/her perceptions with regard to that role. A comparison of the current model with other models in the literature is presented at the end. The final section will present the new knowledge emerged in this study. An explanation of this development will be contextualised by discussion of the overarching themes, allowing reflection on the phenomenological essence of caring, and concluding with the researcher's reflections on her personal journey.

6.2 Phase One: Walking in the Dark

Walking in the Dark' summarised the carers' experience of being in an unfamiliar and alien situation at the start of the caregiving journey; it refers specifically to the sensations of loneliness, lack of direction, and ignorance, and the subsequent fear with which they confronted their responsibilities. Several relatively recent studies refer to similar findings - Theobald and McMurray (2004), Davies (2000) and Leske and Pelczynski (1999). As we have already seen, the implications for a

244

spouse or close family member (such as a sibling), preparing to care for a relative discharged from hospital following acute surgery are very serious. This is true even for family carers who have some background in healthcare. It is quite common in such cases that the carer in question seems either to forget much of their training, or fails to perceive its relevance to the condition and needs of the relative they must care for. It should be remembered in this context that the participants' relatives have just experienced a life threatening illness - some of them becoming ill quite suddenly, so that neither patient nor carer had much time to come to terms with the changed situation, or plan how it should be managed. In the current study such feelings of uncertainty were accentuated by the fact that the patient was discharged within seven days of surgery. None of the prospective carers knew what to expect. An example of the precariousness of this situation for carer and relative alike was provided by the case of Sheena; her husband was discharged within seven days of surgery and fell seriously ill within a few days of returning home. On readmission it was discovered that he had lesion in his lung, and required a further ten days of treatment

Findings confirm that the participants' sense of 'walking in the dark' was significantly exacerbated by inadequate input from health professionals involved with the respective cases. In fairness it should be noted that cardiac surgery patients move precipitately through different areas of the hospital - from theatre to ITU, HDU and finally to a ward, which may mean that within a week prospective carers will potentially meet a large number of healthcare staff, reducing the likelihood that they will be able to form the sort of relationships conducive to a valuable interchange of information. For the majority of participants the question uppermost in their minds was not connected with the technicalities of caring –

dressing, medication and the like - it simply concerned the health status of the patient, 'is my husband/wife/sister well?' 'is he/she alive?' 'when is he/she coming home?' Such were the questions most frequently asked of the hospital staff.

A common feature in all the participants' stories is the fact that for each of them caregiving commenced while their relative was still confined in the hospital – a fact which had the effect of compelling participants to facilitate their relative's recovery by continuing the manner of care given by the hospital staff, for example putting TED socks on the patient, attending to an unhealed wound after a shower, or dealing with a bleeding leg. Participants quickly realised that such tasks require a degree of specialist knowledge, and were thus forced to acknowledge the need of professional assistance. In the absence of such support, carers became increasingly frustrated and isolated, struggling to manage as best they could unaided. A phrase common amongst participants when describing this experience was that they were 'thrown in at the deep end' , ie they were more or less cast into their new situation with little or no preparation for the demands incumbent upon them.

Studies perused in the course of the Literature Review tend to confirm that the attitude of carers to the discharge process is predominantly negative, characterised by expressions of frustration, and complaints regarding deficiency of advice and instruction, a consequent lack of necessary knowledge, and a general sense of being only marginally involved in the discharge planning process (Perreault et al. 2005; Lindhardt et al. 2008). What the current study reveals is that the degree of ignorance endured by the carers was matched by the ignorance manifest amongst the professionals involved with their relatives' cases; hospital

staff seemed to have little conception of the needs of carers, or much idea that the issue of understanding carer need is important. The current study, by inquiring into the experiences of family carers in the aftermath of a relative's cardiac surgery, has endeavoured to address this shortfall.

A further element of carer experience which relates to the notion of 'walking in the dark' concerns ignorance not only of the skills necessary to fulfill caregiving tasks, but of the nature of those tasks themselves. Simply stated, carers did not know what to expect. Hospitals seem, at least partially, to have realised the importance of this issue - a fact suggested by the provision of a general guidance video, offered to carers and their relatives prior to discharge. The purpose of this video appears to be to provide some insight as to what patient and carer should expect in the post-operative period. Participants confirmed that this was a source of some reassurance regarding the long term well-being of their relative, but were at pains to point out certain flaws in the information it offered. Chief amongst these was that any suggestion of the time frame for recovery was left out. Such oversights served to confuse participants, and exacerbated the sense of shock they experienced when they were suddenly and rudely confronted with responsibilities for which they were unskilled and unprepared. Findings in a study by Scott (2000) underline the importance of this issue, emphasising the responsibility of carers for the physical and emotional well-being of the patient, and the consequent necessity that they should be better prepared for their role.

A number of other studies have addressed this issue: as far back as 1995 the Carer (Recognition and Services) Act stipulated that carers should be encouraged to consider the importance of their own needs as well as those of the patient; the 'Partnership for Care', Scottish Executive White Paper on Health (2003),

247

emphasized the need both of knowledge and access to material resources amongst lay carers, and most recently a report entitled 'Caring Together: The Carers Sstrategy for Scotland' (2010) advocated the empowerment of carers to air their concerns in order that positive changes may be made in the healthcare sector. All of these studies emphasize the importance of treating carers as equal partners, and stress that if carers are to be accorded this status it should be on the basis of possessing the necessary knowledge to acquit themselves in the caregiving role – a situation which is only possible if healthcare professionals share experience and information with them.

Although the spirit and general tenor of the above policies is to be applauded, they all tend to focus on the issue of the long-term carer, paying scant regard to those family carers, such as the participants in the current study, for whom the prospective period of caregiving is short-lived. It is very likely the relative brevity of the caregiving period in these cases which has persuaded the healthcare service to overlook the needs of such individuals, although, within the period of care their needs may be as extreme and challenging as for long-term carers.

One of the few studies to focus on the situation for short-term family carers was conducted by Knoll and Johnson (2000). They made the point that carers with previous experience (in the case of their study these were individuals who had cared for elderly relatives in the aftermath of cardiac surgery) manifest significantly reduced levels of strain than do those who have no experience. They add that accustomed carers are more ready to take advantage of care-giving services – a factor which contributes significantly to the reduction of burden and stress.

6.2.1 Nursing the patient

'Walking in the Dark' refers to the sense of disorientation carers experienced as a result of being confronted by responsibilities and tasks for which they were ill prepared and of which they had no expectation. A particular source of disorientation was the obligation felt by carers to assume responsibility for authentic nursing tasks. One participant, Irene, felt the severity of her husband's condition demanded that she act more like a professional than a wife – attending to tasks such as toileting, bathing, dressing and feeding. She explained that such responsibility was something she had not anticipated. A particular example of one such task is illuminating, drawing attention to those factors which add difficulty to the carer's task, and thus to the sense of confusion and anxiety: Irene's husband came home from hospital with an unhealed wound in his leg, which continued to bleed and required regular dressing. Irene phoned the local healthcare practice repeatedly, but was unable to secure an immediate appointment, and was thus obliged to obtain dressing from the high street chemist. It was a week before Irene was able to get any assistance; until then she had no choice but to dress the wound herself – a job in which she had no experience, and for which she had received no training or advice. It is clear from this example that the troublesome nature of Irene's burden results not only from having to tackle a task she is ill-equipped to perform, but also from inadequate provision on the part of professionals from whom she is entitled to expect support.

Other participants faced similar difficulties in attending to other duties such as making the patient comfortable in bed or helping them out of it in the morning – an activity which is quite different when it involves assisting a full grown adult than, for

example, a child. That such negative experiences are all too common is made clear from references to them in other studies, for example Cheung and Hocking (2004).

Irene's own solution to the problem of helping her husband in and out of bed is instructive: while on the hospital ward she observed something she described as a 'rope ladder' which she surmised was some sort of hoist for the purpose of lifting the patient. Remembering this after her husband was discharged, she tackled the problem of helping him in and out of bed by improvising a similar device using a belt. This example demonstrates both the initiative which is necessary in the lay carer, confronted with a range of new and difficult tasks, and the deficiencies of preparation and support such carers are obliged to put up with.

The necessity for carers to subsidise the lack of support and information by using their own initiative is recognised by Scott (2000) who identifies a clear correlation between the carer's level of "self-perceived preparation" and the quality of caregiving they are able to provide. It must be pointed out; however, that simple intuition on the part of the carer may not be sufficient to meet the patient's needs in every case. Another participant, Lillian, was anxious about the task of putting TED stockings on her husband; they seemed to her to be too tight, and she was afraid of hurting him. In such a situation, expert information, rather than intuition, is necessary – something which can only be acquired from professionals. Again, the fact that healthcare professionals have made insufficient effort to anticipate the needs of carers after discharge is underlined.

Perhaps the clearest example of this deficiency is evidenced by the inadequacy of material support – the physical resources carers need in order to dispatch their responsibilities. Hannah, another of the carers in the current study, explained that, having identified the need for a bath bridge in order to bathe her husband before he left hospital, she failed to receive this piece of equipment until a week after his discharge. For many carers, home was felt to be the best place for the patient to rest and convalesce following discharge. These sentiments were motivated by entirely understandable and justifiable psychological and emotional considerations; many, however, were forced to call those sentiments into question because of the simple lack of material provision which should enable them to fulfil their role.

All in all, it is painfully obvious that carers felt unprepared carers for their new roles, and were dissatisfied with how apparently oblivious or careless the healthcare service was of their needs. Such dissatisfaction is likely to be heightened if carers remember a time when patients used to enjoy longer post-op recovery periods in hospital.

6.2.2 Hospital to community care gap

As we have seen above, a significant contributory factor in the confusion and anxiety alluded to by the notion of 'Walking in the Dark' is the lack of information with which participants faced the various responsibilities of caregiving. Such ignorance may be understandable; these were individuals from all walks of life with no specific training in caregiving skills. Given that this was the case it seems reasonable to expect that there should be a degree of formalised co-operation between healthcare staff and carers – the provision of physical assistance to make up the shortfall in practical experience. Evidence in the current study suggests that

there was in fact a problematic gap between hospital and community. A study published by Proctor et al. (1996) supports this finding and confirms the importance of addressing the issue. They investigated the cases of elderly individuals with congestive heart failure, and stressed that, when newly discharged; the patients continued needing the level of assistance to which they had been accustomed while on the ward. They added that the range of needs embraced both specific care requirements and the activities of daily living, (such as transfer, bathing, dressing, meal preparation, shopping, housekeeping and medicine). They also suggested that targeted training could help informal carers negotiate both domestic and care-specific tasks post discharge. Proctor et al. published their study 15 years ago; the suggestions they make seem practical and reasonable, but were based on an expectation of healthcare funding which has altered considerably in the interim. Government facility for providing the sort of social and professional support Proctor et al. recommended is significantly diminished in 2011.

The fact that the above-mentioned study focused on long-term home care situations should not deter us from applying its findings to other cases, such as the short term care situations of the participants in the current study. Rantanen et al. (2004) studied carers who looked after CABG patients, and found that their relatives experienced a similar level and range of dependence as in cases of long term community care. The significance of this finding is that short-term informal carers, just as much as long-term carers, are in need of formal support from healthcare professionals to enable them to take on their roles in the community.

Another aspect of the situation confronted by the participants in the current study which contributed to their difficulties was the relative brevity of the period between their relatives' admission to hospital and their discharge. Most of the patients in the current study were discharged within seven days of surgery - a finding replicated in a study published by Davies (2000). Davies notes that this is liable to leave the family carer inadequate time to prepare themselves for the responsibilities of care. Penny, a participant in the current study explains the situation she encountered:

> We started the week with no advice or support other than a video which showed three bright, optimistic, obviously competent recovering cardiac patients of differing domestic situations. There were some practical tips but very little to show how they coped with ensuing problems. There was no advice on what we, as patient and carer, were entitled to and no suggestion as to who could be contacted for such information. For example, my husband needed a bath seat to help him to have a shower. We found out from the District Nurses attending him for dressings changes that this would have to be ordered from the Social Work Department through them. This was ordered on Monday and didn't arrive here until Friday. (Penny, Diary 2, p4)

Penny's statement clearly reflects her lack of involvement in the process of discharge planning, and the general inadequacy of advice and consultation regarding the needs she would encounter, and how to deal with them. Such findings echo evidence gathered in research conducted almost 20 years earlier; (Tierney et al. (1993), for example, reported numerous examples of unsatisfactory discharge) indicating that little has been done to address this problem, in spite of the attention drawn to it. It remains the case that in 2011 a hospital pharmacy can run low on a key drug, such as metformin, and a diabetic patient can be discharged without it. This was the situation faced by Penny when her husband came home, a situation in which she was forced to leave her husband unattended while she ran to the local chemist to purchase the medication.

During the transition from hospital to home, carers are confronted by multiple responsibilities likely to visit both physical and psychological strain upon them; paucity of information, advice and practical support is certain to increase the level of this strain. Discharge planning is the process which is intended to address the incidence of such stress – a process ideally comprising co-operation between the patient, the carer and the healthcare team in the formulation of a comprehensive effective plan, facilitating a safe return home for the patient, and a seamless transference from hospital to community care. Such a plan is, in fact, considered mandatory by the UK Patient's Charter (1996), in which it is stipulated that a patient's continuing health or social care needs must be addressed before discharge.

Shepperd et al. (2010) confirm the importance of discharge planning, describing the creation of an individualized plan designed to anticipate the needs of a patient about to leave hospital. They make the additional point that, ideally, such planning will drastically cut the patient's length of stay as well as the likelihood of his/her future readmission (Shepperd et al., 2010). There is a certain amount of irony in this observation; it implies that appropriate forethought prior to discharge should facilitate the optimum throughput of patients and use of hospital resources, addressing crucial financial issues the healthcare service is obliged to face. The situation suggested by evidence in the current study is one in which rapid throughput of patients is in fact contributing to inadequate discharge planning. This is brought into sharp focus by the cases of cardiac surgery patients whose movement from theatre to recovery, then perhaps to ITU, HDU, and ward may happen in as little as seven days, severely restricting the opportunity for adequate planning.

Lack of communication between the hospital and community as well as between specific carers and hospital staff was uncovered in the current study. Some of the carers were in fact well aware of the problems of running a hospital, but others complained that, in comparison with other patients, their relatives appeared to be neglected. For example, Penny recalled the experience of dealing with her niece, a cancer sufferer, who seemed to receive a lot of support, and spent a reasonable length of time in hospital, in comparison with which she felt her husband was discharged prematurely, a possibility underlined by the fact that he came home with a seeping wound in his leg. She said:

> When the district nurse came in, and then of course it was a discussion about the district nurse had to cut up all sorts of other dressings that she had in her case because she didn't have what she expected to have from the hospital. So I saw the leg wound from there (ankle) and it was angry and red and kind of leaking and that happened for a long, long time. (Penny, interview 1, p.9)

It is reasonable to suggest that the case of Penny's niece, involving a serious long-term condition, might justifiably have necessitated a longer hospital stay, and may in addition have prompted a more energetic pursuit of support from her carer. The fault here lies in poor communication on two counts: there is lack of mutual understanding between healthcare service and community, whereby the situation prevailing in hospitals and the necessary disparity in the treatment of different cases is not made public; there is also a lack of understanding between a particular carer and the hospital staff, whereby the carer (Penny) was not made aware of the protocol for requesting help and information.

It should not be suggested that there is a total lack of communication between the healthcare profession and its clients; in the current study there were in fact cases in which the planning was good, but these were the exception rather than the rule.

Millie expressed positive feelings toward the professionals who dealt with her husband's case, and seemed to encounter less difficulty on her caring journey. When her husband, Tony, was first investigated, the doctors feared that surgery would not be possible - a suggestion which inevitably caused Millie considerable depression and anxiety. Ultimately the surgeon decided that an operation was possible, but warned Tony and Millie it would be more risky than usual. After the operation, Millie was informed by the surgeon that her husband's operation had been successful. The process of sharing information with the patient, exemplified in this case, seems a very simple matter, but its benefit is clear from the attitude Millie demonstrates in her evidence.

It is of course true that the sharing of information may enable the carer to offer a higher level of practical care, thus improving the chances of a positive physical outcome to the recovery period. It should be obvious, however, that the outcome of Tony's operation would have been the same whether Mille was kept informed or not, and that the value of sharing information in this case, was in lessening the burden of anxiety and depression which might otherwise have weighed upon the carer, and made the caring journey more difficult than was necessary. This is important because it emphasises that in considering the range of information shared with carers healthcare professionals should take account both of the practical and emotional difficulties likely to be faced on the caregiving journey.

Another participant, Maggie, had private health insurance, and was able to contact the surgeon or other healthcare professionals (such as nurse, physiotherapist and so on) directly should something go wrong. The surgeon gave her a list of appropriate telephone numbers to call whenever she required aid for a specific

problem. Again, it is clear from Maggie's evidence that this contributed significantly to her positive sentiments regarding the caregiving experience. However, this level of reassurance and practical support was only available to Maggie on the strength of her private health insurance, and thus her financial status. The existence of this disparity in levels of provision between private and national healthcare can only be a negative reflection on that service which the majority of the public must rely upon. Government policy and levels of funding for hospital care necessitate rapid, often premature, discharge, and contribute to a situation in which staffing resources are so stretched that adequate communication between healthcare professionals and carers and their relatives is often impracticable (Tierney et al., (1993), Bull and Roberts (2001), Atwal (2002)). All these factors, as we have seen, lead to levels of burden which, ideally, are avoidable.

An example of this in the current study is provided by the examples of three participants whose relatives were discharged on a Friday without suitable medication or dressings, and with only a letter to be given to the GP. In all three cases the carer was obliged to settle the patient and go out immediately in order to catch the General Practice staff before they closed for the weekend. Sadly, in one instance the carer failed to arrive at the practice in time, in consequence of which an unnecessarily anxious weekend ensued.

A study by Lindhardt et al. (2008) reiterates the value of relatives as home-based carers, but indicates that inadequacy of communication between healthcare professionals and carers is compounded by reluctance on the part of nursing staff, in particular, to engage with patients' relatives, whom they describe as 'demanding' and 'difficult'. This may be connected with the additional finding that

carers often frown upon the discharge planning process – a situation both Perreault et al. (2005) and Lindhardt et al. (2008) related to the lay carer's lack of knowledge and experience, and consequent failure to understand the importance of the planning process.

Insufficient guidelines and systems, inadequate resources, and failure to understand patient history have already been enumerated as factors which may contribute to inadequate discharge planning, and the consequent sensation described by carers in the current study of 'walking in the dark'. What Perreault et al (2005) and Lindhart et al. (2008) drew our attention to was the fact that responsibility for poor discharge planning should not be laid exclusively at the door of the professional – that there may also be the problem of wavering commitment in the caregivers. Family carers need to gather as much relevant information as possible to ensure success in the decision making process involved in post operative care, yet in both of the above-mentioned studies, situations are described in which family carers demonstrate a less than energetic pursuit of help and information. Given the weight of evidence suggesting the benefit of collaboration between these parties, the finding is hardly reassuring. This is a dilemma which was clearly understood by Pickard and Glendinning (2002). However, their sympathies seem to be more firmly with the carer than with the service; they stressed how important it is that healthcare professionals make a conscious attempt to understand the experiences of informal carers in order to support them and anticipate problems they are likely to face.

Certainly in the last decade, the nature of those problems has become more serious and challenging; the general balance between hospital and home in care

cases has altered, causing complex nursing responsibility to shift from ward-based to primary care, inadvertently emphasizing the role of relatives of patients, and blurring the line between formal and informal care, as family members become involved in what was once thought to be nursing procedure. Yet in 2005 Perreault et al. were reporting the failure of the healthcare service to respond to these changes, with collaboration between professionals and carers continuing to lag behind the needs of patients and carers. A study conducted by Chapman a year later (2006) supports this finding, moreover adding that the increased complexity of caregiving duties needs to be reflected in a more thoroughgoing discharge planning process in which a wider range of parties and agencies should be involved. However, it should not be assumed that findings in this area are exclusively pessimistic; Gerrish (2008) sounded a positive note, publishing evidence in which nurses openly acknowledge their reliance on the input of family carers (in the case of the Gerrish study, the carers were relatives of elderly individuals with long term illness) accepting that the social services might collapse were family carers to give up.

Thorough discharge planning plays a vital role in patients' care management. However, communication that is poorly established between patients, health professionals and their families has been one of the most common obstacles to a successful discharge process. A vigorous reciprocal communication is essential if informal care is to be effective and facilitate successful recovery outcomes. Carers need to feel that they are entitled to seek information, guidance and the opinions of a range of professionals, to understand the nature of their role in relation to the patient. They should also be confident that their own views are welcomed –

enabling the professionals involved with their relative's case to understand their needs and fears (Bull and Roberts 2001).

6.2.3 Playing multiple roles

For all participants in the current study, a significant aspect of the experience of 'walking in the dark' was the obligation of adopting multiple roles – many of them unfamiliar and challenging. This was a valuable issue to explore, in particular, from the perspective of the one male carer involved in the study – Jack, if only because the majority of duties with which he was suddenly confronted might perhaps be described as stereotypically 'female' tasks – a circumstance compounded by the fact that, prior to hospitalisation, his wife took the lead in household duties such as cooking, washing, hanging out clothes, shopping and the like. The unfamiliarity of the roles Jack was obliged to fulfil was thus, in some ways, more overt than was the case with his female co-participants.

Jack's cultural discomfiture at finding himself thrust into his wife's position underlines the link between the unfamiliarity of tasks and the sense of anxiety and confusion. It is of course true that all participants experienced a similar sense of discomfort, since all were cast into strange and challenging roles. However, it seems fair to suggest that in the case of male carers, the sense of strangeness and consequent anxiety may be more pronounced. Studies by King and Koop (1999) and Halm et al. (2007) support this contention, reporting reluctance amongst male relatives to undertake caregiving duties, and a corresponding reluctance amongst their spouses, intimate partners, relatives and friends to rely upon them to meet those demands.

It must be emphasised, however, that in spite of the unaccustomed nature and variety of responsibilities participants in the current study were faced with, all, including Jack, conceded the necessity of accepting their several roles. Within a week of his wife's discharge, Jack, for example, was washing, ironing and cooking. Jenny, whose younger sister underwent cardiac surgery, found it expedient for a while to move in with her sister, and was thus was faced with the dilemma of managing two households – a situation which necessitated her taking time off work. Ultimately the level of demand on Jenny proved untenable, and she was obliged to hire another girl to care for her sister. Even having taken this measure, Jenny continued travelling to her sister's house every day to ensure that she was receiving proper care.

The scope of tasks negotiated by the participants embraced not only those practical domestic chores already alluded to; in addition there were medical, administrative and emotional obligations, all of which contributed to the level of caregiver burden. Amongst the medical responsibilities there were wounds to be dressed (as already mentioned in the case of Penny and her husband), and medication to be administered; administrative tasks ranged from establishing a written timetable for moving, washing, feeding etc, to the business of communicating with healthcare professionals where help, advice and resources were required. It should not, of course, be assumed that such roles and tasks fall into easily defined categories; in reality one responsibility will overlap with others: a medical consideration, such as the prevention of infection, necessitates attention to straightforward domestic hygiene-oriented activities – cleaning, laundry etc; at the same time the administration of medicines and dressings necessitates paperwork in the form of filling out prescriptions, visits to the chemist,

communication with district nurses and GPs. In fact, it could be suggested that the notion of 'multiple roles' might as easily be described in terms of a single multi-faceted role, which expands and changes from day to day, hour to hour, to meet the dynamic and unique requirements of each case. This is clearly demonstrated when one considers the third area of responsibility mooted above – the area of emotional obligations. Perhaps the most general and pervasive aspect of the carer's role – an aspect which touches every other facet, and which was alluded to by all participants in the current study – is the provision of emotional support and guidance. This may range from moderating unrealistic expectations in the patient (a role one participant, Hannah, found herself obliged to fulfil when her husband seemed determined to do 'too much too soon') to the simple but fundamental matter of maintaining the recovering patient in a cheerful and positive frame of mind. As such, it is difficult, and perhaps artificial, to regard this element of caring in separation, since the carer's disposition in discharging any or all of his/her duties is liable to exercise a psychological influence, for good or ill.

It is important, also, not to be mislead by the simple enumeration of such tasks, into assuming that they are simple in reality. The process of obtaining a prescription, for instance, was often complicated by the fact that the carer was obliged to fetch it, but was understandably reluctant to leave his/her relative unattended. In some situations, friends and family were helpful when it came to running such errands, but an extended support network of this type was by no means guaranteed in every case. Some families were unable to offer such practical help, and in addition, some carers found it difficult to ask for the help they needed. Having said this, a few carers exhibited notable competence, efficiency

and independence in this regard, and were very successful in taking care of all their responsibilities themselves.

In the same way, the apparently straightforward issue of supervising the patient's time and movements, although it might ideally be condensed into a written timetable (a strategy adopted by several participants, as mentioned above), in reality involves potentially very delicate negotiations with a loved one who is, in all likelihood, anxious to 'get back to normal' and possibly, therefore, resentful of the necessity of being 'managed' in this way. There is potential for a damaging clash of wills in this area: participants in the current study all understood the significance of the operation which their spouse or sibling had undergone, and that the best course of action for them was to allow the recovery to run a steady course; the patients themselves already felt somewhat recovered even at the very beginning, and regarded the next step as regaining the control temporarily relinquished.

This is a sensitive issue – one recognised in a study by Theobald and McMurray (2004) who refer to the danger of over-protectiveness in carers. In the current study, this particular aspect of the carer/patient relationship followed an interesting pattern; the paternalism described by Theobald and McMurray, was certainly identified in a number of participants at the beginning of the recovery period, but gradually diminished as signs of recovery became more encouraging, to the point at which carers began to feel that their spouse/sibling should be able to act more independently. In several cases this development coincided with a discernible lassitude in the cared-for relative who, having surrendered, as it were, to the care routine, became almost resistant to the notion of taking responsibility for his/her own actions. The consequence of this development was often a sense of guilt in

the carer for entertaining the possibility of withdrawing from the caring role, and deterioration in the relationship of both parties.

Such deterioration may exacerbate a complex of other negative emotions – boredom, tension and loneliness – already potentially afflicting the carer. Of course, in the history of their relationships proceeding the care period, many of the couples had experienced tensions and difficulties, but few had been victim to this particular species of stress. Confronted with a type of friction and tension for which they had no comparable experience, and therefore no ready remedy, many participants described this development as another aspect of 'walking in the dark'.

6.2.4 Caregiver burden

Caregiver burden was apparent in the psychological and physical fatigue of participants. This is somewhat of a generalisation, and is worthy of more detailed definition, both in the context of existing literature, and with reference to the outcomes of the current study. A number of studies refer to a range of specific difficulties which come under the definition of burden: Perry et al. (2006), describe the sensation of vulnerability, Ågren et al. (2010) identify cognitive impairment and physical fatigue, Scott (2000) refers to incidences of depression, anxiety, and despondency. Aspects or indications of all of these difficulties were described by participants in the current study.

The development of burden was identified in three general areas of caregiver experience – practical tasks, emotional commitment and vigilance. This finding is echoed in the earlier study published by Scott (2000), who similarly identifies three areas of responsibility – attention to the physical needs of the patient, their

psychological and emotional needs, and general oversight of the impact of care and the process of recovery. In the current study, physical tasks ranged from basic household chores such as cooking and cleaning to conspicuously unfamiliar and challenging tasks, including nursing duties, such as dressing wounds. The correlation between this range of activities and caregiver burden is more or less self-explanatory, embracing simple physical exhaustion – 'fatigue' - through to physical strain exacerbated by the stress of confronting unusual and specialised jobs. All carers in the study were obliged to tackle normal tasks within the home as well as shouldering the responsibility of those tasks previously discharged by the patient, while at the same time attending to the general needs and the special medical needs of their relative.

Knoll and Johnson (2000) refer to the area of vigilance/monitoring, and identify a range of activities; at one extreme these are a natural extension and aggregate of the physical activities already alluded to, which together comprise the business of running the household in order to sustain patient recovery. Several carers in the current study recorded their ongoing awareness of such issues, for instance recognising that 'the laundry needs doing', or 'the groceries are running low', demonstrating a simple form of vigilance directed towards the ongoing discharge of necessary domestic functions. At the other extreme monitoring becomes less easy to define in practical, quantitative terms – not so much identified with any specific task, but comprising a general vigilance over all aspects of the patient's behaviour and progress. The outcome of such vigilance in the current study was the carer's longitudinal perception of the relative's development, positive or negative, over the course of the three month period of the study. Knoll and Johnson (2000) make the point that carers should not feel alone in exercising

vigilance, but should have access to help and support. In making this point they recognise both the physical and psychological aspects of the carer's role – requiring, on the one hand, practical assistance, for instance, from healthcare professionals, and on the other hand, the sort of support offered by an extended network of family members and friends.

This latter recognition, particularly, apprehends the emotional aspect of caregiver burden, and alludes to the possibility of a range of difficulties associated with emotional and psychological stress. As mentioned above, such difficulties have been identified in several studies already published – 'depression, anxiety and despondency' (Scott (2000)). Psychological burden of this type derives equally from the level of challenge presented by physical duties (which, as we have seen, correlates broadly to their unfamiliarity) and the potentially unremitting degree of vigilance required in the carer. The common element of both – the impulse which motivates equally the dispatch of physical chores and the ongoing sense of concern for the patient - is the emotional relationship which prevails between carer and patient. This refers us to perhaps the most fundamental level of carer stress – the natural anxiety of a spouse or sibling for the well-being of their loved one, (where well-being and the chances of recovery depend, in large part, on the actions, decisions and constant attention of the carer). This may lead to a dichotomy of responsibility and personal isolation which eloquently captures the essence of 'walking in the dark'.

In the current study, this type of anxiety was most evident amongst carers whose relatives had encountered a near-death experience. Unsurprisingly, these carers felt compelled to stay alert at all times, and were amongst those participants who

266

reported significant sleep disturbance. Sleeplessness is in some ways unique as an element of burden because of its double-edged nature – ie it may be a consequence of purely practical elements of the care situation, but it may also be a consequence of depression or anxiety. With reference to the former possibility, Phillips et al. (2009) reported situations in which patients woke during the night, at the same time waking the carer, who felt obliged to rise and attend to them. The resultant sleep deprivation was not so much a consequence of anxiety, as a simple reflection of the carer's expedient response to an event. It should be pointed out however, that the disturbance of sleep patterns, even when they are not directly attributable to anxiety or depression, may give rise to such emotions.

However, as already suggested, anxiety and depression themselves might be the cause of sleeplessness. At its worst, this situation can become a downward spiral whereby depression induces sleeplessness, which worsens depression, in turn further diminishing the quality of sleep. Tsukasaki et al. (2006) and Phillips et al. (2009) studied the quality of sleep amongst long term carers, with the intention of determining levels of care strain they experienced, and in fact were able to confirm the relationship between these two variables. Carers who slept badly were found to be depressed, which meant that care strain was high. They also reported that those with little access to a social network are more likely to suffer from depression – a finding which draws attention again to the potential loneliness and isolation of the carer's experience. In contrast with the findings of Tsukasaki et al. (2006) and Phillips et al. (2009), there was little incidence of depression specifically reported amongst participants in the current study. This tends to confirm the suggestion that depression, as an aspect of caregiver burden, is more generally associated with extended periods of care (ie longer than the three

months of the current study). This should not surprise us; the accumulated attrition of physical duties, emotional and psychological strain, exacerbated by the physical and emotional fatigue induced by broken sleep, is all to likely to lead to the decay of optimism and positivity, and susceptibility to negative thoughts.

How is this finding relevant in a three month study? Although no clear descriptions of depression were elicited in the current study, it behoves us nonetheless to search for those elements of the carers' experience which might, in the longer term, develop into depression. Indeed, a virtue of the current study is that it allows us the opportunity to identify the early signs of mental debility in the carer, thus potentially contributing to the development of measures designed to pre-empt psychological deterioration. Various researchers (Barnes et al., 2006; Dew et al., 2004; Halm et al. 2007; Hunt et al. 2000; Rantanen et al., 2008; Rantanen et al., 2009; Saunders, 2009; Scott, 2000) have pointed to the concept of health-related quality of life (HRQOL), which refers to the sum of an individual's physical, mental and social well-being (Dew et al., 2004). When considering the development of carer depression, this is a useful starting point, but given the qualitative nature of the current work a formal systematic investigation using QOL measures was unfeasible. Nevertheless, many participants alluded to 'quality of life' with reference to negative changes which arose in the course of the caregiving journey. These included periods of self-doubt, specifically regarding the participant's ability to manage the responsibilities of care, bouts of indecision and confusion in the management of finance, scheduling and domestic routine, the necessity of compromising professional commitments (two participants in the current study were obliged to give up work for the first few weeks post discharge), and of accepting restrictions on free time and social outlets. It may be seen how all of

these changes contribute to and/or stem from the phenomenon of carer isolation mentioned above. It thus seems reasonable to suggest that the early recognition and management of psychological debility in the carer must involve an attempt to lessen this sense of isolation, both practically, through regular contact with healthcare professionals, for example, and in terms of moral and emotional support, for instance through contact with a circle of friends.

Overall, findings from Phase 1 indicate the signs of physical, emotional and social extension in participants which are consonant with the description of caregiver burden as it appears in a number of previous studies, (Barnes, et al., 2006; Phillips et al., 2009; Ågren, et al., 2009; King & Koop, 1999; Phillips, et al., 2007). Furthermore, in accordance with suggestions from several of these studies (Ågren, et al., 2009; King & Koop, 1999; Phillips, et al., 2009) a number of carers in the current study described the expectation of emotional responsiveness and support both from the patient, and their social network, which in itself may be viewed as a secondary indicator of caregiver burden.

The fact that lay carers such as the participants in the current study are willing to accept the burden of care should not blind us to the difficult nature of that burden, and the sensations of vulnerability and anxiety likely to attend it. This reservation is supported by the findings of Knoll and Johnson (2000) that identify significant parallels between emotions and reactions among carers of cardiac surgery patients and those experienced by carers in other circumstances. In this latter group Knoll and Johnson (2000) identified three strands of bio psychosocial behaviours, to which they attached the labels 'stress and fatigue', 'vulnerability', and 'putting life on hold'. Evidence from the current study is very much in

consonance with these descriptors; participants were almost unanimous in describing a significant element of sacrifice (putting life on hold) in their caregiving commitment, as a consequence of which they experienced fatigue and a sense of susceptibility (vulnerability) to symptoms of stress and anxiety. A cautionary note should be sounded, however - the extent of carer strain has yet to be conclusively linked to the patient's condition, so it would be rash to make an overt correlation between the care of cardiac surgery patients and any specific profile for caregiver burden. Having said that, it has certainly been stressed in a number of recent studies that carers for cardiac patients do deserve special attention as a category (King & Koop, 1999; Ågren, et al., 2009; Halm, et al., 2007; Hunt, et al., 2000). Having averred the value of these studies, however, it should be pointed out that the researchers involved only went so far as to depict the stress burden for carers, with suggestion of how those symptoms might be lessened. Having confirmed in the current study, that caregiver burden is a reality for the group of carers represented by the research sample, it seems apposite to propose that this specific category of burden warrants fuller quantitative investigation.

The phrase 'walking in the dark' aptly sums up Phase 1, wherein the carers were obliged to accept multiple roles with little or no knowledge to support them in those responsibilities, and were tasked with balancing personal anxiety against the relative's needs and whims. It became obvious that, at its most challenging, the aggregate of physical and psychological demand in this Phase began to represent a serious threat to the carers' emotional wellbeing. It is reassuring, then, that as carers entered the secondary Phase of the caregiving journey, and their situation became easier.

6.3 Phase Two: Getting on With It

'Getting on with it' refers to the development in participants of a degree of pragmatism, and mental and physical resilience, which enabled them to accept and dispatch the responsibilities of caregiving with greater acumen and equanimity. The advent of this change coincided with new optimism, enabled in part by an increased level of help and support from other family members, and promoted by improved quality of sleep. The study published by Knoll and Johnson (2000), entitled 'Keeping Things on Track' ascribes this optimism, in part, to the palpable signs of recovery in the patient – a development which had the effect of mitigating (although not fully removing) the carer's anxiety. Although each participant's caring journey was unique, all had a number of key elements in common; this upturn at the mid-point of the journey is one of them. Indeed, a similar Phase in the caring journey is recognised by Theobald and McMurray (2004) – a stage during which carers acknowledged full acceptance of their several roles and the expedient home routine created to meet them.

The point at which this routine became, as it were 'fixed,' did, however, vary in different participants' cases. Many of the carers settled to the regular fulfilment of their responsibilities early in Phase two, but there were exceptions; Jack, the only male carer, and Jenny, the sibling carer assumed the full weight of their new status and all its inherent changes at a slightly later stage. This does not, of course, mean that they failed to deliver the required caring outcomes before this point – only that their disposition towards their obligations was ambivalent until then. In Jenny's case, the transition from the anxiety and uncertainty of Phase 1 to the pragmatism of Phase 2 was more clearly marked (in this case by her decision

271

to move back home from her sister's house, and establish a routine of monitoring her sister's progress by visits and telephone calls). Her consciousness that she was 'getting on with it' may have been reflected in the very emphatic and clear cut nature of this change. Again, in Jack's case his greater optimism and equability is clearly indicated by acceptance of tasks – cooking cleaning, washing, ironing - which were markedly more alien to him than to his co-participants – a fact which also perhaps explains why it took him a little longer to settle to his routine than some other carers.

The effect of the patient's recovery was an important element in the carer's ability to 'get on with it'. This was shown in several ways. As already suggested, recovery contributed to greater optimism; simply, carers were able to see that their efforts were bearing fruit, and were encouraged to anticipate an end to the caring process. In addition, the greater mobility and increased strength of the recovering patients enabled them to offer some small assistance to their spouse/sibling in carrying out a few household tasks. Anne, for example, reported how her husband was able to help her carrying milk home from their shopping expeditions. Although she was uneasy at first, when he offered, she understood his need to make a contribution, and was heartened when she realised that he was genuinely able to do so. On a purely practical note, it is also worth reflecting that as the patients themselves became more mobile and cheerful they became easier to care for and support – both physically, and emotionally.

A further implication of the improvement in patients was reduced dependence on professional help amongst carers. There were isolated situations in which some professional input continued to be needed; Penny's husband, for instance, still

needed his wound to be dressed by a nurse, but for the majority of participants, the frequency of visits and/or consultations with GPs and nurses was greatly reduced.

'Getting on with it' was characterised by qualities of persistence and stamina amongst the participants. In week six post discharge, many continued to report the necessity of attending to a wide range of duties including cooking, washing, supervising their relative's exercise, and spoke of ongoing fatigue, but few complained about these realities. It would be over-simplistic, of course, to suggest that all carers displayed a similar degree of 'toughening up'; the particular situation in each carer-patient scenario was unique, and therefore presented a specific and unique pattern of development at common points in the journey. One female participant (Millie) was able to return to work at the advent of Phase 2, whereas another, (Jenny) was unable to do so, as a consequence of her cancer. Although Jenny's sister was getting better during this Phase, Jenny worried that her own illness might negatively influence her sister's progress; therefore she continued to keep accept compromise in her personal situation, and to maintain multiple roles. In another case, that of Sheena and her husband, it was a further complication in the patient's condition -the discovery of a possibly cancerous lesion in his lung - which caused the progress of the carer's journey to be stalled. Sheena's husband was readmitted two days after his surgery and remained in the hospital for another 10 days. Although Sheena was positive and optimistic about the surgery her husband received, and his heart problem improved, she was still worried about his overall health at a point where many other participants were becoming more sanguine - seeing genuine and permanent signs of recovery in their relatives, and beginning to reclaim areas of their customary lives

This Phase can be identified with the stage described in the study of recovering cardiac patients by Knoll and Johnson (2000). In that study the authors speak of a situation in which patients have regained a significant amount of their strength, but not so completely that carers are able to relinquish their multiple responsibilities - hence the notion, coined by the authors as the title of the study, 'keeping things on track'. For one carer in the current study, however, (Sheena) the notion of keeping things on track was not pertinent. As mentioned above, she was faced with the unexpected discovery of a lesion in her husband's lung - a development which for her in many ways meant a return to Phase 1 care concerns.

The reduction in carer's dependence on professional support at this Phase has already been alluded to. At the same time carers referred increasingly to the importance of physical and moral support from the extended family. Two participants, Maggie and Jack, both spoke about family members who contributed to regular household activities: Maggie's daughter made regular visits and helped with shopping and cooking; Jack's granddaughter similarly helped with shopping, as for a long time after surgery her grandmother (Jack's wife) had trouble walking. An additional and equally important benefit of this extended familial and social support was the opportunity for carers to 'let off steam', share some of their concerns, and offload a certain amount of the emotional burden of coping with the caregiving situation. This contributed to a gradual increase in positivity and optimism - an ability to see and appreciate the signs of recovery in their relative, and to anticipate a return to normality.

It should not be thought that carers were completely independent of the need for professional support in this Phase. There continued to be instances where participants were obliged to rely on external assistance. Jenny, who cared for her younger sister recognised the need of some expert professional assistance to facilitate her sister's return to mobility, and duly organised visits from a physiotherapist. What is significant about this circumstance is not so much that such help was still required as the fact that Jenny was more assured in identifying her sister's need and acquiring the necessary help than would have been the case in Phase 1. This demonstrates the growth of confidence and pragmatism referred to at the beginning of this section. It is worth reflecting also that the involvement of professional help was also identified as a further means by which the carer's sensation of isolation was lessened; while 'getting on with it', carers still benefitted by receiving continued social support.

The findings in Phase 2 continued to show the demanding nature of the carer's role. At this stage participants were still dedicating a substantial amount of time to the practicalities of caring – a finding supported in several previous studies (Census, 2001; Stewart & Patterson, 2010), and remained in some way dependent on professional support (Henwood, 1998). Henwood investigated the situations of a sample of long-term lay carers; he noted that at least 75% of the sample took on the role with no formal help whatsoever, and in consequence were heavily reliant on help from family members. He draws attention both to the financial and personal emotional and health costs involved for carers and for those family members who supported them – a cost which is evidenced in the current study, despite the fact that the participants in this case were carers in the short term. This

fact reminds us that there is much to be learned for short term carers from the experiences of long term carers.

6.4 Phase 3: Looking Forward to the Future

In Phase 3, the caring journey ended with carers 'looking forward to the future'. In the majority of cases, this change became noticeable in week twelve post discharge. It was marked by a recovery in the patient sufficient to allow them to resume the pattern of their accustomed lives.

Carers spoke of 'seeing the light at the end of the tunnel', and finding a better balance between the needs of their relatives and their own needs. This highlights a point at which the experience of short-term carers and the experience of long-term carers diverge. At a similar chronological stage in the caregiving period, those caring for long-term or terminally ill patients report that their needs alter and increase – perhaps in consequence of the anticipated death or removal of their relative into a long-term care setting. In marked contrast, carers in the current study were united by a sense of optimism, encouraged by improvements in their situation, and looking forward to life. This is a new concept – a permanent positive development - which has not previously been documented within the literature, and indeed, something which seems to run contrary to what has been found in other studies which have focused on carers' experiences of caring for those undergoing CABG, for example, and where carers reported living for the present because they had no confidence in the future (Karlsson *et al.* 2006), and carers of dementia suffers who had a negative outlook (Hooyman, 1985).

At the beginning of the caring journey, participants in the current study were inclined to keep any expressions of stress or frustration to themselves – concerned not to have any negative effect on their relative's recovery. But by the end of this journey, they were confident in discussing their hopes and plans for the future. All carers agreed that this stage represented an improvement on the state of their relationship as it stood at the beginning of the caring journey. Indeed, some carers went further, confirming that their relationship with the patient was stronger than at any time before his/her illness. Knoll and Johnson (2000) shed further light on the positive impact of recovery on the spousal partnership in care situations; they found that the mutual consideration which existed between couples before the partner's hospitalisation evolved in the aftermath of discharge to form an integral and beneficial element of the carer-patient relationship – a development which, as suggested, is referred to by several carers in the current study.

A particular aspect of this improvement reported by a number of participants was the evolution of greater honesty between couples/siblings, characterised by a freer and more open exchange of thoughts and emotions. Hannah, for instance, was one of number carers who described a gradual transition from introspection at the beginning of the caregiving journey (compelled by a fear of causing upset to her husband) to full and frank discussions of the future, and reflections on the previous three months' experiences, at the end of the period of care. This was a common experience amongst the couples investigated in the study, all of whom describe the increasing ability to accept their situation, and make the most of it.

Hannah was one in a majority of participants for whom the post-operative recovery period, (once its multifarious and unusual responsibilities had been assimilated),

was uneventful. An exception to this situation was evident in the case of Sheena, for whom Phase 2 was complicated by the discovery of a new and different threat to her husband's health. The difficulty of this time made it necessary for them to sit down and talk to each other about their feelings and hopes and fears for the future. Naturally, these discussions focused on more than the positive issues of recuperation and restoration to normality which occupied the thoughts of other participants. In many ways, it might be suggested that the experience for Sheena and her husband partook of both the experience of the short-term and the long term carer, since for them the issues of recovery, for a while at least, were counterbalanced by notions of terminal illness and permanent deterioration. As such, it is interesting to note Sheena's reaction to the discussions which took place between herself and her husband at that time. The fact that she described these discussions as having little mollifying effect on her distress and anxiety, may give us some understanding of the specific nature of burden which afflicts the carer in an unsuccessful recovery process. It seems that, at least within the limited time period in which the possibility of terminal deterioration was entertained, honesty, however necessary, did little to ease the immediate distress provoked by their forebodings. Sheena was prepared to admit however, that this experience and the level of candour it compelled may have long term benefits, strengthening their relationship for the future.

Knoll and Johnson (2000) reinforce the current study's findings regarding this Phase of the caregiving journey. They colloquially summarise the role of the carer as "returning things to normal" (Knoll and Johnson, 2000, p. 68). For participants in the current study it was of course impossible that they remain equally and consistently positive throughout the journey but for all except one of them, the

recuperation of their relative was successfully realised, their optimism vindicated, and the task of restoring normality made possible. The exception was Sheena who, at the end of the research period, was still awaiting news from the oncologist regarding her husband's diagnosis.

The 'return to normality' described by Knoll and Johnson (2000) is mirrored in other short-term care situations, (such as the cases of post-operative convalescence from defibrillator implants studied by Dougherty and Thompson (2009)) – a restoration of physical and mental health in the patient with a corresponding lightening of burden in the carer. But this pattern is self-evidently unlikely in long-term care situations. A co-relational study involving 49 caregivers and elderly female patients conducted by Kneeshaw et al. (1999), found that the relationship between patient and carer grew closer in the immediate aftermath of hospital discharge, but was deteriorating by the third month of the caregiving situation. This was explained as a consequence of the long-term nature of the caregiver burden, the effect of an unremitting and steadily increasing pressure on the carer-patient relationship. For long-term carers there is no restoration of normality, or permanent positive development, such as was described by carers in the current study. The caregiving journey in such cases only truly ends with the patient's demise.

The following diagram has been reproduced at this point to remind the reader of the relationship between the overarching themes, the essence of caring and the carer's journey.

Figure 11 The essence of carer's experience of caring

Changing nature of relationship

Reassurance

Being there

Walking in the dark

- Nursing the patient
- Playing multiple roles
- Finding a balance
- No yardstick for knowing
- Hospital to community care gap
- Psychological and physical tiredness

Getting on with it

- Continuing care
- Still playing multiples roles
- Continuing support

Looking forward to the future

- More honest now
- Being back to normal life

The essence of the experience of caring: person – to carer – to person

Three Month Period

Phase 1

Phase 2

Phase 3

Recuperationn

280

6.5 Overarching themes

The three overarching themes were conceived as such to reflect their general relevance to the whole of the caregiving journey. The first of them concerns the changing nature of the relationship between the carer and the cared-for person throughout the three phrases of research. All participants were compelled to adapt their relationship to the radically altered circumstances which prevailed at the start of the recovery, and to accept subsequent ongoing adaptation as the recovery progressed. Understandably, the reality of a close relative experiencing severe illness and subsequent confinement to hospital will compel drastic attitudinal and emotional adjustment on the carer's part. The essential nature of such adjustment is underlined by the life-threatening nature of the illness which necessitated the hospital admission. In the current study, several relatives were discharged with wounds which needed to be dressed, and with impaired ability to wash and dress themselves. The consequence of these conditions was the obligation carers felt to behave rather as nurses than as spouses or siblings. Similar pragmatic self adjustment is recorded amongst carers investigated in studies published by Proctor et al. (1996), Pickard and Glendinning (2002), and Rantanen et al. (2004).

In the current study the participant-patient relationship may be summarised as undergoing a two-fold process of change during the caring journey – the participant changing from a lay-person to a carer and back to a lay-person. This change process may be expressed in terms of a movement through relational roles. The limitation of such a description, however, is that it proposes a definition of the carer which is restricted by his/her relevance to the patient-relative. A

definition of the change process which perhaps takes us closer to the essence of the phenomenon of transition as experienced by the participant may be furnished by the notion of a secondary and parallel process of change, with regard to the nature of the carer's daily experiences. This can be described as a deviation over time, away from normality (a field of familiar activities), towards abnormality (a field of unfamiliar activities), back to normality.

It has been mentioned already that many carers described greater closeness in the spousal relationship during the period of recovery; further, a number of carers confirmed that the shared experience of the caregiving journey wrought permanent positive relationship changes, indicating the possibility of fundamental (as opposed to temporary) relational adjustment as a consequence of the care situation. Here is Jack describing the changes he perceived in himself as a husband as a consequence of caregiving:

> 'I've been more like a carer who's become no(t) a man and wife but a
> carer and somebody' (Jack, interview 1, p3; Chapter 5, p 151)

This finding returns us to a notion proposed by a number of scholars (Ågren, et al., 2010; Dougherty & Thompson, 2009) who suggest that the quality of spousal caregiving depends not only on formal marital relationships but also on the extent of intimacy and trust between couples.

A further significant deviation from 'familiar activity' for carers was the need to exercise vigilance over the cared-for person's status and movements throughout the day. This represented an extreme evolution of that general mutual concern for wellbeing which may prevail on a largely subconscious level in spousal or sibling relationships. It is worth reflecting that the basic motivation behind this fundamental relational change was the carer's fear of the threat presented by

illness to their loved one's life. Knoll and Johnson (2000) refer to the notion of vigilance, and note the development in the carer of a paternalistic disposition toward the cared-for relative. They express this as a shift of emphasis in the relationship from a commitment based on mutual parity of need to a commitment in which one individual's need outweighs the other.

The changes described above were in fact only the initial elements of an ongoing process of adjustment - which is why 'the changing nature of relationship' was identified as an overarching theme. It is hoped that an understanding of the essential aspects of this theme might be a source of insight to healthcare professionals regarding the context and detail of the carer's experience, and thus enable them to anticipate the carer's needs and difficulties and offer appropriate support.

It is this researcher's belief that carers involved in the post-discharge period of acute cases such as cardiac surgery, represent a category which might be described as 'hidden carers', on account of the comparative paucity of literature investigating their circumstances. This description is particularly apt with regard to the short-term sibling carer, about whom there is almost no authentic research. Although sibling carers have been investigated in some relatively recent literature (Twigg, 1992), the focus has been on siblings involved in long-term care situations. In the current study there was one example of a caregiving situation involving siblings (Jenny - an elder sister caring for a younger). The theme of relational change in this case was therefore of particular interest; significant parallels and contrasts between spousal relationships in long and short-term caregiving situations might be anticipated, and the lack of research into the latter partially

recompensed, but relationship changes between siblings are unlikely to be so easily comparable with spousal cases.

Having said this in Jenny's case too, the relationship was significantly changed; the older sister recalled her changed perception of the younger, whom she saw as becoming '*an extra child*' – the sibling bond temporarily transformed into something more closely resembling a mother-daughter relationship. The fact that there is no instance of a similar transformation recorded in other literature suggests the significance of the finding, yet it is worth reflecting that in some ways the change described by Jenny is parallel to the relationship changes described by spousal carers, inasmuch as the development of paternalism (or in Jenny's case we might say 'maternalism') in both situations is synonymous with the carer's change from lay-person to nurse, and the relative's change from spouse/sibling to patient.

More specifically, then, the value of investigating the changing nature of the sibling relationship is the opportunity to compare the experience of nursing as it pertains to a sibling with that of a spouse. It is possible for instance to suggest that there is a more obvious element of obligation in the relationship which obtains between spousal partners, if only because, in the majority of cases, such relationships are formalised with a legal marriage contract, and that the assumption of caregiving responsibilities may be similarly dictated by an element of obligation. In the case of siblings, while there may well be a significant element of loyalty, it is highly unlikely that the element of loyalty will be the subject of a formal promise. It is thus perhaps reasonable to suggest that in sibling care situations there is a greater element of conscious choice in the acceptance of caregiving duties – that readiness to care

may offer an impression of the moral and sentimental character of a sibling carer...their facility for generosity and self-sacrifice. From this perspective, the changes which take place in the sibling relationship in a care situation may be suggestive of the emergence of altruistic and selfless qualities – albeit within the context of sibling loyalty; the role Jenny adopted may have arisen from a kinship obligation, supplemented by an underlying emotion of sisterly love.

There is a certain amount of evidence in the current study to support the above contention; the fact that Jenny also cared for her younger sister through Hodgkin's Disease (a non life threatening condition) suggests a heightening of commitment which, unlike the commitment displayed by other carers in the study, was unaffected by fears for the patient's life. It is also significant that, at the point of recovery the younger sister and elder sister underwent a role reversal when Jenny was diagnosed with cancer and required care in her turn. Both situations have as their common impetus an unselfish sisterly loyalty which, it might be argued, represents more nearly the essence of the phenomenon of the family carer. Indeed, Jenny's account of this development specifically associates the role of caregiver with the natural hierarchical relationship liable to obtain between family members:

> 'So it seems strange to have her (the younger sister) support me because all my life I've been the oldest sister.'
> 'Yes, well it does feel strange. I'm used to being the supporter not the supported'. (Jenny, interview 2, p.3)

There seems to be an element of reluctance in the tone of Jenny's evidence here. This was perhaps influenced by a disturbing diagnosis which, regardless of the prevailing care situation, might be difficult to accept; but it is perhaps more likely that the transition of the role from carer to cared-for person was the more

problematic aspect, running counter to that hierarchical element of the relationship already alluded to. It is thus perhaps reasonable to suggest that a viable model for care as a fundamental concept – the foundation (or *arche*) of the concept of the care professional – is the family member. A further point in the evidence which is related to and supportive of this possibility is the fact that the sister in question, Jenny, was confirmed in her role as carer not only by her younger sister's need, but by the incidental needs of her own daughter, who was pregnant at the time of the study. In such circumstances, an individual may become effectively 'locked' into a specific familial caring role, and find it difficult to countenance reversal. This is a new concept that has not previously been documented within the literature.

It might be presumed that the familial role reversal described above may be seen in an elderly care population, where one individual, initially the frailer and more dependent party, is unexpectedly promoted to the status of senior when the main carer's health deteriorates. Perhaps the more frequently observed role reversal; however, is the situation in which offspring of elderly relatives are thrust into the position of caring as their parent's health deteriorates. This is a fundamental subversion of the most natural and instinctual caring relationship – that of the parent for the child. Research into this area, unsurprisingly, tends to be dominated by long-term care situations, very often featuring elderly dementia sufferers, in which the concept of recovery is, in the majority of cases, irrelevant. In the current study, the majority spoke positively of the caregiving experience – referring to the necessity of perseverance in coping with a range of unaccustomed tasks, but at the same time describing a greater level of closeness in their relationship with the cared-for person. By the end of Phase 3, both carer and cared-for person looked forward to their lives together with optimism. Studies of care situations involving

dementia sufferers, such as that published by Hooyman (1985), report negative carer outlook. This should not surprise us; carers of cardiac surgery patients, albeit initially prey to stress in the face of new responsibilities and anxiety regarding the health of their relatives, may gradually and increasingly focus on an end to the caring role and resumption of 'normal' life; but for carers of dementia sufferers their role will only end with separation – the removal of the cared-for person into a permanent care setting, or his/her death.

The needs of the family carer need vary throughout the course of the caregiving journey. Indeed the specific nature of those needs in some ways correlates to the changing nature of the relationship between carer and relative discussed above. However there is one need which remains constant throughout the care period – the need of reassurance. Hence 'Reassurance' was identified as the second overarching theme.

While the need for reassurance remains constant, various sources from which reassurance is sought correspond to the different types of reassurance needed at different times, and thus may be traced back to the issue of the changing needs of the family carer (thus perhaps further back to the changing nature of the carer-patient relationship). Sources of reassurance include, at the most practical and obvious extreme, healthcare professionals, whereas family and friends, and indeed the cared for relative him/herself, may be a source of practical and emotional support. The notion of the patient as a source of support is particularly pertinent in the final Phase of the caregiving journey – with recovery. This reflects the cared-for person's improved physical status, but may also reflect the carer's own need to move on from the intensity of the caregiving situation and embrace

the future. It is possible that at the stage of recovery, the cared-for person is better disposed to look to the future, and more naturally predisposed to optimism, if only because he/she experiences the evidence of recovery at first hand. All participants in the current study referred to the positive impact of reassurance from these sources throughout the caregiving period, affirming its benefit in terms of the comfort and security so provided, which eased somewhat the burden of care.

Findings reported by Ågren et al. (2009) emphasise the informal carer's need for 'security, rest and inner strength', describing particularly the pronounced periods of loneliness, uncertainty and insecurity the informal carer may endure in the acute stage (ie when the patient is on the operating table or in the ICU) (Ågren et al., 2009, p. 287). Similar feelings were described by the participants in the current study, but unlike the sample examined by Agren et al. the participants in the current went further to describe the development of their feelings over time, and a concomitant development of their needs, and the changing nature of the assurance they craved at different stages of the caregiving journey. It has proved valuable to examine how these carers obtained reassurance over time, and the way in which the reassurance received contributed to their security and the growth of optimism.

The final overarching theme, 'Being there for Each Other', reflects the mutual constancy of participants and their relatives throughout the caregiving journey. To a significant degree, of course, this quality of commitment may be seen to reflect the conventional bonds of loyalty which characterise marital or sibling relationships, yet at the same time it must be emphasised that these relationships must undergo an unusual degree of strain through the caregiving period, in the form of physical

and emotional stresses which far exceed the habitual expectations of such familial bonds. What emerged very clearly from the current study, however, was not only the solidity and stability of the relationships between the participants and their relatives, but the very significant positive contribution those relational qualities made to the caregiving (and care receiving) experience.

These findings are supported by findings in two previous studies of this issue; Hunt et al. (2000) followed 123 adult patients who had undergone CABG surgery during 12 months and found that stable relationships between care recipients and care providers (who were either married or formed intimate partnerships) played a significant part in reducing caregiver burden, and so improving the overall quality of life for both carer and cared-for person. In addition, Halm et al. (2007) investigated elderly caregivers (n = 166) for a year following their partner's coronary artery bypass (CAB). The findings from this study also indicated that the quality of intimate partnership may mitigate the negative reactions associated with caregiver burden. Testimony to the validity of these findings is provided by two examples from the current study; the first speaker is Maggie:

> "That's right I mean my time was for him and whatever it took really, because he would obviously do - well he was the same for me' (Maggie, interview 1, p. 9)"; her sentiment is echoed by Anne:
> "It's not a duty, that's the wrong word it's just I don't know what the word is, it's just that's what you do, you look after one another and yes, that's, so I probably am thinking of his welfare. But not in an oh dear, oh dear way - just making sure that things are done properly for the two of us really..." (Anne, interview 2, p4).

In healthy sibling relationships there is a similar mutual loyalty and commitment to the happiness and well-being of the brother/sister. The key difference between sibling and marital relationships, of course, is that in Western culture, marriage, or

an intimate relationship, is entered into out of choice, while the bonds between siblings are entered into at birth. The significance of this distinction and its specific bearing upon the carer-patient relationship has already been discussed in the analysis of 'The Changing Nature of the Relationship' above.

6.6 The Essence of the Experience of Caring

To essay a definition of the essence of the caregiving experience presents the researcher with a serious challenge. McCance, et al. (1997) and Morse et al. (1990) propose that caring is manifested in interpersonal relationships, and can be experienced either in concrete or abstract form. This may be simplistically summarised as a referring to the situation in which one individual minister, or is predisposed to minister to the needs of another as best he/she can. McCance et al. (1997) confirm the necessity of predisposition, suggesting that carers 'need to want to care' if they are to devote the time and energy necessary to meet the needs of the cared-for person. Thus, we might define informal, or family, carers as large-hearted individuals who care for their sick relatives at home.

For the participants in the current study the meaning of caring may be generally expressed in the pattern of the caregiving journey. The fact that the end of the caring journey was never out of sight meant that all were able to entertain a degree of optimism throughout, partly as a response to the patient's survival of surgery, and partly in the prospect of their full recovery. The persistence of the fundamental element of hope from the outset of the caregiving period was a crucial element dictating the relatively simple pattern of the journey. For carers who look after those with long-term conditions, the journey may correspond to a less straightforward structure, with the possibility of significant negative change in the patient's condition, and a less hopeful outcome.

Brilowski and Wendler (2005) state that a relationship, defined by action in which attitude derives and is mutually accepted, within permissible variable bounds, broadly comprises the caring process. Other sub-categories of mutual behaviour may be adduced within this model, such as trust, rapport, understanding and commitment; their presence is absolutely necessary for caring to take place at all. It is the concurrence of these elements which leads to the situation in which the patient's needs are met, with the additional consequence that the carer may feel personally satisfied. The current researcher contends that the above mentioned model for caregiving may be identified in the pattern of the caregiving process as journey, comprising three Phases, in which a lay person is temporarily transformed into a carer, and ultimately reverts to being a lay-person. For participants in the current study, the journey was distinguished by significant levels of stress; these varied throughout the course of the journey, leading to specific types of need, whose nature the researcher has sought to identify. In spite of the stressful nature of the caregiving experience, all participants described the journey as ultimately positive. In this respect the experience of carers in the current study diverged significantly from the experiences of long-term carers, for whom the end point of caring is uncertain and frequently negative.

A big concern is that the idea of person-centred care, which is central to a general understanding of person-centredness and which includes respect for the person and doing good to others (McCormack, 2003) is now also part of the bigger agenda. This idea of person-centred care by virtue of necessity, and particularly when the care is being delivered by lay carers in their own home, must involve carers in the caring relationship. More crucially, it must also reflect the carer's and family' values if this kind philosophical approach to care is to be meaningful to, and for, them. However, and given that one of the main premises which underpins

person-centred care is that professionals are the ones who provide person-centred care, the question of how carers can and should be treated as being a partner with the health care professional and the patient has to be asked. Given the current situation where this is not happening, it is difficult to see how the Princess Royal Trust for Carers (2009) and government strategy (Carers Strategy, 2010) that better support for the carers can be achieved. Further examination of this will be immensely helpful.

The tripartite structure of the caregiving journey sketched above may be more closely defined in terms of the changing nature of the relationship between the carer and the cared-for person: in Phase 1 participants felt that they have adopted a nursing role in relation to the spouse/sibling; in Phase 2 this role evolved into a more recognisable caring capacity; at the onset of Phase 3, participants described a sense of returning to former roles, becoming themselves again. This representative structure represents the identification of a pattern in the caregiving process which is unreported in existing literature.

6.7 Reflection on the researcher's journey during this research

In the following section, the researcher will adopt the use of the first person - 'I' - to convey her personal reflection on the research process. The self-reflection process will embrace consideration of my cultural and ideological background, and my perception of the differences in care practice between hospitals in the UK and Taiwan. An incidental element in this reflective process will be a brief review of the challenge of conducting research and data analysis in a non-native language.

In one of the reflective diaries on 5/6/2005, I initiated the process of self-reflection in the passage included below, which was composed prior to the commencement of data collection:

"I am an overseas student from Taiwan who currently undertaking a PhD degree in Edinburgh. I speak Chinese and English is not my first language. I am aware of the culture differences between my participants in this study and myself. My personal belief was developed throughout my childhood and adulthood as well as working in an intensive care environment because I saw lots of people struggle through their lives in there and also saw what the carers went been through. My parents are both Buddhists who believe the concept of fate but also taught me about doing what you have to do to get what you want. Although they were both Buddhists, I do not share their religion. There is no doubt that my parents' religion and beliefs have influenced me and I am aware of myself sometimes following this belief to do things perfectly. Therefore, no matter how hard it will be or how tired it will make me, I will do what I need to do until I achieve the goal. This is my belief which also made me always keep things in my mind and not speak out. This is a similar attitude to the attitude of the carers in my home country."

In carrying out this research, I was always aware of the difference in my cultural background from the cultural context of the research setting, and anticipated particularly how the differences between the healthcare settings of the UK and Taiwan would impact on my study. There is undoubtedly some benefit in being an 'outsider'; it may enable a certain objectivity of perspective which is difficult to achieve for one brought up with expectations based on the cultural mores prevalent in the research setting, and the practical beliefs of the indigenous healthcare system. However, it is equally a challenge to assimilate and understand

preconceptions and practices which comprise the culture and healthcare system of another country.

Before and during the data collection period, I wrote entries in a reflective diary. . This included observations of behaviour and practice in the hospital ward and notes on the cultural differences between the UK and my home country. For example, on 20/10/2005. I wrote:

"In order to understand the culture difference between my country and UK, I went to observe the hospital ward and joined the pre-clinic meeting before I collected my data. I discovered the major difference between UK and my country was that carers were not beside the patients at all times and the hospital staff took all the responsibilities of care for the patients. Moreover, during hospitalization carers only visited the patients in the visiting time and then went home after the visiting time. However, the carers in Taiwan are totally different. They have to stay in the hospital with the patients and do some of the caring jobs such as feeding the patients, helping with baths or changing position as well as putting clothes on patients. Therefore, carers are familiar with some of the caring duties when the patient is ready to go home. This means that they become more prepared for the situation that they might encounter at home. Carers usually follow up the routine that they have learnt from hospital to check the patient at home. Thus, the patient will be always the patient and the carer will be in that role for a long time.

Additionally, if the carers are unable to stay in the hospital, the family members will hire someone (like a care assistant) to help with the patient's care and stay in hospital with the patient. This will not be paid by the National Health Insurance and it often costs lots of money. Therefore, most of the family members will look after the patient themselves because most Chinese families adhere to traditional

notions of filial piety based on the Confucian ideology. For example, if the patient has a spouse, the spouse will do the care; if not, the patient will be cared for by their children. This means that the different generations will stay together in the same house. This is the obligation for Chinese family members to care for their spouses or parents during the illness period. This is different in UK because the carers do not have to stay beside the patient at all times in the hospital. This is an expectation clearly not shared in the Scottish culture.

Another difference between the UK and my home country is the days of hospital stay for the patient. In the UK, the patient is usually discharged at seven days after surgery. However, in contrast, in Taiwan the patient stays in the hospital for 14 days which means that the patient will stay in ITU for three to four days and then transfer to the ward after about 10 days until most of the wounds are healed. Moreover, there should be one carer with the patient at all time no matter if the patient is in ITU (if the patient is in ITU, there is a small bed outside the ITU for the carer) or ward. Carers in Taiwan feel that it is better for the patient to stay in the hospital until they are cured because they are afraid of leaving without the professionals' help in the community. This also reflect the findings in the current study as carers feel that they are 'walking in the dark' and they need 'reassurance' to help them to go through the recovery period after hospital discharge. This is another different aspect which is not shared in the culture of Scotland.

In the early days, the NHI paid medical fees to healthcare providers on a "fee-for-service" basis. In recent times the "case-payment" method has been gradually introduced and a global budget payment scheme has been promoted at the same time to improve the quality of service. Thus, people in Taiwan who need to access the health care system should now pay a basic fee and get the treatment they need. There are many hospitals in Taiwan including more than 10 academic

hospitals and numbers of county or community hospitals. There is thus now a wide range of choice for patients; the patient is able to decide the hospital at which they would like to be treated, depending upon the cost they are able to pay. An academic hospital, for instance, will cost more than the Local Medical District, yet some patients and their carers, able to afford the higher fees, will go to the academic hospital for their treatment without any referral (This has lead to a number of problems for the NHI such as wasted government health expenditure and delayed discharge). Although the social care system was poorly developed in Taiwan, there is no long waiting list for people who need to go to see the doctors as the health care system in Taiwan is different than in the UK. This means that if anything goes wrong, the carer could bring the patient to the hospital to get their treatment immediately".

While collecting my data, another challenge I had to face was the language barrier. Often, when discussing issues with a participant it was clear that there were certain difficulties of understanding, generally indicated by the question,

Carer: "Do you understand what I mean?"

It was clear that participants were concerned I might have difficulty catching their meaning, particularly since some of them had very strong regional accents. As a remedy against this possibility I adopted the strategy of including two simple questions:

Researcher: "Do you mean that you have not been provided with any information during this time? "

Researcher: "Can you explain it further?"

The above sentences were designed make sure that I caught the full meaning of a carer's statement. I also asked my supervisory team for clarification if I struggled

to understand words the carers used in interviews. These steps ensured full appreciation of the information and ideas participants sought to express.

In the initial stage of listening back to interview tapes, I translated each word into Chinese, in order that I could think about their meaning in a Chinese way. I then wrote my responses and thoughts in Chinese-English sentences. This provided problems of understanding for my supervisory team. When they pointed this out I made an effort to attend some English courses, and endeavoured not to think exclusively in Chinese. This was extremely challenging, but I did my best to improve in this area, and believe it has made an important and positive difference.

The above reflection was included in the diary composed during the research process. It was valuable in enabling me to address the issue of cultural difference, to prepare myself for the subsequent difficulties I was liable to face, and to understand how the attitudes and preconceptions I brought to the study might influence its outcome which was already presented in chapter 4.

6.8 Comparisons of the current model with other models in the literature

In the current study, a model was presented in page 53. This model outlines the experience of caring by those looking after cardiac surgery patients.

Figure 12: Three different models of carers

Stages	Wilson's (1989) model of carers in Alzheimer 's disease suffers	Nolan & Keady's (1994) model of carers in dementia suffers	The current model (2011) of carers in cardiac surgery patients
1	Noticing. Discounting/normalization Suspecting Searching for explanations recasting	Building on the past Recognizing the need	Walking in the dark
2	Taking it on	Taking it on	
3	Going through it	Working through it	Getting on with it
4	Turning it over	Reaching the end A new beginning	Looking forward to the future

These three models (Wilson 1989, Nolan and Keady 1994, Chiu 2011) demonstrate that caring is a journey which comprises a number stages. Wilson, Nolan and Keady, both see it as having 4 stages. On the other hand Chiu's model has only 3 stages. The first stage comprises a period of noting and recognising the need for care. Because the carers in Wilson's and Nolan and Keady's work were looking after those with dementia the start of their journey was difficult to identify thus they went through a stage of trying to work out why their relatives were behaving in slightly odd unexpected ways whereas in the current work the carers were dealing with an acute episode of illness resulting in major surgery. The theme which identified this part of the journey in the present work is walking in the dark. This was accentuated by the fact that the patients were catapulted from good health to a life threatening condition and surgery. This also means that after surgery they are looked after in critical care, high dependency, and a ward then are discharged from hospital all of which occurs within a week. This can be accentuated by being discharged on Friday afternoon. This meant that these carers felt as if they were 'walking in the dark' without knowledge or support to carry out the caring role. The acute nature of their caring context (heart surgery),

the threat to life and enforced caring role, may all suggest why it was that the carers in Chiu model talked about their need for reassurance which was present throughout their journey but which has not featured in the Wilson's and Nolan and Keady's work.

Stage 2 for both Wilson and Nolan and Keady was 'taking it on' which certainly for these carers was a huge decision. This stage of the journey was not matched in the Chiu model. The carers in the current work were simply faced with an acute situation where their relatives had been discharged from hospital following surgery in a vulnerable state needing care. Most of the group were spouses and so the decision to adopt the caring role had already been made at the point of marriage where they had all promised 'to have and to hold, in sickness and health…' The carers were apparently not really conscious of making the decision apart from the sisters where one sister simply moved to her sister's home to look after her because she clearly needed full time care but it was a matter of management rather than choosing to carry out the role.

Thus there is no match for this stage of the journey in the Chiu model.

Stage 3 is called 'going through it' (Wilson) or 'working through it' (Nolan and Keady) and 'getting on with it' (Chiu). Having made the choice to adopt the role all these carers found the demands of their role had an ever ending nature leading to feelings of burden, loneliness and not being able to make independent choices about activities. Perhaps this is the most important shared understanding of the models and where the acts of caring were similar and how they learned the necessary skills to perform their roles, although the preparation, timeframe and opportunities to develop their caring skills and 'expertise' may have been different, for example, taking place over a longer period of time in the case of Wilson and Nolan and Keady's models.

Stage 4 for Wilson was characterised by 'turning it over' while for Nolan and Keady they understood it in terms of 'reaching the end' and then 'a new beginning'. This shared understanding was engendered by the continued diminution of the abilities of the cared for person as well as the increasing frailty of the carer whose life was becoming increasingly untenable. This meant that these carers had to make extremely hard decisions to get permanent help to look after their relatives who had to go into permanent care. Of course this did not mean that they stopped caring but that it was being done at a rather more distant level. Some of them must have found this decision incredibly hard to make and although there was a new beginning perhaps this would not really have come about until after the cared for person had died. On the other hand in Chiu's work this stage had a much more positive aspect for her stage 4 was seen as being 'looking forward to the future'. This resulted from the patients recovering and the carers returning to their usual lives and so the normal sharing of activities and shedding of the carer's role.

Because the journey in the current work had a longitudinal aspect it was clear that there were 3 other aspects which were identified as being consistent throughout the journey. These were the 'changing nature of the relationship' 'reassurance', 'being there' and enunciating the changes in the relationship and how these carers saw themselves during the journey. They were aware that they were no longer spouses but had become nurses of ill people at the start which continued until they their relatives had recuperated but still needed some help until the felt really well again.

The aspect that they all mentioned was reassurance which they received throughout the process from professionals, extended families and friends. They were reassured by the improvement in the cared for person, that they were 'doing things properly' such as moving the patient, doing dressings and keeping them

comfortable. From other lay people the reassurance took the form of diminishing the feelings of loneliness and tiredness as well as doing basic tasks such as shopping which meant that the carer did not have to rush out, feel guilty about leaving the patient and feeling even more weary.

The next aspect of the model is 'being there' which continued throughout the journey' and was their expression of the marital or familial bond. It is perhaps most surprising that these familial and marital bonds had no expression in the other models since they must have been present.

In the current work they all spoke of how the other partner 'would do the same for me', and indeed this was demonstrated by one of the sisters who before the end of the journey became ill herself with a diagnosis of breast cancer and the reciprocal nature of the relationship was demonstrated. This is perhaps explained by the fact that their journeys were short lived and the people themselves did not change. Whereas for the carers of dementia sufferers who often speak of how they have lost their partners because they are not the people they married.

Essentially it is important to note that the fundamental difference between these models is that two are for long term care while the other is for short term care. It would be of interest to see how closely this model would fit in another short term surgical intervention.

However, the final stage represents the most remarkable difference between the two models and the experiences of carers in the current study, because in the current work all but one of the carers' lives returned to normal, and indeed they were looking forward to the future, because of the recovery of their relatives who had had surgery. This divergence is explained by the fact that one group of carers were looking after those with a degenerative condition while the others had and acute illness treated with a surgical intervention which restored them to full

health or as near to that as possible. This of course does not mean that the carers of AD relatives might in the long term experience a better future outlook after a period of time which will differ in length according to the progress of the 'patient'. This time will however probably be tinged with enormous sadness at loss and death compounded by the carer's own increasing age and possible frailty.

Although Wilson (1989) and Nolan and Keady (1994) gave a valuable picture of the carer's experience for people who look after AD or dementia sufferers. They did not go beyond those two groups. The similarity of their studies was that they presented an equivalent model. Although the stage of caring would be different, the explanation of each stage could be applied to each other. This might be because they examined the same long term aspect of caring. However, the realty of caring for acute stage people who suffer from short tem disease is unlikely the same as carers of dementia suffers and it has been elucidated and this is possibly transferable to other acute conditions. Because the cardiac surgery patients have been sent home within one week of surgery, they were quite ill and needed a lot of nursing care such as doing dressings, positioning the patient in bed or getting the patient up or where to equipment for the patient, how to observe the patient's progress or supervise the exercise of the patient. When the patient was discharged, the shifted of care was to the lay carers, and they were left on their own but they needed help from health care professionals to show them how to do these things.

6.9 The new knowledge that emerged from this study

The new knowledge arises from this research and as well as making a specific contribution to the body of knowledge concerning carers of cardiac surgery patients. The new knowledge showed in this study is:

- Looking after a 'patient' was a real experience for all carers. The most important aspect was that all of these patients were discharged one week after surgery. This meant that they were not able to self care, move easily around in bed because of the scar or undertake their normal activates. For example, Johnson and Knoll (2000) described the range of basic caregiving chores of carers within this strand includes controlling meals and intake of medication, visitation schedule, physical exercises and recreational activities. However, none of these carers mentioned that they had to look after their relative's wound or lifting them from the bed. In the current study, carers described that they had to change dressing of a bleeding leg or trying to lift the patient in and out of the bed was the most difficult things. Carers reported that their relationships changed in terms of their own identity of becoming nurses, being responsible for everything. This differs from Wilson (1989), Nolan and Keady's (1994) studies. They described carers felt the relationship change with their relatives gradually, and importantly, carers did not clearly mention that they felt they were looking after a patient. In the present work, the carers and patients relationship re-established when they improved. Clearly, this was not an option in Wilson, Nolan and Keady's study.

- A key feature in this current study was carers needed reassurance throughout their caring journey. This was unlike carers in Wilson, Nolan and Keady's study as well as other CABG carers in Karlsson et al.'s study. This

should have to be supplied by a mixture of professionals and a wider group of family and friends. Of particular significance is the information which can be given by carers about what it feels like to care for their relative in the first three months after cardiac surgery and their need for support during this period. For example, because these carers were acting like nurses, they needed reassurance that what they did for the patient was alright, how to supervise the patient's progress and what to expect if things go wrong. Although Ågren et al. (2009) pointed out the burden of care and the needs of carers and conceptualized a model of individual needs of spouses called 'confirmation', this 'confirmation' was focused on the carers' inner strength and it was different from the current study. The current study showed that carers wanted to gain confidence not only from the health care professionals but also from their family members, friends and the patient.

- The essence of the caring experience of carers of cardiac surgery patients changes the nature of the relationship from being a person, to being a carer and back to being a person. In the beginning, carers said that they were like 'a carer and somebody, not man and wife' but at the end they felt that their lives were back to normal. This also showed that carers experienced a positive outlook in the future. In the current study, all the carers except one, were looking forward to things getting back to normal, unlike Karlsson et al.'s (2006) work. They reported that carers of CABG patients experienced a negative outlook on future life.

6.10 Summary

This chapter describes the outcomes of research into the experiences of carers of patients with cardiac disease. Anxiety and stress are identified as prominent issues, stemming largely from the inadequate support and information given to carers at the point of discharge and post discharge. A key issue which emerged was the necessity of understanding a carer and his/her unique circumstances in order to offer support and advice for what he/she is likely to experience in the caring role. The study also found that the experience for carers of coronary surgery patients has significant parallels with the experiences of carers in other circumstances, particularly where emotions and behaviour of carers are concerned. Moreover, discharge planning has remained a problem for the past 30 years and the involvement of carers in the process remained inadequate. Although it is accepted that the continuing push to shorter hospital stay and improved technology makes this an increasing challenge for an aging population since older people need more support. However, after patient's discharged, carers said that they still need more information regarding the availability of professional support within their community.

This chapter culminates in a synthesis of the key findings relating to the carers of cardiac surgery patients, with a brief discussion of existing literature and comparison with concepts identified in the current study. There is also a consideration of the extent to which the initial aims of the study have been met followed by an in-depth discussion of the findings in conjunction with the relevant literature.

Chapter 7

Chapter 7 Conclusions

The results of this research revealed the experiences of the carers of cardiac surgery patients following discharge. It also provided the drawing up of a conceptual model. After a comparison and other models in the literature it became clear that the current one reveals the differences in the caring journey for those giving long and short term care form the perspectives of the carers. . In order to optimise home care, it is essential for health care professionals be made aware of the lay carers' experiences in order to prepare them to adapt to their caring role.

These carers saw their experiences as being a journey of three phases. The main themes were 'Walking in the Dark', 'Getting on with it' and 'Looking forward to the Future'.

1. This experience of Phase 1 (3 weeks after discharge) was 'walking in the dark' which was the most profound and lasting feeling that the carers had about their journey for it described how they felt when taking on a role for which they felt unprepared. This matched with Johnson and Knoll (2000), Wilson's (1989) study. In the current study, the carers had lived through a life threatening possibility for their souses or sister and were relieved that that had passed positively and were glad also that their relatives were considered well enough to go home. However then they were faced with the reality of not knowing what to expect or how to carry out the necessary tasks which the situation required of them. This Phases most important sub-themes were firstly 'looking after the patient'. They spoke of not being wives of husbands but rather nurses in the sense that they were looking after patients who needed to be nursed. This was because they had nursing tasks to carry out such as giving medicines changing dressings and also putting on TED stockings. However the second subtheme was having 'no

yardstick of knowing'. This showed how they had tasks to complete but had not way of knowing if they were doing the right things or if they were being carried out properly. This made some carers become resourceful and for example one of them made an improvised hoist to help her manage to keep her husband comfortable in bed. During this stressful period at the start of their journeys since they felt that they were looking after a patient and had no way of knowing how to do this or what they were looking for when assessing the patient's condition; they were seeking support from professionals, either doctors or nurses. This would have given them assurance that things were normal, that the patient's signs and symptoms were within reasonable bounds and also importantly that they were managing things well. However for most this was not forthcoming. Several of these patients had been discharged at the weekend and so there was no immediate recourse to known medical staff. In some cases they also needed equipment to be provided such as dressings or bathing equipment and specific guidance about how to look after the patient. Sadly this was not always forthcoming. In one extreme case the patient who was diabetic had been sent home without any provision of medicines and since he had taken his whole supply in to the hospital with him and handed it over to be returned home without any supply because the hospital pharmacy had no stock meant that the carer had to leave her husband and rush out to get a repeat prescription from the Chemist.

2. During the second Phase (6 weeks following discharge) of the journey the theme of 'getting on with it' showed that carers had become increasingly familiar with their situation and role. This matched with Wilson (1989), Nolan and Keady's (1994) study. This meant that they were seeing an

improvement in the patient's condition and had an ability to do more things for themselves and so the situation was much more controlled and the carers felt more secure in the knowledge that they were doing the right things in the correct way. This meant that there was less worry on the part of the carer. Also by this stage all of them had had reassurance from the health carers in shape of the GP or Nurse. This made them feel more able to cope. They did however realize that there was no one else to carry out the tasks and so there was no option but to cope with the problems which gave them skills and confidence which added to a good outcome. For most of the carers this marked a shift from 'walking in the dark' to feeling a sense that the routine and care needs were stabilizing and that they were beginning to have some time to sit down and not feel as concerned about the patient's condition. This feeling of managing and simply having to continue with the caring contributed to a sense of stability in their lives.

3. Some 12 weeks into the caring journey marked the final Phase when the theme was 'looking forward to the future'. This was highlighted by the participants as was the process of things being back to normal. However, this was different from Karlsson et al's (2006) study. In the current study, the relatives were in much better health and the anxiety of impending death had almost gone. It also gave them, time to return to their own tasks and interests. At this time carers reflected on their experience and this led them to realizing that there had been changes in their relationships because they had become more honest and open with each other and they seemed to know and appreciate how they would like to live their lives better together afterwards. It provided a positive outcome to this caring journey. This was new in the literature.

All of these experiences led to an understanding of the concept of caring which was understood in the three overarching themes which were the 'changing nature of the relationship', 'reassurance' and 'being there'. All of these overarching themes where seen throughout the journey and were seen in all cases.

4. There was a marked acknowledgement for them all that there was a measure of the 'changing nature of their relationship'. It is important to note that although the most marked change described occurred at the start of the journey, namely that of not considering themselves to be husbands or wives but nurses and patients. Even in the case of the sisters the carer saw herself as being the mother and her sister a child. However by Phase 2 a change was starting to be noticed with the improvement in the health of the patient. This meant that they were beginning to adopt some of the lighter tasks that they would normally have carried out such as drying the dishes or carrying a few messages from the shop. They were also in the main able to care for themselves in terms of bathing and dressing and keeping themselves comfortable in bed. By Phase 3 things had returned to normal and so they were again operating either as sisters or spouses. But it is important to note that this journey had a lasting effect since this momentous experience of near death had made them reassess how they wanted to spend the rest of their days together. This was new in the literature.

5. As was clear at the start of the journey 'reassurance' was an especially important element for the carers. They sought it so that they would feel more able to manage the activities of caring during the journey. These carers were adopting a role for which they felt quite unprepared. This was

similar to Johnson and Knoll's (2000) study. Whilst Johnson and Knoll (2000) reported this unprepared feeling in some carers. In the current study, all carers felt that they had little idea of what to expect. And though they had been given a video about what would happen when they were at the booking in clinic it was obviously not clear as to what timescales of when they could expect improvement. Nor did it give guidance on quite mundane activities such as what to give the patient to eat or how often but on more technical issues such as how to deal with activities such as doing dressings or putting on TED stockings. This lead to carers feeling isolated and worried. Clearly all these carers managed to care for their relatives well but this part of the journey could have been made smoother and less anxious. By Phase 2 they had worked things out and be experience they knew that things were all right and so they simply kept going and by that time they had had some input from professionals and so this was much less urgent. By the time that Phase 3 had come the reassurance that they required and sought was from their wider social circle. Family and friends could reassure them that the patient was obviously improving and this helped the journey to pass. The need for reassurance thus altered as the journey proceeded. .It also helped them to survive the experience of caring and manage the return to normality and normal relationships by the end of the journey.

This need for reassurance was complicated by the fact that these carers had had a relative who had a life threatening illness had been admitted for surgery and had possibly been to ITU, HDU and an ordinary ward all in seven days till discharge. This means that these carers had had no one on the staff with whom they had a close relationship. Thus when discharge was spoken of there was no one of whom they could ask 'daft questions'. This

was compounded by the fact that there is huge pressure on beds and so there are still large numbers of weekend discharges which leaves this group in a particularly vulnerable situation with a lack of available professional community staff such as GPs, Community Nurses and in some cases pharmacists. All of these people are all in a position to provide the necessary reassurance and guidance as well as the equipment required to care for the patient appropriately.

6. The second overarching theme which was present throughout the journey was 'being there' for each other which was exemplified by all the couples (both spouses and siblings), and its most important sub-theme was 'being honest with each other'. All these carers were willing to accept their roles as such because of their marital vows of caring for each other in sickness or health or the familial relationship of love for each of the family's members. This notion was underpinned by the idea of reciprocity so that in different circumstances the other partner would have done the same for them. In fact the sisters demonstrated this aptly for before the end of the caring journey the carer sister had a diagnosis of breast cancer and so the patient became the carer immediately and so started a new caring journey. This was similar to Theobald and McMurray's (2004) study.

7. The essence of the carers' experience is that it alters the relationship. AT the start the person who is going to care becomes a carer rather than a person and by the end of the journey has returned to being a person. So at the start they begin by being spouses or siblings and then change to being carers who had total responsibility for their relative's wellbeing and then return to being spouses or siblings where the responsibilities are again

shared. These changes happened over the three month recovery period. This is new in the literature.

8. The caring experience is a journey of some complexity and that change is continuous throughout the course of the journey. This was similar with Wilson (1989), Nolan and Keady's (1994) study.

This was the experience of all of the carers. This is in fact the essence of the concept of the short term caring.

Chapter 8

Chapter 8 Recommendations

8.1 Introduction

The findings of this study provide a clear picture of the experience of caring by those who look after cardiac surgery patients following hospital discharge. As a result, this study has important implications for nursing practice, education as well as further research.

8.2 Recommendations for nursing practice and policy

Person-centred care is said to be an approach to service delivery and service development, ensuring that services are developed in partnership with people and their carers (McCormack, 2003). This should be happened in both hospital and community. Family practitioners currently work mainly with family with children, however, there is clearly a role for them to expand this role to other carers. This seems to be an essential component in the realm of person-centred care.

This serve to reinforce the importance of the need for health care professionals (hospital staff and community nurses, GPs) to work more effectively together, and to understand the experience of these carers to help them cope better with the role of carer and that they are appropriately and more clearly prepared for it.

The health care professionals need to better understand:

1. The Government must develop a national discharge planning policy which needs to include the involvement of carers and a compilation of a carer's information pack. This pack should include the practicalities of what to expect when the patient leaves hospital, an outline of a general rule of thumb of how to gauge the milestones of the patient's returning health, a checklist of the items that the patient should take home such as medicines, dressings, a list of

useful websites, and contact details of professionals with whom they could then discuss any situation which arises. In addition, they need information regarding the district nursing service's role how to ask to a visit. The pack should also include detailed instruction of how to assess the patient's progress, how to change dressings, what diet the patient should follow; what medicines should be administered; how to move the patient; put on TED stockings or order patient's aids.

2. The whole issue of discharge planning needs to be re-assessed. This is a topic which has been spoken off for more than 30 years and there are still hospital patients being discharged over the weekend resulting in profound problems for lay carers trying to look after quiet ill relatives without the necessary back up from GPs, Pharmacists or community nursing staff. Discharge planning is defined as the development of an individualised plan for the patient prior to leaving hospital, with the aim of containing costs and improving patient outcomes (Shepperd et al., 2010). This individual plan should involved carers at an early stage and treated each family as an individual. The idea of person-centredness is to encourage the health care professionals to provide person-centred care, however, this model should also be reflected in family carer role as well as the cared-for person.

The gap between hospital and the community seems to be getting wider and though it is understandable with shorter hospital stay and pressure on beds. There is a need to have joint working group to devise a model which makes sure that all players in the provision of care are involved. Thus we look much more to join-up discharge planning. This should involved hospital staff, GPs, practice nurses, district nurses, physios, patients and carers.

Another important aspect is to revisit the discharge letter from hospital to the GPs. This letter should contain information regarding what discharge planning has been made in the community. This should include information about plans have been made by the immediate carer or the extended family. This letter also needs to reflect what the health care professionals have discussed with the carers about the role they are about to adopt.

There is still a problem with Friday discharges and this should be stopped.

3. The NHS should set up a 'buddy' system of contacts. These buddies should be past carers who had looked after such short term patients in the community so that carers could talk to someone who had been through the whole caring experience.   These buddies could help carers solve problems, gain reassurance that they were doing the right things or simply that they were doing their jobs well.

4. Rehabilitation nurses should provide both carers and the patients a more realistic picture of what they can expect of the patient's progress, what milestone they can expect or when these milestones occurred. Thus carers and patients are not under any misapprehension that patients who are discharged home will have returned to full health.

5. Health care professionals in hospital and community should work together to revisit and review the information and advice contained on the video. It would be apposite to include a group of carers and some patients in such a group to represent their stance more clearly. It would also be helpful to make sure that the video is understood by the carers given the lack of appropriate personnel to do this given the short hospital stay that this group has.   This would make sure that the carers and the assigned staff group does this before discharge giving them time and opportunity to ask questions.

6. It is recommended that the video provided for the patient and the carers by the hospital before discharge should be revisited and reviewed with the carers themselves. Particular attention needs to be placed on the stages of recovery and take into account what patient can or cannot do in each stage. One of the important aspects which must be included in the video is information about how to carry out some nursing activities. For example, wound dressings, getting the patient in and out of bed, monitoring and reporting the patient's progress, diet, medication and administration. The video should d also contained the information about the possible sources of support for the carers in the community such as GPs, district nurses and practice nurses.

8.3 Recommendations for Education

1. It is essential for carers to be more involved in sharing their experiences within universities to help student nurses (undergrad nurses) to better understand the reality of their experiences and how nurses could help them care for short term patients more effectively. Being able to do this and for student nurses to hear this from the carers' own mouths can be a more powerful and more effective learning experience which is more likely to have an impact than only hearing about these and other issued from the professional's perspective.

2. There should be continuing education offered to hospital staff that would help them to understand what carers needs are when they adopt a caring role. It would be good to provide the current model as continuing education material for staff and undergraduate nurses in hospital and in the community; it would help them to have a better understanding of these carers.

3. Student nurses need to be given help to gain a much clear understanding of what discharge planning is and how it ought to response to the short-term

318

carers. Moreover, findings from the current research will help the student nurses to understand the different needs that carers who provided short term and long term care.

8.4 Recommendations for Further Research

1. A replication study should be carried out in Taiwan to establish the differences which the social and culture context in which health care is embedded. This would provide an understanding of the carers experience there where the discharge is later than in the UK and where patients remain patients for the rest of their lives at least in the eyes of the extended family. This means that the concept of a short term caring journey may not exist.

2. It is vital to conduct a phenonemological study of young carers providing help to a short term patient.

3. To test quantitatively the Chiu model using a sample of student nurses, hospital staff, and community staff, to investigate their understanding of carers' needs.

4. Examining how the Chiu model could be advanced and explored as an assessment tool for practitioners to improve hospital discharge planning.

5. Moreover, there is a need for research to understand the current process of caring for this group in the community and how their transition from community to hospital and return to community and who had been informed and what information they get. This would help to plan for further intervention in discharge planning for this group.

References

References

Ågren, S., Evangelista, L., and Strömberg, A., 2010. Do partners of patients with chronic heart failure experience caregiver burden? *European Journal of Cardiovascular Nursing*, 9, pp.254-262.

Ågren, S., Frisman, G. H., Berg, S., Svedjeholm, R., and Strömberg, A., 2009. Addressing spouses' unique needs after cardiac surgery when recovery is complicated by heart failure. *Heart & Lung: Journal of Acute & Critical Care*, 38(4), pp. 384-291.

Alloy, B.L., Just, N. & Panzarella, C., 1997. Attributional Style, Daily Life Events, and Hopelessness Depression: Subtype Validation by Prospective Variability and Specificity of Symptoms. *Cognitive Therapy and Research*, 21(3), pp.321-344.

Artinian, N.T., 1991. Stress experience of spouses of patients having coronary artery bypass during hospitalization and 6 weeks after discharge *Heart & Lung: Journal of Acute & Critical Care*, 20(1), pp.52-59.

Astin, F., Atkin, K., & Darr, A., 2008. Family support and cardiac rehabilitation: A comparative study of the experiences of South Asian and White-European patients and their carer's living in the United Kingdom. *European Journal of Cardiovascular Nursing*, 7, pp.43–51.

Aston, G., 2010. Creating a cardiac care continuum. *H&HN: Hospitals & Health Networks*, 84(9), pp. 32-36.

Atwal, A., 2002. Nurses' perceptions of discharge planning in acute health care: a case study in one British teaching hospital. *Journal of Advanced Nursing*, 39(5), pp.450–458.

Aveyard, H., 2007. *Doing a literature review in Health and Social care: a practical guide*. London: Open University Press.

Baillie, L., 1995. Ethnography and Nursing Research: a critical appraisal *Nurse Researcher*, 3(2), pp5-21.

Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S. & Small, N., 2006. Characteristics and views of family carers of older people with heart failure. *International Journal of Palliative Nursing*, 12 (8), pp. 380-389.

Barodawala, S., 1996. Care of older people: community care: the independent sector. *British Medical Journal.* 313 (7059), pp.740-743.

Bauer, M., Fitzgeral, L., Haesler, E., & Manfrin, M., 2009. Hosptial discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence *Journal of clinical nursing* , 18 (10), pp2539-2546.

Bell, J., 2006. *Doing your research project: A guide for first-time researchers in education, health and social science* (4th edition). London: Open university press.

BHF., 2008. *Coronary heart disease statistic.* British Heart Foundation Statistic Database. Accessed from http:// www.heartstats.org on 10-06-2009

Bloom-DiCicco, B., & Crabtree, B.F., 2006. The qualitative research interview. *Medical Education*, 40, pp.314-321.

Blount, A., DeGirolamo, S. & Mariani, K., 2006. Training the collaborative care practitioners of the future. *Families, Systems, & Health*, 24(1), pp.111–119.

Bolden, L., & Wicks, M.N., 2009. Predictors of Mental Health, Subjective Burden, and Rewards in Family Caregivers of Patients With Chronic Liver Disease. *Archives of Psychiatric Nursing*, 0 (0), pp1-15

Bolger, N., Davis, A., & Rafaeli, E., 2003. Diary methods: Capturing life as it is lived. *Annual Review of Psychology*, 54, pp. 579–616.

Bradburn, N., Rips, L., & Shevell, S., 1987. Answering autobiographical questions: the impact of memory and inference on surveys. *Science,* 236, pp.157–161.

Brännström, M., Ekman, I., Boman, K. & Strandberg, G., 2007. Being a close relative of a person with severe, chronic heart failure in palliative advanced home care – a comfort but also a strain. *Scandinavian Journal of Caring Sciences*, 21(3), pp. 338-344.

Brilowski, G.A. & Wendler, M.C., 2005. An evolutionary concept analysis of caring. *Journal of Advanced Nursing*, 50(6), pp.641-650.

Britten, N., 1995. Qualitative Research: Qualitative interviews in medical research. *BMJ*, 311, pp.251-253.

Bryman, A., 2004. *Social Research Methods*. Oxford: Oxford University Press.

Bryman, A., 2008. *Social Research Methods* (2nd edition). Third Edition. Oxford: Oxford University Press.

Bull, M. & Roberts, J., 2001. Components of a proper hospital discharge for elders. *Journal of advanced Nursing*, 35(4), pp.571-581.

Bull, M.J., Hansen, H.E., and Gross, C.R., 2000. Differences in family caregiver outcomes by their level of involvement in discharge planning. *Applied Nursing Research,* 13(2), pp. 76-82.

Burns, N., & Grove, S.K., 2005. *The Practice of Nursing Research: Conduct, Critique, & Utilization* (5th edition) London: W.B. Saunders.

Burns, N., & Grove, S.K., 2009. *The Practice of Nursing Research: Conduct, Critique, & Utilization* (6th edition) London: W.B. Saunders.

Byrne, M., 2001. Sampling for qualitative research. *AORN*, 73(2), pp.494-498.

Canning, R.D., Dew, M.A., & Davidson, S., 1996. Psychological distress among caregivers to heart transplant recipients. *Social Science and Medicine,* 42(4), pp.599-608

Carer Scotland. (2010). *Tell the next government it's time to support carers.* Accessed from http://www.carersscotland.org/Newsandcampaigns/Itstime on 10-12-2010.

Carers (Recognition and Services) Act. 1995 (c.12). London: Stationery Office. Accessed from http://www.opsi.gov.uk/acts/acts1995/Ukpga_19950012_en_1.htm on 10-06-2008.

Carers Scotland., 2005. *Care 21: The Future of Unpaid Care in Scotland*. Glasgow: Carers Scotland. Accessed from http://www.scotland.gov.uk/Resource/Doc/112273/0027313.pdf on 10-06-2008.

Carers Scotland., 2007. *Real change, not short change: Time to deliver for carers.* Glasgow: Carers Scotland. Accessed from http://www.carersuk.org/Professionals/ResearchLibrary/Financialimpactofcaring/1201109152 on 20-09-2010.

Chapman, L., 2006. Discharge planning: A family affair. *Nursing,* 37(5), pp.56hn12-56hn13.

Cheung, J., & Hocking, P., 2004. Caring as worrying: the experience of spousl carers. *Journal of Advanced Nursing*, 47(5), pp.475-482.

Clayton, A., & Thorne, T., 1994. Diary data enhancing rigour: analysis framework and verification tool. *Journal of advanced Nursing*, 32(6), pp1514-1521.

Cohen, M.Z., 1987. A Historical Overview of the Phenomenological Movement. *IMAGE: Journal of Nursing Scholarship*, 19(1), pp. 31-34.

Colazzi, P., 1978. Psychological research as the phenomenologist view it In Valle, R. & King, M., (eds.) 1978. *Existential-Phenomenological Alternatives for Psychology* New York : Oxford University Press, pp48-71.

Colella, T.J. & King, K.M., 2004. Peer support. An under-recognised resource in cardiac recovery. *Europe Journal of Cardiovascular Nursing*, 3(3), pp211-217.

Cormack, D.F.S., 2000. *The research process in nursing* (4th edition). Oxford: Blackwell.

Creswell, J. W., 2009. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* London: Sage.

Davies, N., 2000. Patients' and carers' perceptions of factors influencing recovery after cardiac surgery. *Journal of Advanced Nursing*, 32(2), pp.318-326.

Denzin, N. K., & Lincoln, Y.S., 2005. *The SAGE Handbook of Qualitative Research* (third edition). London: Sage.

Department of Health., 1996. *The Patient's Charter and you.* London: HMSO. Accessed

from
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Executiveletters/DH_4017675 on 20-10-2010.

Department of Health. 2003. *Discharge from Hospital: Pathway, Process and Practice*. London: HMSO. Access from http://www.wales.nhs.uk/sitesplus/documents/829/DoH%20-%20Discharge%20Pathway%202003.PDF on 15-04-2010.

Dew, M.A., Goycoolea, J.M., Harris, R.C., Lee, A., Zomak, R., Dunbar-Jacob, J., Rotondi, A., Griffith, B.P., & Kormos, R.L., 2004. An internet-based intervention to improve psychosocial outcomes in heart transplant recipients and family caregivers: development and evaluation. *The Journal of Heart and Lung Transplantation*, 23(6), pp. 745-758.

Dougherty, C.M. & Thompson, E.A., 2009. Intimate partner physical and mental health after sudden cardiac arrest and receipt of an implantable cardioverter defibrillator. *Research in Nursing & Health*, 32, pp. 432–442.

Flood, A., 2010. Understanding phenomenology. *Nurse Researcher*,17(2), pp.7-15.

Gadamer, H.G., 1976. *Philosophical Hermeneutics*. University of California Press: Berkley CA.

Gerrish, K., 2008. Caring for the carers: the characteristics of district nursing support for family carers. *Primary Health Care Research & Development*, 9, pp.14–24.

Gillon, R., 1994. Medical ethics: four principles plus attention to scope. *BMJ*, 309(6948), pp184.

Giorgi, A., 1985. *Phenomenology and Psychological Research*. Pittsburgh, PA: Duquesne University Press.

Giorgi, A., 1989. Some theoretical and practice issues regarding the psychological phenomenological method. *Saybrook Review*, 7, pp.71-85.

Giorgi, A.P., & Giorgi, B.M., 2003. The Descriptive Phenomenological Psychological Method In Camic, P. Rhodes, J. E. Yardley, L. (eds.) (2003)

Qualitative Research in Psychology Washington, D.C.: American Psychological Association pp.243-273.

Glaser, B., & Strauss, A.L., 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine: New York.

Goldsmith, D.J., Lindholm, K.A., & Bute, J.J., 2006. Dilemmas of talking about lifestyle changes among couples coping with a cardiac event. *Social Science & Medicine*, 63, pp.2079–2090.

Grad, J., & Sainsbury, P., 1966. Problems of caring for the mentally ill at home. *Proceedings of the Royal Society of Medicine*, 59(1), pp.20-23.

Grbich, C., 2007. *Qualitative data analysis : an introduction*. London: Sage.

Halm, M.A., Treat-Jacobson, D., Lindquist, R., & Savik, K., 2006. Correlates of Caregiver Burden after Coronary Artery Bypass Surgery *Nursing Research*, 55(6), pp426-436.

Halm, M.A., Treat-Jacobson, D., Lindquist, R., & Savik, K., 2007. Caregiver burden and outcomes of caregiving of spouses of patients who undergo coronary artery bypass graft surgery. *Heart & Lung: Journal of Acute & Critical Care*, 36(3), pp.170-187.

Hamill, C. & Sinclair, H., 2010. Bracketing-practical considerations in Husserlian phenomenological research. *Nurse Researcher*, 17(2), pp.16-24.

Hatchett, R., & Thompson, D.R., 2007. *Cardiac Nursing: a comprehensive guide*. Edinburgh: Churchill Livingstone Elsevier.

Heidegger, M., 1962 *Being and Time*. Oxford: Blackwell.

Henwood, M., 1998. *Ignored and invisible? Carers' experience of the NHS*. London: Carers National Association.

Hoenig, J., & Hamilton, M.W., 1966. The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12(3), pp.165-176.

Holloway, I. & Wheeler, S., 1996. *Qualitative Research for Nurses*. Oxford: Blackwell.

Holloway, I. & Wheeler, S., 2002. *Qualitative Research in Nursing*. Oxford: Blackwell.

Holloway, I., 2005. *Qualitative Research in Health Care*. Maidenhead: Open University Press.

Hu, Y.G., 2007. *Medical and Surgical Nursing in Taiwan*. Taipei: Hwa-Sin.

Hunt, J.O., Hendrata, M.V., & Myles, P.S., 2000. Quality of life 12 months after coronary artery bypass graft surgery. *Heart & Lung: The Journal of Critical Care [Heart Lung]*, 29(6), pp. 401-411.

Husserl, E., (translated by Gibson B.W.R.). 1931. *Ideas : a general introduction to pure phenomenology*. London : Allen and Unwin.

Hutchfield, K., 1999. Family-centre care: a concept analysis. *Journal of Advanced Nursing*, 29(5), pp.1178-1187.

ISD Scotland., 2009. *Coronary Heart Disease*. Office for National Statistics.

I-TEC., 2008. *Qualitative Interviews*. USA: Washington.

Johnson, M.E., 2000. Heidegger and meaning: implications for phenomenological research. *Nursing Philosophy*, 1(2), pp.134-146.

Johnson, P., Chaboyer, W., Foster, M., & van der Vooren, R., 2001. Caregivers of ICU patients discharged home: what burden do they face? *Intensive and Critical Care Nursing,* 17, pp219–227.

Jurgens, C.Y., Dumas, M.A. & Messina, B.A., 2007. Update on heart failure management: psychosocial aspects of heart failure management. *Progress in Cardiovascular Nursing*, 22(3), pp. 169-172.

Kärner, A.M., Dahlgren, M.A., & Bergdahl, B., 2004. Rehabilitation after coronary heart disease: spouses' views of support. *Journal of Advanced Nursing,* 46(2), pp.204-215.

Kennedy, C., Christie, J., Harbison, J., Maxton, F., Rutherford, I., & Moss, D., 2008. Establishing the contribution of nursing in the community to the health of the people of Scotland: integrative literature review. *Journal of Advanced Nursing*, 64(5), pp. 416-439.

King, K.M., & Koop, P.M., 1999. The influence of the cardiac surgery patient's sex and age on care-giving received. *Social Science & Medicine*, 48, pp. 1735-1742.

Kneeshaw, M.E., Considine, R.M., & Jennings, J., 1999. Mutuality and preparedness of family caregivers for elderly women after bypass surgery. *Applied Nursing Research,* 12(3), pp. 128-135.

Knoll, S.M., & Johnson, J.L., 2000. Uncertainty and Expectations: Taking Care of a Cardiac Surgery Patient at Home. *Journal of Cardiovascular Nursing*, 14(3), pp.64-75.

Koch, T., 1995. Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing, 21*, 827-836.

Koch, T., 1999. An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, 6(3), pp20-34.

Kristofferson, M., Lofmark, R., & Carlsson, M., 2005. Coping, social support and quality of life over time after myocardial infarction. *Journal of Advanced Nursing*, 52(2), pp113-124.

Kristofferson, M., Lofmark, R., & Carlsson, M., 2007. Striving for balance in daily life: experiences of Swedish women and men shortly after a myocardial infraction. *Journal of Clinical Nursing*, 16 (6), pp391-401.

Kval, S., & Brinkmann, S., 2009. *InterViews: Learning the craft of qualitative research interviewing* (2nd edition). London: Sage.

Kvale, S., 1996. *InterViews: Learning the craft of qualitative research interviewing*. London: Sage.

Lapum, J., Angus, J.E., Peter, E., & Watt-Watson, J., 2010. Patients' discharge experiences: returning home after open-heart surgery. *Heart & Lung: The Journal of Acute and Critical Care*,70(5), 754-762.

Laugharne, C., 1995. Ethnography: research method or philosophy? *Nurse Researcher*, 3(2), pp45-54.

Leininger, M.M., 1985. Ethnography and ethnonursing: models and modes of qualitative data analysis in Leininger, M.M. (ed) *Qualitative Research Methods in Nursing* Orlando FL: Grune and Stratton Inc.

Lenz, E.R., and Perkins, S., 2000. Coronary artery bypass graft surgery patients and their family member caregivers: outcomes of a family-focused staged psychoeducational intervention. *Applied Nursing Research*, 13(3), pp. 142-150.

Leonard, V., 1989. A Heideggenan phenomenologic perspective on the concept of the person. *Advances in Nursing Science*, 11,pp.40-55.

Leonard, V.W., 1999. A Heideggarian phenomenological perception on the concept of the person. In Polifroni, E.C. & Welch, M. (Eds) *Perspectives on Philosophy of Science in Nursing: An Historical and Contemporary Anthology*. Lippincott: Philadelhia PA.

Leske, J.S. & Pelczynski, S.A., 1999. Caregiver satisfaction with preparation for discharge in a decreased-length-of-stay cardiac surgery program. *Journal of Cardiovascular Nursing*, 14(1), pp. 35–43.

Lincoln, Y., & Guba, E., 1985. *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lincoln, Y.S., & Denzin, N.K., 2005. *The Handbook of Qualitative Research* (3rd edition). London:Sage.

Lindhardt, T., Hallberg, I.R., & Poulsen, I., 2008. Nurses' experience of collaboration with relatives of frail elderly patients in acute hospital wards: A qualitative study. *International Journal of Nursing Studies*, 45, pp.668–681.

Lopez, K.A. & Willis, D.G., 2004. Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research*, 14(5), pp.726-735.

Marshall, C., & Rossman, G.B., 1999. *Designing qualitative research* (3rd edition). London: Sage.

Marshall, C., & Rossman, G.B., 2006. *Designing qualitative research* (4th edition). London: Sage.

Marshall, M.N., 1996. Sampling for qualitative research. *Family Practice*, 13(6), pp522-525.

Mason, J., 1996. *Qualitative researching*. London: Sage.

Mason, J., 2006. *Qualitative researching* (2nd edition). London: Sage.

Matthews, J., 2006. *The carer's handbook: essential information and support for all those in a caring role.* London:oxford press.

McCance, T.V., McKenna, H.P., & Boore, J.R.P., 1997. Caring: dealing with a difficult concept. *International Journal of Nursing Studies*, 34(4), pp.241-248.

McNamara, C., 1999. *General Guidelines for Conducting Interviews*. Lecture notes. http://www.mapnp.org/library/evaluatn/intrview.htm

Menand, L., 2007. Woke Up This Morning. Why do we read diaries? *The New Yorker*. Accessed from http://www.newyorker.com/arts/critics/atlarge/2007/12/10/071210crat_atlarge_men and on 15-03-2010

Mohan, S.M., Wilkes, L. & Jackson, D., 2006-2007. Coronary heart disease in Asian Indians: perspectives of family members. *Contemporary Nurse*, 23(2), pp. 189–201.

Molloy, G.J., Johnston, D.W., Johnston, M., Gao, C., Witham, M.D., Struthers, A.D. & McMurdo, M.E.T., 2008. Using the demand–control model of job strain to predict caregiver burden and caregiver satisfaction in the informal caregivers of heart failure patients. *British Journal of Health Psychology*, 13, pp. 401–417.

Monahan, D.J., Kohman, L., & Coleman, M., 1996. Open-Heart Surgery: Consequences for Caregivers. *Journal of Gerontological Social Work*, 25(3/4), pp.53-70.

Montgomery, J., Gonyea, J., & Hooyman, N., 1985. Caregiving and the experience of objective and subjective burden. *Family Relations, 34*, pp.19-26.

Moran, D., 2000. *Introduction to Phenomenology*. London: Routledge.

Morse, J.M. & Field, P.A., 1996. *Nursing research: the application of qualitative approaches* (2nd edition). London: Chapman & Hall.

Morse, J.M., Solberg, S.M., Neander, W.L., Bottorff, J.L., & Johnson, J.L., 1990. Concepts of caring and caring as a concept. *Advances in Nursing Science*, 13(1), pp.1-14.

Naughton, C., Cheek, L. & O'Hara, K., 2005. Rapid recovery following cardiac surgery: a nursing perspective. *British Journal of Nursing*, 14(4), pp. 214-219.

Naylor, M.D. & McCauley, K.M., 1999. The effects of a discharge planning and home follow-up intervention on elders hospitalized with common medical and surgical cardiac conditions. *The Journal of Cardiovascular Nursing*, 14(1), pp. 44–54.

Naylor, M.D., 2000. A decade of transitional care research with vulnerable elders. *The Journal of Cardiovascular Nursing*, 14(3), pp. 1–14.

NHS Scotland., 2009. *Better Heart Disease and Stroke Care Action Plan*. Edinburgh: Healthcare Planning Division. Accessed from

http://www.scotland.gov.uk/Resource/Doc/277650/0083350.pdf on 15-03-2009

on20-3-2010.

Nolan, M., Grant, G., & Keady, J., 1996. *Understanding family care: a multidimensional model of caring and coping.* Maidenhead: Open University Press.

O'Farrell, P., Murray, J., & Hotz, S.B., 2000. Psychological distress among spouses of patients undergoing cardiac rehabilitation. *Heart & Lung: Journal of Acute & Critical Care*, 29(2), pp.97-104.

Oiler, C., 1982. The phenomenological approach in nursing research. *Nursing Research,* 31(3), pp.178-181.

Oppenheim, A.N., 2000. *Questionnaire design, interviewing and attitude measurement.* London: Pinter.

Oxman, A.D., 1994. Systematic review, checklists for review articles. *British Medical Journal*, 309, pp648-651.

Paez, K.A. and Allen, J.K., 2006. Cost-effectiveness of nurse practitioner management of hypercholesterolemia following coronary revascularization. *Journal of the American Academy of Nurse Practitioners*, 18, pp. 436–444.

Paley, J., 1997. Misinterpretive phenomenology: Heidegger, ontology and nursing research. *Journal of advanced Nursing*, 27, pp817-824.

Perreault, M., Tardif, H., Provencher, H., Paquin, G., Desmarais, J., & Pawliuk, N., 2005. The Role of Relatives in Discharge Planning from Psychiatric Hospitals: the Perspective of Patients and their Relatives. *Psychiatric Quarterly,* 76(4), pp.297-315.

Perry, J., Lynam, M. J., & Anderson, J.M., 2006. Resisting vulnerability: the experiences of families who have kin in hospital – a feminist ethnography. *International Journal of Nursing Studies*, 43, pp. 173-184.

Phillips, A.C., Gallagher, S., Hunt, K., Der, G. & Carroll, D., 2009. Symptoms of depression in non-routine caregivers: the role of caregiver strain and burden. *British Journal of Clinical Psychology,* 48, pp. 335–346.

Pickard, S., & Glendinning, C., 2002. Comparing and contrasting the role of family carers and nurses in the domestic health care of frail older people. *Health and Social Care in the Community*, 10(3), pp.144–150.

Pinch, W.J., 1995. Synthesis: Implementing a complex process. *Nurse Educator,* 20(1), pp.30-40.

Polit, D.F., & Beck, C.T., 2003. *Nursing research: principles and methods*. London: Lippincott Williams & Wilkins.

Polit, D.F., & Beck, C.T., 2004. *Nursing Research: principles and methods*. London: Lippincott.

Polit, D.F., & Beck, C.T., 2006. *Essential of Nursing Research: methods, appraisal and utilization* (6th edition). Philadelphia: Lippincott.

Polit, D.F., Beck, C.T. & Hungler, B.P., 2001. *Essential of Nursing Research: methods, appraisal and utilization* (5th edition). *P*hiladelphia: Lippincott.

Pope, C., & Mays, N., 2000. *Qualitative Research in Health Care*. London: BMJ book.

Proctor, E.K., Morrow-Howell, N. & Kaplan, S.J., 1996. Implementation of discharge plans for chronically ill elders discharged home. *Health & Social Work,* 21(1), pp.30-40.

Rantanen, A., Kaunonen, M., Åstedt-Kurki, P., & Tarkka, M-T., 2004. Coronary artery bypass grafting: support for patients and their significant others. *Journal of Clinical Nursing,* 13(2), pp.158-166.

Rantanen, A., Kaunonen, M., Tarkka, M., Sintonen, H., Koivisto, A., Åstedt-Kurki, P., & Tarkka, M., 2008. Factors associated with health-related quality of life in patients and significant others one month after coronary artery bypass grafting. *Journal of Clinical Nursing*, 17(13), pp.1742-1753.

Rantanen, A., Kaunonen, M., Tarkka, M., Sintonen, H., Koivisto, A., Åstedt-Kurki, P., & Tarkka, M., 2009. Patients' and significant others' health-related quality of life one month after coronary artery bypass grafting predicts later health-related quality of life. *Heart & Lung: The Journal of Acute and Critical Care*, 38, pp318-329.

Reed, J., 1994. Phenomenology without phenomena a discussion of the use of phenomenology to examine expertise in long-term care of elderly patients. *Journal of Advanced Nursing,* 19, pp.336-341.

Richardson, A., 1994. The health diary: an examination of its use as a data collection method. *Journal of Advanced Nursing*, 19(4), pp. 782-791.

Robinson, A., Elder, J., Emden, C., Lea, E., Turner, P., & Vickers, J., 2009. Information pathways into dementia care services: Family carers have their say. *Dementia*, 8(1), pp17-37.

Roche, M., 1973. *Phenomenology, Language and the Social Sciences*. London: Routledge & Kegan Paul.

Rubin, H., & Rubin, I., 2005. *Qualitative Interviewing: the Art of Hearing Data*. London: Sage.

Saks, M., & Allsop, J., 2007. *Researching Health: Qualitative, Quantitative and Mixed Methods*. London:Sage.

Santavirta, N., Kettunen, S., & Solovieva, S., 2001. Coping in Spouses of Patients with Acute Myocardial Infarction in the Early Phase of Recovery. *Journal of Cardiovascular Nursing*, 16(1), pp.34-46.

Saunders, M.M., 2003. Family caregivers need support with heart failure patients. *Holistic Nursing Practice,* 17(3), pp. 136-142.

Saunders, M.M., 2009. Indicators of health-related quality of life in heart failure family caregivers. *Journal of Community Health Nursing,* 26, pp. 173–182.

Schultz, A., 1967. *The Phenomenology of the Social World*. London: Heinemann Eduational Book.

Scotland's Census. 2001. Edinburgh: General Register Office for Scotland. Accessed from http://www.gro-scotland.gov.uk/files1/stats/supporting_information.pdf on 10-05- 2008.

Scott, L.D., 2000. Caregiving and care receiving among a technologically dependent heart failure population. *Advances in Nursing Science,* 23(2), pp. 82-97.

Scottish Executive., 1999. *Strategy for Carers in Scotland*. Edinburgh: St. Andrew House.

Scottish Executive., 2001. *Introduction the Strategy for Carers in Scotland: Report of the Scottish Carers' Legislation Working Group*. Edinburgh: St. Andrew House.

Scottish Executive., 2003. *Partnership for care Scotland's health white paper*. Edinburgh: Scottish Executive. Accessed from http://www.scotland.gov.uk/Resource/Doc/47032/0013897.pdf on 15-03- 2009.

Scottish Executive., (2005). *Building a Health Service Fit for the Future*. Edinburgh: Blackwell. Accessed from http://www.scotland.gov.uk/Resource/Doc/924/0012113.pdf on15-03- 2009.

Scottish Government., 2003. *Scottish Household Survey (2001/2002).* Edinburgh: St. Andrew House. Accessed from http://www.scotland.gov.uk/Resource/Doc/47133/0024905.pdf on 10-05-2009.

Scottish Government., 2007. *Better Health, Better Care*. Edinburgh: St. Andrew House. Accessed from http://www.scotland.gov.uk/Resource/Doc/210642/0055693.pdf on 10-05- 2009.

Scottish Government., 2009. *Scottish Household Survey (2007/2008).* Edinburgh: St. Andrew House. Accessed from http://www.scotland.gov.uk/Resource/Doc/282618/0085510.pdf on 10-05-2009.

Scottish Government., 2010. *Caring Together: The Carers Strategy for Scotland 2010 – 2015.* Edinburgh: St. Andrew House. Accessed from http://www.scotland.gov.uk/Resource/Doc/319441/0102104.pdf on 10-07- 2010.

Scottish Government., 2010. *Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland.* Edinburgh: Scottish Government. Accessed from http://www.scotland.gov.uk/Resource/Doc/319575/0102110.pdf on 26-07-2010.

Seddon, D., Robinson, C., Reeves, C., Tommis, Y., Woods, B., & Russell, I., 2007. In their Own Right: Translating the Policy of Carer Assessment into Practice. *British Journal of Social Work*, 37, pp.1335–1352.

Shepperd, S., McClaran, J., Phillips, C.O., Lannin, N.A., Clemson, L.M., McCluskey, A., CameronI.D., & Barras, S.L., 2010. Discharge planning from hospital to home. *Cochrane review*, 1, pp.1-77.

Silverman, D., 2010. *Doing Qualitative Research* (3rd edition). London: Sage.

Sliverman, D., 2004. *Qualitative research : theory, method and practice* (2nd edition). London: Sage.

Spiegelberg, H., 1976. *The Phenomenology Movement: A Historical Introduction* (2nd edition). Martinus Nijhoff: The Hague.

Stewart, M., Davidson, K., Meade, D., & Weld-Viscount, P., 2001. Group support for couples coping with cardiac condition. *Journal of Advanced Nursing*, 33(2), pp.190-199.

Strauss, A., & Corbin, J., 1990. *Basics of qualitative research: Grounded theory procedures and techniques.* London: Sage.

Strauss, A., & Corbin, J., 1998. *Basics of qualitative research : techniques and procedures for developing grounded theory.* London: Sage.

Streubert, H.J., & Carpenter, D.R., 1999. *Qualitative Research in Nursing: Advancing the Humanistic Imperative* (2nd edition). New York: Lippincott.

Streubert, H.J., & Carpenter, D.R., 2007. *Qualitative Research in Nursing: Advancing the Humanistic Imperative* (3rd edition). New York: Lippincott.

Taylor, A., & Taylor, I., (ed) 2000. *The Assassin's Cloak: an anthology of the world's greatest diarists.* Great Britain: Canongate Books.

Taylor, M., (2010). Shutting the door on readmissions: hospitals improve discharge and care transition procedures to reduce the need for patients to come back. *H&HN: Hospitals & Health Networks*, 84(1), pp. 33-34, 36.

The Princes Royal Trust for Carers Centre., 2009. What is a carer? Accessed from http://www.carers.org/what-carer on 26-07-2010.

Theobald, K., & McMurray, A., 2004. Coronary artery bypass graft surgery: discharge planning for successful recovery. *Journal of Advanced Nursing*, 47(5), pp.483-496.

Tierney, A. J., Closs, S.T., King, C., Worth, A., & Macmillan, M.S., 1993. *A national survey of current discharge planning practice in acute hospital wards throughout Scotland.* Nursing Research Unit, Department of Nursing Studies, University of Ednburgh.

Tierney, A., & Closs, J., 1993. Discharge planning for elderly patients. *Nursing Standard*, 7(52), pp.30-33.

Todres, L., 2005. Clarifying the life-world: descriptive phenomenology. In Holloway, I. (Eds) (2005) *Qualitative Research in Health Care*. London: Open University Press, pp. 104-122.

Tsukasaki, K., Kido, T., Makimoto, K., Naganuma, R., Ohno, M. & Sunaga, K., 2006. The impact of sleep interruptions on vital measurements and chronic fatigue of female caregivers providing home care in Japan. *Nursing and Health Sciences*, 8, pp. 2–9.

Twigg, J., & Atkin, K., 1994. *Carers Perceived: policy and practice in informal care*. Open University Press: Buckingham.

Usher, B.M. & Cammarata, K., 2009. Heart failure and family caregiver burden: an update. *Progress in Cardiovascular Nursing*, 24(3), pp. 113-114.

Valle, R., 1998. *Phenomenological Inquiry in Psychology: Existential and Transpersonal Dimensions.* Springer: New York.

Van Kaam, A., 1966. Application of the phenomenological method. In Van Kaam A. *Existential foundations of psychology*. Lanham MD: university Press of America.

Van Manen, M., 1984. Practicing Phenomenological Writing. *Phenomenology and Pedagogy*, 2(1), pp. 36-72.

Van Manen, M., (Eds) 2002. *Writing in the dark: phenomenological studies in interpretive inquiry*. Canada: The Althouse Press.

Vannier, S.A., & O'Sullivan, L.F., 2008. The feasibility and acceptability of handheld computers in a prospective diary study of adolescent sexual behaviour. *Canadian Journal of Human Sexuality*, 17 (4), pp.183-92

Walker, A., 1995. Integrating the family in the mixed economy of care. In *The Future of Family Care for Older people* (eds Allen I. & Perkins E.) HMSO:London, pp201-220.

Wang, W., Thompson, D.R., Chair, S.Y., & Twinn, S.F., 2008. Chinese couples'' experiences during convalescence from first heart attack: a focus group study. *Journal of Advanced Nursing*, 61(3), pp307-315

Weaver, K., 2007. Ethical sensitivity: state of knowledge and needs for future research. *Nursing Ethics*, 14(2), pp.141-155.

Wheeler, L., & Reis, H.T., 1991. Self-recording of everyday life events: origins, types, and uses. *Journal of Personality*, 59, pp.339.

Whittingham, K., 2009. The physical and psychosocial impact of being an unpaid carer for a heart failure patient. *British Journal of Cardiac Nursing*, 4(8), pp. 354-358.

Wiles, J., 2003. Informal caregivers' experiences of formal support in a changing context. *Health and Social Care in the Community*. 11 (3), pp.189-207.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J., 1980. Relatives of the impaired elderly: Correlates of feelings of burden. *The Geronotologist*, 20(6), pp.649-655.

Appendices

NAPIER UNIVERSITY
EDINBURGH

An Exploration of Support Needs of Cardiac Surgery Patient's Relatives or Friends after Hospital Discharge

Invitation Letter

Hello there,

My name is Wen Chiu, from Taiwan a nurse doing PhD study in the School of Acute and Continuing Care Nursing at Napier University, Edinburgh. I would like to invite you to participate in my research project.

Providing support for you is important, in order to help you to care for patients after their heart surgery. Research has shown that some relatives/friends of heart surgery patients feel stressed. This means that people like you, may need additional support in order to help them to care for the patient after heart surgery at home. However, so far there has been no research done which has tried to gain a real understanding of your needs. This may result in a lack of support being offered to you or little information about sorts of help that you could get.

If you are willing to help me, could you please read the information sheet that is enclosed which will tell you more about this study. After reading the sheet if you are still happy to help me, please sign the consent form which is also in this pack and return it to me and then I will ring you to give you the diary and arrange for the first interview.

Appendix II Information letter

Participant Information Sheet
The Support Needs of Relatives or
Friends of Cardiac Surgery Patients
Following Hospital Discharge

You are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. 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 support needs of relatives or friends when they caring for cardiac surgery patients following hospital discharge. I am trying to find out what types of things you do and what support you get as well as what kind of support you think you might need.

Why have you been Chosen?

As you know the liaison sister has given you this pack, I am looking for volunteers to help with this project. You are welcome to take part if you are:

1. Aged over 18 and you are the patient's relative or friend.

2. You live with a person who has had cardiac surgery or you will visit him/her at least once a day during the first three months at home.

NAPIER UNIVERSITY

Do you 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 and return it to me in the self-addressed envelope. Your decision will not effect any further care. You are free to withdraw at any time without giving a reason.

What will happen to you if you take part?

I would like you to keep a diary once a week for the first three weeks after the patient goes home. Afterward, I will contact you to find when I can interview you for about 1 hour. There will be two interviews, one at week 6 and the other at week 12. I want to find out about your experience of being the person who helps the patient most. The interview will be tape-recorded and then transcribed.

What are the possible risks of taking part?

It is possible that you may feel upset or sad during the interview. This is natural and you should not worry about it.

Will your taking part in the study be kept confidential?

All data collected will be anonymous. Your name will be replaced as well as the patient's with a made up ones. It will not be possible for you to be identified in any report of the study. Any information that I

341

get will be kept in a safe place to which only I have access. Both the interview and diary information will be kept till the end of the study.

What will happen to the results of the research study?

The results will be shared with my supervisory team. At each stage of the study I will share your information with you. At the end I will publish what I have found in articles or at conferences.

Where can I ask for information about this study?

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to ring Linda Veitch at 0131-455-5659. You may also contact my supervisors, Dr.Maureen S. Macmillan at 0131-455-5663 or Dr. Norrie Brown at 0131-455-5712 or if you want to write to them. We can all be found at the following address:

Address: School of Acute and Continuing Care Nursing

Napier University

74 Canaan Lane, Edinburgh EH9 2TB

If you have a complaint regarding hospital staff or the patient's care, please contact the Patient Liaison Office at: The Royal Infirmary of Edinburgh 51 Little France Crescent Old Dalkeith Road, Edinburgh EH16 4SA

Telephone: 0131-242-3379

If you want to make complaints about the researcher or the study, please contact the Director of studies: Dr. Maureen S. Macmillan at 0131-455-5663 or the head of school: Mrs. Anne Waugh at 0131-455-5650.

If you have read and understand this information sheet, and you would like to take part in the study, please contact me to discuss with further. Thank you very much.

I look forward to hearing from you.

Contact details of the researcher
Name of researcher: Wen Hsi Chiu (Wen) Research student
Address: School of Acute and Continuing Care Nursing

Napier University

74 Canaan Lane, Edinburgh EH9 2TB

Email / Telephone: w.chiu@napier.ac.uk / 0131 455 5704

NAPIER UNIVERSITY
EDINBURGH

Informed Consent Form

An Exploration of Support Needs of Cardiac Surgery Patient's Relatives or Friends after Hospital Discharge

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 participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Contact details of the researcher

Name of researcher: Wen Hsi Chiu (Research Student)

Address: School of Acute and Continuing Care Nursing

Napier University

74 Canaan Lane, Edinburgh

EH9 2TB

Email / Telephone: w.chiu@napier.ac.uk / 0131 455 5704

**NAPIER
UNIVERSITY**

An exploration of Support Needs of Cardiac Surgery Patient's Lay Carers after Hospital Discharge

Diary Guidelines

The diary is a short record of your experience of caring for your relative following discharge from hospital. It's about your experience and no one else's. For this reason, it is vital that you write in a manner you feel comfortable with. Write what you want to write about the kinds of care you are giving and, what you think your support needs are. Remember my aim is to explore your support needs and I can only find out if you write them down. There is no right or wrong way to write your diary. I would like you to complete your diary at the end of each week, please date each diary entry. You can write in it as often and as much as you like. Please be open and honest in what you write. I am looking forward to receiving your diaries and thank you for taking the time to read this.

 Chiu Wen Hsi

Appendix V Interview Guide

NAPIER UNIVERSITY

An exploration of Support Needs of Cardiac Surgery Patient's Lay Carers after Hospital Discharge

Semi-structure Interview Guide

In your diaries that you completed and returned to me, there are some points which I would like to clarify from your diaries.

5. From what you have said in your diary, you said that you……… Can you explain it further?
6. In your diary on week….., you said that ……. Why do you think that way?
7. You wrote down ………on week three in your diary, what do you mean by that?
8. In your diary on week…., you mentioned that……, How do you know that?

Thank you very much. I feel clearer of what you wrote down in your diaries. Your diaries were really helpful of my research. Now, I would like to ask some more in-depth questions about your opinion of support needs. You can talk anything you want to talk to me.

5. From what you have said before, what do you feel now?
6. In comparison with the first three weeks, can you tell me what you feel now?
7. Some probing questions I can ask during the interview:

    Can you tell me more detail about it?

    What do you mean by that?

    Please explain it further.

    How do you know it?

    Why do you fell that way?
8. Is there anything else you would like to say which you did not mention before?

Appendix VI Diary week 1

NAPIER UNIVERSITY

An exploration of Support Needs of Cardiac Surgery Patient's Lay Carers after Hospital Discharge

Diary Questions week 1   Date:

1. Would you please recall the day that your husband or wife was discharged from hospital and write down what things you had done for him/her?

2. What were the things that you did not normally do during this week when your husband or wife was discharged from hospital?

3. How did you feel about those changes during this week and why did you feel that way?

4. What things did you find especially difficult during this week and how did you deal with it?

5. **Did anyone help you with any of those things?**

6. **Who did help you when you needed it and how often did that happen?**

7. **Was there any help that you needed but you did not get?**

8. **Can you describe the help you get from the health care professionals during this week? How did that happen?**

9. **Was there any help that you needed but no health care professionals gave it? Can you describe it?**

10. **Can you please give me your opinion of what sort of support would have helped you best during the first week?**

Appendix VII Diary week 2

NAPIER UNIVERSITY

An exploration of Support Needs of Cardiac Surgery Patient's Lay Carers after Hospital Discharge

Diary Questions week 2   Date:

1. **What were the things that you did during this week when your husband or wife was discharged from hospital?**

2. **How did you feel during this week and why did you feel that way?**

3. **What things did you find that you would not usually do during this week and how did you deal with it?**

4. **Did anyone help you with any of those things?**

5. **Who did help you when you needed it and how often did that happen?**

6. **Was there any help that you needed but you did not get?**

7. **Did you get any help from the health care professionals during this week? How did that happen?**

8. **Was there any help that you needed but no health care professionals gave it? Can you describe it?**

9. **Can you please give me your opinion of what sort of support would have helped you best during the second week?**

**NAPIER
UNIVERSITY**

An exploration of Support Needs of Cardiac Surgery Patient's Lay Carers after Hospital Discharge

Diary Questions week 3   **Date:**

1. **Can you describe how you feel during this week and why?**

2. **From what you have wrote in your diaries during the past two weeks, can you describe your opinion of 'support' means to you?**

3. **As a carer of cardiac surgery relative, what information would you like to add which could help you but you did not mention before?**

Appendix IX Ethic Approval Letter

NAPIER UNIVERSITY
EDINBURGH

Ms W H Chiu
15a Eden Lane
Edinburgh
Midlothian
EH10 4SD

11th November 2005

Dear Wen-Hsi

APPLICATION FOR ETHICAL APROVAL FOR A RESEARCH PROJECT

I am pleased to confirm that Ethical Approval has now been granted.

If you have any questions please do not hesitate to contact me, or Dr
Maureen Macmillan (m.Macmillan@napier.ac.uk tel. 0131 455 5663).

Yours sincerely

Lesley Laidlaw
Assistant Faculty Manager
Faculty of Health & Life Sciences
Email: l.Laidlaw@napier.ac.uk
Tel: 0131 455 5622

NAPIER UNIVERSITY
EDINBURGH

5 June 2006

OUR REF   YOUR REF

To Whom It May Concern

Dear Sir

'An Exploration of Support Needs of Cardiac surgery Patients' Relatives or Friends' Wen-Hsi Chiu

I am writing to confirm that the University is committed to acting as a research sponsor in relation to the above grant. The conduct of the work will be monitored by the University's Research Ethics and Governance Sub-Committee. I note that the applicant is a registered as a research student and can confirm that all appropriate indemnity insurances for negligent and non-negligent harm are in place.

Yours sincerely

Colette Pemberton
Research Officer
0131455 2499
c.pemberton@napier.ac.uk

352

Lothian NHS Board

NHS
Lothian

Lothian Local Research Ethics Committee 02

Telephone: 0131 536 9061
Facsimile: 0131 536 9346

22 June 2006

Miss Wen Hsi Chiu
15a Eden Lane
Edinburgh
EH10 4SD

Dear Miss Chiu

Full title of study:	**An Exploration of Support Needs of Cardiac Surgery Patients' Lay Carers**
REC reference number:	**06/S1102/17**

Thank you for your letter of 31 May 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 21 June 2006.

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.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

INVESTOR IN PEOPLE

353

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	5.1 (2)	20 May 2006
Investigator CV		13 April 2006
Protocol	Revised V2	30 May 2006
Covering Letter		13 April 2006
Letter from Sponsor		30 March 2006
Compensation Arrangements		30 March 2005
Interview Schedules/Topic Guides	Revised V1	24 May 2006
Sample Diary/Patient Card	Revised V1	24 May 2006
Letter of invitation to participant	Revised V1	24 May 2006
Participant Information Sheet: Relatives/ Friends	Revised V1	24 May 2006
Participant Consent Form	1	13 April 2006
Response to Request for Further Information		31 May 2006
Supervisor CV		13 April 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.
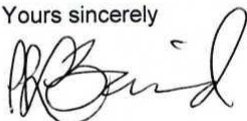
Statement of compliance

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.

06/S1102/17   **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Professor P. Hayes
Chair

Email: lyndsay.baird@lhb.scot.nhs.uk

Enclosures: Standard approval conditions
                          Site approval form

SF1 list of approved sites

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ

NHS
Lothian

HAC/JD/approval/Macarthur

7 August 2006

Mrs Juliet Macarthur
PRDE D Block
Western General Hospital
Crewe Road
Edinburgh
EH4 2XU

Dear Mrs Macarthur

**RESEARCH &
DEVELOPMENT
OFFICE**

Tel: 0131 242 3330
Fax: 0131 242 3343
Email
R&DOffice@luht.scot.nhs.uk

Director:
*Dr Heather A Cubie
FRCPath*

PA to Dr Cubie:
Miss Jill Dobbie

Commercial Research
Manager:
Douglas Young
PhD MBA

Research Governance
Co-ordinator:
*Mrs Susan Shepherd
MSc*

Accountant:
*Ms Sheevaun McIntyre
BAcc*

Assistant Accountant:
Mr Neil McLean

Trial Support Officer:
*Ms Dorothy Aitken
BA*

Office Manager:
Mrs Glynis Omond

Administrator St John's
Mrs Anne Addison

LREC No:	06/S1102/17
R&D ID No:	2006/R/NUR/03
Title of Research	*An exploration of support needs of cardiac surgery patients' relatives or friends*

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.

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.

Please note that under Section A, Q35, NHS Lothian provides indemnity 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. NHS Lothian does not provide indemnity against negligence for healthy volunteer studies. This is the personal responsibility of both NHS and honorary employees and is usually arranged with a medical defence organisation or through the University of Edinburgh.

This letter of approval is your assurance that NHS Lothian is satisfied with your study. As Chief Investigator or local Principal Investigator, you should be fully

355

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

Heather A Cubie

Dr Heather A Cubie
R&D Director

enc   **Research Governance Certificate**   ☑ (to be signed and returned)
       NRR authorisation   ☑ (to be signed and returned)
       Tissue Policy (if applicable)   ☐
       MTA (if applicable)   ☐ (to be signed and returned)

cc   *Administrators, Research Ethics Committee*
       Miss Wen His Chui, Napier University ✓

Appendix X : Summary of articles.

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
Ågren, Frisman, Berg, Svedjeholm, and Strömberg (2009) Sweden	To identify, describe, and conceptualize the individual needs of spouses of patients with complications of heart failure after cardiac surgery	Spouses of patients with heart failure developed after cardiac surgery (emergent/planned CABG, heart valve surgery, or a combination of both). Data were collected from spouses, 10 women and 3 men, from February 2005 to June 2007. The age of participants varied from 39 to 85 years old.	Grounded theory Interviews processed via open-minded inductive analyses (qualitative) 12 interviews were recorded.	No	The core category was confirmation with three subcategories binds together. The three subcategories were Security Rest for mind and body Inner strength.	The researcher only interview once within three years. There was no longitudinal investigation for these caregivers. The researcher described both acute and rehabilitation together, it was unclear how long it last in each stage and how the carers experience in each stage.
Ågren, Evangelista, and Strömberg (2010) Sweden	To describe the levels and identify independent predictors of caregiver burden in partners of patients with heart failure	The 135 partners to patients hospitalized with HF exacerbation at the departments of emergency medicine and cardiology at a university hospital as well as all previously hospitalised patients visiting a nurse-led HF clinic at a county hospital. The partners had a mean-age of 69 years and 75% were females.	Quantitative Data for this descriptive correlational cross-sectional study were collected between January 2005 and September 2008. The dependent variable consisted of the Caregiver Burden Scale total score index. Socio-demographic and clinical characteristics, health-related quality of life, symptoms of depression, perceived control, and knowledge on heart failure were included in a regression	Caregiver burden Predictors of caregiver burden in chronic disease but the researcher not clearly mentioned	Nearly 70% (91/135) reported low caregiver burden and 30% (40/135) reported moderate caregiver burden. Age, gender and knowledge of chronic HF were not related to caregiverburden. Poor mental and physical health of p't and a low	The early post-discharge time was not clear. Sample size is small.

357

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
			analysis to determine independent predictors of caregiver burden.		perceived control in partners predicted a high caregiver burden	
Brännström, Ekman, Boman, and Strandberg (2007) Sweden	To illuminate meanings of being a close relative of a person with severe, chronic heart failure (CHF) in palliative advanced home care (PAHC).	One couple were interviewed over a 4.5 years time, they were in their 70 and had experience of palliative advanced home care (PAHC) ranging around 2 years. 26 interviews were conducted at 3-5 months intervals over a 4.5 years. Wife cared for her husband	Narrative interviews were tape-recorded, transcribed verbatim and a phenomenological-hermeneutic method (qualitative) was used to interpret the text.	phenomenological-hermeneutic method	Theme: integrating the unpredictable illness into life, enduring suffering and enjoying life Sub-theme: 1. living life as it has become 2. adapting to versus struggling against fatigue 3.learning to take the good with the bad:striving to keep a check on the failing heart 4.finding meaning in togetherness with the spouse, others and God	This research provided a better understanding of the experiences of the couple. It represented the long term perspective of both carers and patient. This might only provided partial understanding of carers perspective in a long term basis.
Bull, Hansen, and Gross (2000) USA	To determine whether there is a difference between elder and family member satisfaction with discharge planning 2 weeks and 2 months after hospitalization and what	The sample consisted of 130 elders hospitalized with heart failure/family caregiver dyads. Elders ranged in age from 55 to 94 years with a mean of 72.9 years. Caregivers ranged in age from 26 to 86, with a mean age of 59.3 years	Questionnaires interviewing by telephone interviews with family caregivers 2 weeks and 2 months after hospitalization. Descriptive statistics were obtained on all variables. t-tests Regression analyses A correlation matrix of satisfaction scores and all possible predictors of satisfaction was created. The	Professional-patient partnership model of discharge planning Discharge planning satisfaction The assimilation-contrast model Perceptions of care continuity and	46.2% (n=60) of caregivers reported little involvement with the discharge planning and they felt little prepared for taking on the caregiving role。。family caregivers who involved in discharge planning had a better scores on general health.	This research provide a basic understanding of family's involvement in discharge planning. However, it was unclear how these families were involved and when.

358

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
	factors predict satisfaction with discharge planning 2 weeks and 2 months after hospitalization for elders hospitalized with heart failure and their family caregivers.		correlation matrix was examined and variables were entered in a hierarchical regression and clustered according to the conceptual model and the literature reviewed.	preparedness		
Canning, Dew, and Davidson (1996)

USA | To test the hypothesis that family caregivers to heart transplant recipients may experience higher than average levels of distress during the period post-transplant and explore the correlates of distress. | The primary family caregiver to each of 83 heart transplant recipients were interviewed on three occasions during the first year post-transplant. Data is available from 83 caregivers at time 1(2 months), 72 of those caregivers at time 2 (7 months), and 65 at time 3 (12 months). Caregivers ranged in age from 18 to 62 and recipients from 24 to 60 years of age. Caregivers were predominantly women and married. | Quantitative Repeated measures analysis of variance was used to examine the temporal pattern of symptom change during the study period for those caregivers with complete data at all three time points. Next, linear multiple regression analysis was used to examine the unique effects of predictors in each of the three predictor domains on caregivers' subsequent distress over the first post-transplant year. In order to reduce the likelihood of overfitting, given the sample size, the regression analyses were performed in two steps. Then, to compare the relative contributions of predictors across domains, the identified predictors were entered into a | Psychological distress Caregiving Burden Predictors | 1.employment status and caregivers' physical health were strong predictors of post-transplant distress while psychiatric history was not; 2. the burden of caregiving was associated with increased distress early post-transplant but not in later months; 3. intrapersonal and social support resources early post-transplant were associated with distress both short-term and long-term. 4. caregivers felt | The study support their hypothesis in the early stage and the distress decreased at month 7 and 12. it was unclear that how early the social; support resources should be provided. |

359

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
			single final regression model constructed for each time point.		more distress at months 2 and decreased to near normal during months 7 and 12.	
Davies (2000) UK	To examine the congruence between patients' and relatives' perceptions of recovery following cardiac surgery one week after Hospital discharge and six weeks later.	Of the 86 patients recruited to the study, 41 were sent questionnaires 1-week post-discharge and 45 at 6 weeks post-discharge. Thirty-three patients approached at 1 week responded (80á5%) and 27 (60%) at 6 weeks. Questionnaires were returned by all carers except for one patient followed-up at 6 weeks. The age range of the patients was wide: 18±75 years. However, most of the patients were in their 60s with the mean age being 62 years. Most were male and had undergone coronary artery bypass graft (CABG). The main carer was usually the patient's partner (n=47, 80%). The remainder were children (n=7, 12%) or friends (n=5, 8%). Most carers	A descriptive survey (mixed design) Patients were sent two questionnaires: one for self-completion, the second to be completed by their main carer. Numerical data were keyed into the computer and analysed using the Statistical Package for the Social Sciences. The Likert scales and HADS were analysed using the appropriate non-parametric tests (Spearman's rank correlation coefficient, the Mann-Whitney U-test and the Kruskal Wallis one-way analysis of variance by ranks) The patients' and carers' responses to the open-ended questions were analysed by content analysis	Discharge planning Informal carers Communication Satisfaction Anxiety Depression Discharge	Anxiety and depression experienced by patients and carers Association between perceived adequacy of information / advice provided by hospital staff is essential and it could reduce anxiety and depression scores	This research showed the carers and patients had higher anxiety and experienced depression following week 1 and 6. Information was the most important things that gamily mentioned in this study. However, it was unclear what information they received and how they deal with the immediate discharge patients and what they experienced at home.

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
		were female (n=43, 73%).				
Dew et al. (2004) USA	To understand the Quality of life (QOL) between patient and caregivers	Heart recipients (intervention group n=24 and comparison group n=40: male) and family caregivers (intervention group n=20 and comparison group n=40: female) the age of both group were less than 55 years old.	Mixed A prospective study based on focus group work and previous research A multifaceted web-based intervention was developed with stress and medical regimen management workshops; monitored discussion groups; access to electronic communication with the transplant team; and information on transplant-related health issues. Data collection: interviews, ratings Descriptive information was examined regarding website accessibility and user opinions. Differences between patients and caregivers were evaluated via Mc-Nemar's chi-square statistics for paired proportions. Analysis of variance (ANOVA) was used to examine patient and caregiver changes in continuous variables. Medical compliance was similarly tested using chi-square tests of proportions.	Quality of life (QOL) Patients' depressive and anxiety symptoms Caregivers' anxiety and hostility symptoms Psychiatric symptom levels Mental health The first empirical evaluation of an internet-based psychosocial intervention for heart recipients and their families.	Caregivers and patients who used the web-based intervention had a better QOL and their mental health were better. It also reduced the anxiety of the caregivers and the patients.	The web-based intervention provided a better follow-up care in carer and patient at home. However, not all carers and patients had this ability to access the internet. The age groups in this study were younger than the other study.

361

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
Dougherty and Thompson (2009) USA	To describe the physical and mental health of the intimate partners of persons receiving <u>an implantable cardioverter defibrillator (ICD)</u>	The intimate partners were 60.96 +- 12.87 years of age, 82% female.	<u>Quantitative</u> A prospective longitudinal repeated measures design was used, with data collected at hospital discharge, and at 1, 3, 6, and 12 months after implantation. Questionnaires, interviews Patterns of response across study variables for the group by time were identified using descriptive statistics, plots, and Pearson product–moment correlations. Analysis of variance with repeated measures (ANOVA) was used to examine patterns of change in responses across time from baseline through the 12-month measures.	Caregiver burden Intimate partners' physical health, symptoms, and depression Caregiving demands Anxiety Psychological adjustment. Healthcare utilization Relationship impact	1.Intimate partners' physical health, symptoms, and depression significantly declined over the first year. Although anxiety was significantly reduced over time, it remained elevated in partners after 1 year. 2. The impact of implantation of the ICD on the intimate relationship and care demands was most dramatic at hospital discharge. 3.Health care use was low throughout the year.	The partner's mental health improved over time and the physical health decrease over time. It pointed out that the partner's reported their physical score were slightly higher than those who with chronic illness. It was unclear that the tense and the quality of burden during the first three months were similar with those who with chronic illness or not.
Halm, Treat-Jacobson, Lindquist, and Savik (2007) USA	To investigate patient-spouse caregiver relationship and role variables associated with caregiver burden during the first year after <u>coronary artery bypass (CAB) surgery.</u>	Spouses (n = 166) The majority of spouses were elderly (mean age = 64.7 years), women (81.9%), Caucasian (98.8%), college-educated (59%), retired (51.2%), and married over 30 years (72.9%). Similarly, CAB patients were elderly (mean age = 66.8 years) but male (81.9%).	<u>Quantitative</u> A cross-sectional descriptive comparative design Survey Data were entered and analyzed using SPSS Version 11. After the data were analyzed for normality, descriptive statistics were used to summarize sample characteristics. A correlation matrix was then developed between total caregiver	Caregiver burden Caregiver's quality of life (HRQL) Personal gain Caregiver competence	1.Total, objective, and subjective burden levels were low to moderate. 2.Although no burden differences were found between groups, men had higher total burden but more positive caregiving outcomes.	Burden levels were not lower, nor were caregiving outcomes higher, in the 12-month group, suggesting a steady caregiving demand across the first year after coronary artery bypass graft surgery. It was unclear that why the carers future outlook

362

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
			burden as the dependent variable and the independent variables identified in the conceptual model at 3, 6, and 12 months, and was then examined for significance.		3. Future outlook and social activities were less positive in the 6-month group.	were low at month 6.
Hunt, Hendrata, and Myles (2000) Australia	To assess the relationship between preoperative risk factors, postoperative chronic pain, sleep, and gender on perceptions of quality of life (QoL) in patients 12 months after surgery.	The 123 coronary artery bypass graft (CABG) surgery patients (mean age = 64 years) were followed up to 12 months. The patient's spouse or next of kin (NoK) was asked questions about their perception of change in the patient's QoL.	Quantitative A cross-sectional comparative study Results were assessed using The Medical Outcome Study Short Form–36 (SF-36) questionnaire and additional questions given at 12 months after CABG surgery. The Cleveland Clinic Clinical Severity Score (CSS) was used preoperatively as a tool to predict QoL outcome. Data were analyzed using SPSS V8.0.	Quality of life	1.Significant improvements in QoL were seen in physical functioning, bodily pain, social functioning, and role limitations resulting from emotional status. 2.Other significant associations were found between poor QoL and patients who reported severe pain or poor quality sleep. 3. Alteration in QoL was reported equally by patients and their spouses or NoK. 4.Short-term memory impairment was reported by 41% of spouses or NoK.	During the early stage of recovery, the patients might experience physical uncomfortable needing help from the spouses and NoK.
King and Koop (1999)	To examine the characteristics of the informal	Patients' expected postoperative care-givers (n=60)	Mixed A prospective, non-randomized design	Care-giving	1. The burden of care-giving continues to rest	This study examined the caregiving received

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
Canada	care-givers of cardiac surgery patients from three hospitals and the effect of patient characteristics (sex, age) on their experience of receiving that care.	A sample of 120 patients (60 males and 60 females)	Patients were interviewed preoperatively and then at monthly intervals through the third postoperative month. Data were primarily categorical (nominal) and qualitative in nature. Descriptive analysis of numerical data was undertaken, as well as the appropriate parametric (ANOVA) and non-parametric (chi-square) analysis to make comparisons between the sex and age groups of the patients and to assess changes over time. Content analysis of the qualitative data rendered identification of response categories.		predominantly on women. Female patients relied on their spouses for help less frequently than did male patients and their care-givers were more frequently employed outside the home 2. 30% of care-givers were reported to have a health problem of their own to manage while caring for the recovering patient.	by patients.
Kneeshaw, Considine, and Jennings (1999) USA	To identify caregivers' feelings of mutuality and reported preparedness for caregiving at hospital discharge and to examine the relationship between these measures and the recovery outcomes of elderly women after coronary	A sample of 49 dyads Forty-nine elderly women completed the study. Their ages ranged from 65 to 87 years, with a mean age of 72.6 years. The primary caregiver for the majority of the elderly women was a daughter (n = 28, 57.2%). However, 10 (20.4%) primary caregivers were husbands, 6 (12.3%) were sons, and 2 (4.1%) were nieces. The ages of	<u>Quantitative</u> A descriptive correlational study design Interviews Questionnaires Regression analyses	Mutuality and preparedness for caregiving	1.A significant decrease between the MS means at hospital discharge and at 3 months 2.the carers felt they were not prepared for their caregiving roles 3. The primary caregivers' PCS scores were high, but 24 caregivers had concerns about fulfilling their role. 4. the findings	Caregiving during recovery after CABG surgery can be complicated. In this study, it was not clear how these caregivers experienced their lives during the early stage of the recovery.

Author/year /Country	Purpose/resea rch questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
	artery bypass graft (CABG) surgery	the primary caregivers ranged from 28 to 80 years, with a mean age of 50.1 years. The majority were female, married, and working outside the home.			showed a negative relationship between the caregiver's state of health and preparedness that was significant	
Knoll and Johnson (2000) Canada	To increase understanding of the experience of being a family member caring for a patient who has undergone cardiac surgery and who has been discharged early from the hospital. The objectives of the study were to describe and interpret the experience of taking on the caregiving role and to identify the effect on family members.	The participants ranged in age from 58 to 80 years; six of the participants were female, two male, and all were part of a husband or wife dyad. Five primary carers (8 days following discharge) and three secondary carers (one year following discharge).	Qualitative Interpretive Description In-depth interview using content analysis	Interpretive Description	1.the process of caregiving at home a) vigilance and monitoring, b)keeping things on track, c) seeking help and support 2. the effect of caregiving a) Being stressed and tired b) A sense of vulnerability c) Putting life on hold	A model showed the participants lived experiences was apparent. However, it was unclear that how this experience change over time.
Lenz and Perkins (2000)	To examine the effectiveness of a psychoeducati	The sample was comprised of 38 coronary artery bypass graft (CABG) surgery patient-	Quantitative Experimental study Pre-test/post-test control group design	No	1. Family caregivers reported more depressive symptoms than	It was unclear that why family felt more depressed at the later stage of

365

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
USA	onal intervention delivered over 12 weeks.	family member caregiver dyads who completed all six data collection points.	Analysis of variance		patients preoperatively and at later stages of recovery. 2. Experimental and control groups did not differ in emotional health, functional health status, or satisfaction.	recovery.
Leske and Pelczynski (1999) USA	To examine caregiver satisfaction with preparation for discharge in a decreased length of stay cardiac surgery program.	A convenience sample of 289 patients and caregivers participated in the telephone survey. The article reports data obtained from caregivers (*N* = 53) of cardiac surgery patients discharged on postoperative day 4 or 5.	Quantitative A descriptive, retrospective design was used with existing data collected from telephone surveys of patients Descriptive statistics	Preparation for discharge	1. the majority of caregivers preferred earlier discharge but did not feel prepared for the responsibility of patient care	Most carers preferred early discharged but they did not feel prepared. It was unclear that how these carers were involved in the discharge planning.
Mohan, Wilkes, and Jackson (2006-2007) Australia	A part of a larger study that explored the experiences and/or understanding of coronary heart disease in Asian Indians from the perspective of patients, family	The 5 family members of Asian Indians who had experienced a cardiac episode/ event took part in the study. a minimum time frame of six months would have elapsed after the cardiac episode, to enable them participate in the study	Qualitative Using a constructivist approach semi-structured in-depth interviews were conducted	Not clear	Findings are represented under the following main categories: 1.A period of complexity for family members; 2.Indian culture: Its influence on health/health behaviour and illness experience; 3.Impact of	This could research provided he carers from different culture perspective of cardiac surgery patients in an foreign country. It indicated that the culture different might impacted on the patient's care and the carers burden.

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
	members and 'healthy' participants.				migration and societal discrimination; 4.Disappointment with health care services and the health system; and 5.Strategies to prevent cardiac illness and attain optimal health.	
Molloy et al. (2008)

UK | To extend previous work using the D–C model of job strain to predict caregiver burden and satisfaction in the informal caregivers of patients with heart failure. | 60 caregiver/patient (congestive heart failure (CHF)) dyads | Quantitative A cross-sectional design | Caregiver burden Demand –Control model | 1.Higher caregiving demand was not associated with higher caregiver burden and Lower control is associated with significantly higher levels of caregiver burden. 2. There were no significant bivariate associations between demand and control and caregiver satisfaction.. | The D–C model may have some potential in understanding health outcomes in informal caregiving, however, However both of these studies exclusively used self-report measures of demand and control to predict generic health outcomes. Therefore further replication of these effects in different caregiving populations using different methods of measurement would go some way towards clarifying whether the D–C |

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
						model should receive further attention in relation to understanding the health effects of providing informal caregiving and whether main or interactive effects of demand and/or control best explain caregiver health outcomes.
Naylor and McCauley (1999)

USA | to understand knowledge development and linical practice during the past decade resulting from testing and refining of the transitional care model with hospitalized elders. | 202 patients hospitalized with common medical or surgical cardiac conditions who completed a 24-week postdischarge follow-up program as part of a large-scale randomized clinical trial. Subjects were age 65 years or older, admitted from their homes with one of the following diagnosis-related groups: heart failure, angina, myocardial infarction, coronary artery bypass graft surgery, or cardiac valve replacement. | Quantitative
The intervention consisted of comprehensive discharge planning and home follow-up by an advanced practice nurse (APN) for 4 weeks after discharge. Control subjects received usual care.

Surveys
Interviews
Statistical analysis | Discharge planning | A comprehensive discharge planning and home follow-up intervention decreased hospital admissions in both medical and surgical cardiac patients compared with usual care. | A good discharge planning was not only benefits to carers but as well as patients. |
| O'Farrell, Murray, and Hotz (2000) | To identify common sources of distress in spouses of | 213 female spouses (mean age 53.3 ± 10.2) of patients undergoing cardiac rehabilitation participated in this study. | Quantitative

A cross-sectional analysis

Unpaired t tests compared | distress | Symptoms of psychologic distress: feeling tense, having trouble falling | Many spouses of patients undergoing CR experience psychologic distress and report |

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
Canada	patients undergoing <u>cardiac rehabilitation</u> and to compare spouses classified as being in distress and those classified as non-distressed on demographic variables, their experiences of stress, coping strategies employed, marital intimacy, and level of family functioning.	Sixty-six percent of the spouses met the criteria for distress.	distressed and non-distressed groups on standardized scores (T scores) on heart disease hassles, coping strategies, marital intimacy, and level of family functioning. As response options differed among scales, scores were standardized to enable differences between scales to be meaningfully compared on the same metric. Chi-square analysis was used to compare categorical variables.		asleep and feeling easily hurt. Stressors: (1) worries about treatment, recovery, and prognosis; (2) moodiness of the patient; (3) worries about the patient returning to work and about money; (4) sexual concerns; and (5) helplessness or apathy on the part of the patient and increased spousal responsibility.	numerous stressors related to living with a partner with heart disease. Additional studies are needed to test the effect of counseling on spousal distress levels and how this affects their ability to cope and to provide support to the patient. It would
Phillips et al. (2009) UK	To examined the relationship between the strain and burden of caregiving and depression and anxiety in a large community sample. Social support and sleep quality	393 caregivers Members of the youngest cohort were all aged around 24-years-old, the middle cohort were all around 44-years-old, and members of the older cohort were all around 63-years-old at the third contact with respondents (1995/1996).	<u>Quantitative</u> Cross-sectional and prospective observational study	Caregiver burden	Caregiving strain and burden were associated with depression and anxiety symptoms cross-sectionally, and with a worsening of symptoms 5 years later The demands of caregiving and associated sleep	both the independent and dependent variables are self-report measures; some caregivers may simply report more strain, burden, and depression than others.

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
	were investigated as potential mediators.				disruption contribute to symptoms of depression and anxiety in caregivers.	
Proctor, Morrow-Howell, and Kaplan (1996) USA	This study addressed the extent to which discharge plans for elderly patients with <u>congestive heart failure</u> were implemented as planned, tested the consequences of implementation problems, and identified factors associated with implementation problems.	Data are reported on the implementation status of discharge plans of 205 patients (mean age 77.51 years old.) with 16 months	<u>Quantitative</u> This prospective study documented discharge plans and then followed patients to determine the extent to which expected or arranged care was in fact implemented. structured interview by telephone	Discharge planning Adequacy of care Home health care Informal care	1.40% of patients, one or more components of the discharge plan were not implemented as planned 2. Implementation discrepancies had negative consequences in terms of unmet needs, deficient quantity of help, and less than adequate care. 3. These reflect instances in which the social worker anticipated no services but the patient reported a need for assistance and the receipt of assistance at two weeks postdischarge.	1. Gaps between planned and actual informal care reflected the failure of family and friends to provide the care expected or anticipated by the hospital social worker. 2. Rarely does the acute care environment allow time for professionals to work with families to plan long-term care. In what is often "crisis" or immediate planning, families often overestimate their capacities for caregiving, especially if they are new caregivers and if there is a strong desire for the patient to return home.
Rantanen, Kaunonen, Åstedt-Kurki,	To describe social support for <u>bypass</u>	Questionnaires were mailed to 146 subjects and 103 responded. The	<u>Quantitative</u> A descriptive study using a questionnaire	social support Caregiving	1. the spouse, children and friends were the major	The low level of support reported by significant others

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
and Tarkka (2004) Finland	surgery patients and their significant others from the social network and nurses during hospitalization and the association between demographic variables and support received from nurses.	final sample numbered 100, with 53 patients and 47 significant others. The majority of respondents was men (70%), whereas the majority of significant others was women (70%).	Descriptive statistics were used to examine the demographic data. The social network of the patients and significant others was described using frequencies and percentages. Mean values were used to describe the sum variables of social support received from the social network and nurses. The relationship of the background variables with social support from nurses was analysed using t-test and ANOVA. The different types of social support for patients and significant others from the social network and nurses were examined using t-test.		sources of support for patients and significant others 2. significant others reported the highest level of affect and the lowest level of affirmation from the social network	may be explained by the fact that they do not have the opportunity to discuss with staff when visiting the patient or do not want to disturb staff with their questions. It is also possible that significant others are fearful or nervous of the situation, which makes it difficult for them to ask questions or accept the support offered by nurses. It was not clear in this study.
Rantanen et al. (2008) Finland	To describe and compare the health-related quality of life of patients and their significant others and to identify factors associated with health-related quality of life one month after coronary	270 patients and 240 significant others	Quantitative The questionnaire data for the study were collected one month after the surgical procedure. Data analysis was by descriptive and inferential statistics. Stepwise linear regression analysis was used as a multivariate method.	health-related quality of life	1.Patients had a lower HRQoL than significant others in I month after CABG. 2. Significant others who had no chronic diseases had a better HRQoL than those who did have chronic diseases.	The generalizability of its results is affected by the sampling method whereby all patients and their significant others admitted to 1 hospital during a certain period of time were selected if they met the sampling criteria. The reasons for

371

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
	artery bypass surgery					nonresponse by patients and significant others are not known. it does not know how many of the patients or significant others possibly died during data collection.
Rantanen et al. (2009)

Finland | To describe and compare the health-related quality of life (HRQoL) and to identify factors associated with HRQoL after coronary artery bypass grafting (CABG). | Patients (N=367) and significant others (N=367) | Quantitative
HRQoL was measured 1, 6, and 12 months after CABG. The focus in this study is on HRQoL at the second (6 months) and third (12 months) stages of the recovery process. Stepwise linear regression analysis was used to identify the associations of independent variables with HRQoL. | health-related quality of life | 1.Patients' and their significant others' health-related quality of life was at its lowest one month after the operation and improved during follow-up 2. none of the background variables used in the study or social support were associated with change in HRQoL | The sample for this study consisted of patients and significant others recruited from one university hospital in Finland, which limits the generalizability of the results. No background data were collected on the significant others who did not reply and therefore nonresponse analysis was not possible. The reasons for nonresponse are not known for all those who declined to participate. It is not known exactly how many respondents died during the follow-up, which |

372

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
						might have affected the results. The scales used to measure social support were specially designed for this study and require further testing.
Saunders (2009) USA		50 caregivers of older patients living with heart failure (HF)	Quantitative A cross-sectional, correlational design A correlation matrix was constructed using SPSS v. 11.5	Caregiver depressive symptoms Caregiver burden Health-related quality of life (HRQL)	1.increased burden in the dimensions of family support, finances, schedule, and health to be associated with decreased HRQL. 2.caregivers who had low self-esteem related to caregiving had decreased HRQL 3. caregivers with lower HRQL felt more depressed These caregivers also reported higher numbers of medical illnesses 4. Lower caregiver HRQL was not associated with increased levels of caregiver perceived patient disease severity	A nonrandom sample, cross-sectional design, small sample size, and self-report data were other limitations to the study.
Scott (2000)	To examines	20 end-stage heart failure	Quantitative	Caregiver burden	1. the caregivers	1.The number of

Author/year /Country	Purpose/resea rch questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
USA	the variation in HRQOL among HF patients receiving community-based inotropic infusions and among their family caregivers.	patients receiving community-based inotropic infusions and their 18 family Caregivers	A descriptive, exploratory research design Questionnaires	Health-related quality of life (HRQL)	reported that they were somewhat prepared for the role. The caregivers perceived that they were more prepared to access resources (M 3.39), obtain services (M= 3.29), and provide physical care (M 3.00) than they were to handle emergencies (M 2.94) and psychosocial issues (M 2.67). 2. The majority of the participants felt positive about their role as caregiver. Yet the caregivers experienced negative aspects of providing care in other areas, particularly affecting their daily schedule, health, and finances. 3. the caregivers reported perceptions of	participants remained low. Generalizability would be facilitated with a larger, random sample 2. The focus of the QLI is on satisfaction and importance of various aspects of life; it does not contain items pertaining to personhood or the meaning of life.

Author/year /Country	Purpose/research questions	Sample	Design/ Data Collection Methods	Framework/ concepts Used	Findings and results	Comments
					higher HRQOL The caregivers expressed moderate dissatisfaction in their employment status and travel restrictions. Furthermore, the caregivers were dissatisfied with lifestyle changes and the stress associated with caregiving.	
Tsukasaki et al. (2006)

Japan | To examine the impact of sleep interruptions on daily changes in blood pressure and chronic fatigue in middle-aged and elderly caregivers. | 35 female caregivers who were not taking antihypertensive and/or sleeping drugs | <u>Quantitative</u> Face-to-face interview Questionnaires Observation | Caregiver burden and caregiver health | 1.Caregivers who provided care at night suffered from a general sense of fatigue, physical disorders, and reduced mental energy compared with employed women 2. Caregivers without sleep interruption had the worst score for chronic fatigue | The use of an actigraph to measure sleep status among caregivers is still rare. In this study, the participants were asked to select a day that could be expected to be a typical caregiving day. No attempt was made to verify if the day was representative of caregiving days. |

Appendix XI An audit trail showing the links between the raw data and the development of themes and sub-themes

At the end of each data collection point, the researcher drew themes and sub-themes into the various phases which reflect the carer's experience during that time period. On further analysis, it was observed that three sub-themes -'Changing Nature of Relationship', 'Reassurance' and 'Being There' appeared in all of the three phases and they are consistent fixture at each phase and so they were labelled as being overarching themes This consistency needed to be captured as an essential part of the essence of the participant's experience. At this point, therefore, the researcher decided to place them at the top of the diagram in order to demonstrate their importance in this analysis. The sense of change for the short term care of carers was moving from a person to a carer and return to a person. The final representation of the developing diagram is shown on the following pages. A detailed audit trail maps are shown the links between the raw data and the development of themes and sub-themes in the following pages.
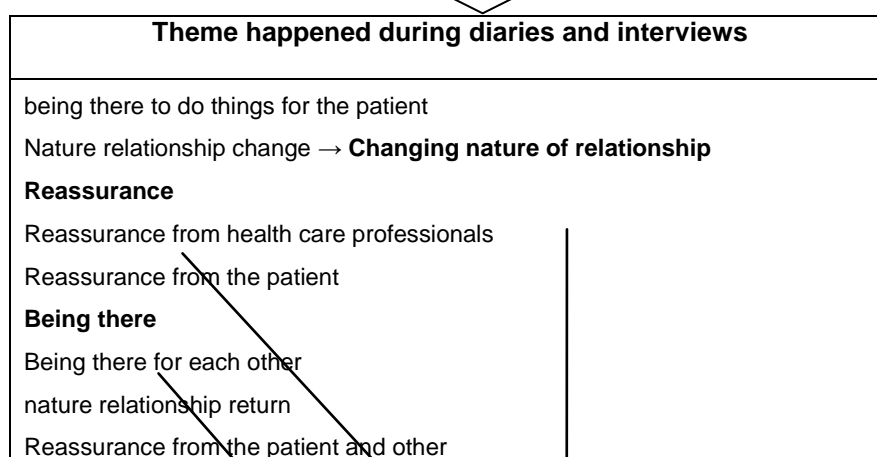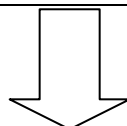
An audit trail showing the link between the raw data and the development of themes and sub-themes

Participant's Diaries	Themes and sub-themes
Joey is normally very independent; so unlike some men can exist efficiently on his own as regards *household duties- **washing, ironing, shopping, cooking. These were duties we shared (and will again of course) but meanwhile Joey is edgy and depressed that I'm doing all those things without his having an input.***	More responsibility(being there to do things for the patient)
Normally, I don't help Joey with ***personal hygiene, washing etc nor do I take the lead in arranging for friends/family to visit*** but at present I feel protective and want to regulate times and length of visits.	More responsibility
The experience that I've been through has been quite ***mentally and physically tiring** – the effort to strike a balance between being helpful / supportive and yet not being felt to attack the patient's independence is trying.*	Physical and psychological tired Finding a balance
Well, because I've been doing everything. I've been more like a carer who's become no man and wife - carer and somebody.	Nature relationship change Physical and psychological tired
I started off alright but as the week went on ***I got more uptight and worried.***	reassurance
I felt I was hurting him when I put his stockings on because ***I didn't know how to do it without hurting him I needed reassurance.***	Do not know what to do (no yard stick of knowing)
JD's phone call. It turned out that he wanted to know what information I wanted. I pointed out that ***nobody had spoken to me about practical support I could have or about what aids could be possible such as an in-bath seat for my husband's showers or help in getting him home***, especially at such short notice. I pointed out that ***I had nobody at home to help me out.***	No help
However it was later retracted . JD said that it might be easier to do through our GP because he'd need to ***go through an assessment procedure before it could be lent.*** All in all, ***no help at all***.	Carer was left on her own No assessment has been made No help at all Hospital-community gap
She (The nurse) says that the ***chest wound is a bit inflamed and is surprised that the hospital haven't given him antibiotics to cure this. I'm then shocked to find out that he should have been sent home with a 7-day supply of dressings for the nurse to use***. Collapse exhausted in front of the TV	Hospital-community gap Physical and psychological tired Reassurance from health care professionals
Our ***cardiac rehabilitation nurse visited*** on Wednesday and her grasp of the situation and frank speaking practical and kindly was salutary for the patient Moria to call next Wednesday and ***I look forward to seeing her again.***	
The cardiac nurses are available and needed-otherwise no extra help needed.	Feel in the dark, not knowing.
Not knowing what was happening made me feel in the dark.	Fear, not know what to do, going in the dark
That was the one thing I felt I never expected anything to go wrong. You know, and when it did I was in the dark about it.	

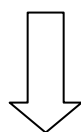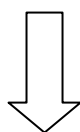| Interview 1 from participants	Theme and sub-theme
When he first came home the first two or three weeks it was like nursing a patient. Yes he wasn't well enough to you know to cope by himself. *It was like being a nurse.*	Nursing a patient Nature relationship change
Well no, no a few weeks after - they didn't say exactly how long after it was and they seemed to get on smashing but My wife's struggling to walk. She's only been out the house I would say four or five times in the two months.	Continuing to care and support his wife
We just had to get on with it.	Get on with it
So apart as I say from, I mean *he was able to shave and he showered,* I was there, *he went in and he showered and I stood and I waited with the towel until he came out* **and I was quite happy then you see but other than that I just, I'm just trying to think of what were, I mean** *he was dressing himself and doing everything,* **I had the cushion on the chair raised and he was managing, I had a cushion for him you know to help him get up and down.**	Less responsibility than first three weeks (relationship still the same as before)
a lot better because *I saw him for myself I saw him getting better and he would say he feels better.* **I think there's no more reassurance than him telling me himself**	Reassurance from the patient
he does his walking but I don't let him do anything **about the house just now till I know he's**	Still doing lots of works (playing more roles)
I coped with it myself. *I got on.* **I had support of friends and my son and daughter - support in that they came to see us and they rang to see how he was, frequently.**	Get on with it Support from friends and families
We ***supported each other***. Definitely. *I'm always there.* **I'd always be here (for him).**	Support each other Being there
Well, eventually I was *getting into a routine.* **I wasn't so worried.**	Getting on with a routine
We did support each other **because My husband was positive and he didn't, moan and groan. He didn't try to make me feel bad.**	Continuing support from each other
It's funny I had, and that's maybe why *I see my sister as an extension as another child* **- because I was probably comparing it with when I was helping my daughter when she had her operations but it was testing, testing it was a testing experience but not a great extent not something I'd ever thought that I'd have to cope with.**	Nature relationship change
I mean my time was for him and whatever it took really, because he would obviously do - well he was the same for me.	Being there

378

Interview 2 from participants	Theme and sub-theme
I just feel very happy. And I just feel that **my life is back to normal,** how it used to be. My husband has done really, really well and it's just like it never happened. You know it's like something that, I mean I haven't forgotten about it, I don't think you can ever forget about it but **our life is just returning back to normal**.	Back to normal (nature relationship return)
He's not having to go back into hospital. He's doing alright.	Reassurance from the patient
I meant that **we're more honest than we had been before**. Frank is maybe a better word because Joey was thinking what he thought and I was thinking what I thought and we were both worried and we weren't telling each other, but now you can't go on like that. You've got to say, I really am worried Joey. I wish you would talk to me about this.	More honest now
It changes quite quickly, you know - it hasn't been drastic but I think what we both **look forward to**, both of us, is getting out a bit more when, you know going out for a nice meal maybe one evening or going to the cinema, something like that. Not just being in the house so much as we have been over the past.	Look forward to the future life
That was a little episode in our lives that while you don't forget about it, you can put it there now and leave it. Let's get on now. **We're looking forward** we're not looking back to what has happened. **We're now looking forward to what can we do now and enjoying life.**	Looking forward to life
I would say that now we have more or less reverted to our normal natural way of living	Back to normal life
I would rather look forward and I think I would always try and **encourage my sister to look forward** as well rather than look back because if you look back at the last year and you think oh that was horrible, and it was, it was beastly and then you start thinking - oh poor me and you know you don't want to do that..	Looking forward to future
We'll be able to do a lot more together whereas I used to do a lot of things on my own you know that he didn't do.	Being there for each other
But against that there was my husband's recovery where it was finite and it was getting better and **I could see an end** to that so I could give all my energies to doing what had to be done for a recovery and for me the fact that it was finite was helpful because I knew it wasn't going to be forever.	Back to normal

Diaries themes and sub-theme (first 3 weeks)	Diary + interview 1 themes and sub-theme (6 weeks)	Interview 2 themes and sub-theme (12 weeks)
More responsibility(**being there to do things for the patient**)	Nursing a patient (in the first two to three weeks)	Back to normal (**nature relationship return**)
More responsibility	**Nature relationship change**	More honest now
Physical and psychological tired	Continuing to care and support his wife	**Reassurance from the patient and others**
Finding a balance	Get on with it	
Nature relationship change	Less responsibility than first three weeks (relationship still the same as before)	Look forward to the future life
Physical and psychological tired		Looking forward to life
reassurance	**Reassurance from the patient**	Back to normal life
Do not know what to do (no yard stick of knowing)	Still doing lots of works (playing more roles)	Looking forward to future
No help	Get on with it	**Being there for each other**
Carer was left on her own	Support from friends and families	
No assessment has been made	Being there	
No help at all	Getting on with a routine	
Hospital-community gap	Continuing support from each other	
Hospital-community gap	Nature relationship change	
Physical and psychological tired	**Being there**	
Reassurance from health care professionals		
Feel in the dark, not knowing.		
Fea**r**, not know what to do, going in the dark		

Theme happened during diaries and interviews

being there to do things for the patient

Nature relationship change → **Changing nature of relationship**

Reassurance

Reassurance from health care professionals

Reassurance from the patient

Being there

Being there for each other

nature relationship return

Reassurance from the patient and other

The three themes happened over the three months time could be three **overarching themes**

380

Diaries themes and sub-theme	Diary + interview 1 themes and sub-theme	Interview 2 themes and sub-theme
More responsibility	Continuing to care and support his wife	Back to normal
Physical and psychological tired	Get on with it	More honest now
Finding a balance	Less responsibility than first three weeks (relationship still the same as before)	Look forward to the future life
Physical and psychological tired		Looking forward to life
Do not know what to do (no yard stick of knowing)	Still doing lots of works (playing more roles)	Back to normal life
No help	Get on with it	Looking forward to future
Carer was left on her own	Support from friends and families	
No assessment has been made	Being there	
No help at all	Getting on with a routine	
Hospital-community gap	Continuing support from each other	
Hospital-community gap	Nature relationship change	
Physical and psychological tired		
Feel in the dark, not knowing.		
Fear, not knowing what to do, going in the dark		
Nursing a patient (in the first two to three weeks)		

In the dark (theme)	Get on with it (theme)	Looking forward to future (theme)
Sub-themes	**Sub-themes**	**Sub-themes**
• Do not know what to do (no yard stick of knowing)	• Less responsibility than first three weeks	• Back to normal
• Carer was left on her own	• Continuing to care and support his wife (the patient)	• More honest now
• Nursing a patient	• Continuing support from each other	• Back to normal life
• More responsibility (playing more roles)	• More responsibility (playing more roles)	
• Physical and psychological tired (fear)	• Support from friends and families	
• Hospital-community gap		
• No help at all		
• No assessment has been made		
• not knowing what to do		

Phase I: data collected from Diary and interview

Walking in the dark

- **Nursing the patient**
- **Playing multiple roles**
- **Finding a balance**
- **No yardstick for knowing**
- **Hospital to community care gap**
- **Psychological and physical tiredness**
- **Changing nature of relationship**
- **Reassurance**
- **Being there**

Phase II: data collected from interview 2

Getting on with it

- **Continuing care**
- **Still playing multiples roles**
- **Continuing support**
- **Changing nature of relationship**
- **Reassurance**
- **Being there**

Phase III: data collected from interview 3

Looking forward to the future

- **More honest now**
- **Being back to normal life**
- **Changing nature of relationship**
- **Reassurance**

Over a three month period

Diagrammatic Representation of the Experience of Caring

- **Changing nature of relationship**
- **Reassurance**
- **Being there**

Phase I

Walking in the dark

- **Nursing the patient**
- **Playing multiple roles**
- **Finding a balance**
- **No yardstick for knowing**
- **Hospital to community care gap**
- **Psychological and physical tiredness**

- **Changing nature of relationship**
- **Reassurance**
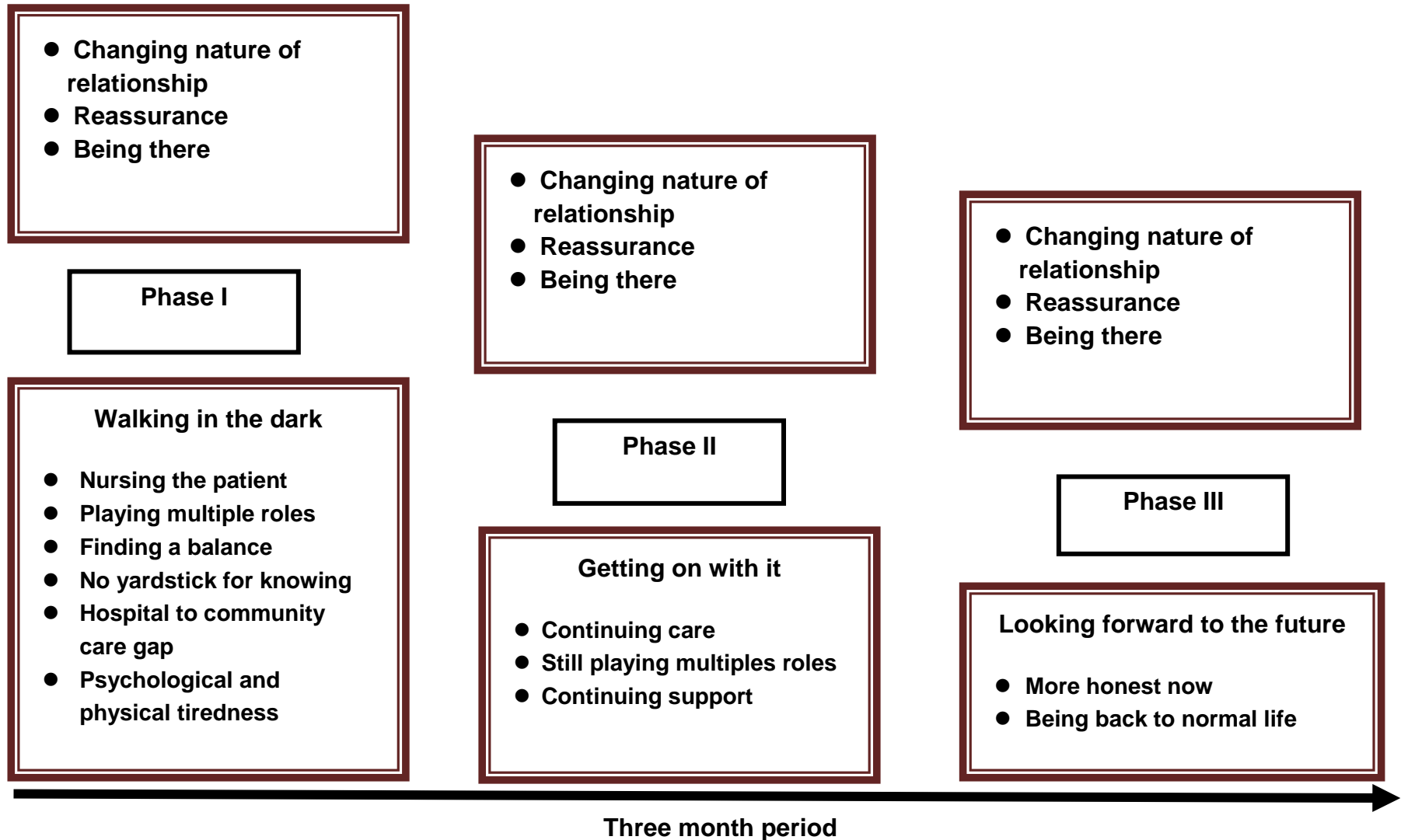- **Being there**

Phase II

Getting on with it

- **Continuing care**
- **Still playing multiples roles**
- **Continuing support**

- **Changing nature of relationship**
- **Reassurance**
- **Being there**

Phase III

Looking forward to the future

- **More honest now**
- **Being back to normal life**

Three month period

Appendix XII Summary of three models

Wilson's (1989) model of carers in Alzheimer's disease suffers	Nolan et al., (1996) model of carers in dementia suffers	The current model (2011) of carers in cardiac surgery patients
Noticing: the carers could only recall their memory retrospect and be aware of the gradual change of the unusual behaviour of the cared-for person. **Discounting or normalizing**: the reason to explain the behavioural change. The carers tried to normalize the situation or behaviour until they could not discount it. **Suspecting**: carers started to realize the abnormal situation or behaviour. **Searching for explanations**: carers seek for information to confirm the diagnosis of AD, however, it compressed uncertainty and problems. **Recasting**: carers recalled their memory and formulated pictures of previous events of their demented relative after diagnosis. **Taking it on**: carers face making a decision to taking on the caring role or not, however, the responsibilities of this role are usually not in the carers awareness. **Going through it**: carers took on their role to care for their demented relative. They learned their skills and resolved their problems by trial and error. **Turning it over**: carers realised that their own health is suffering and placed their relative in institution, however, they were reluctant to let go of control in direct care.	**Building on the past**: an antecedent event regarding the relationship between the carer and cared-for person. It means the nature and quality of past interaction between the carer and the cared-for person; it impacts on the care provided by carers. **Recognising the need**: carers become aware of their relationship change with the cared-for person. During this stage, noticing, normalizing and confirmation occurred. **Taking it on**: carers were aware of their role, however, if carers faced things that cannot improve, they may be reluctant to 'take on' the role. Moreover, tension between professional and carers would appear because of different opinions during this stage. **Working through it**: carers become experts in the day-to-day aspects of their role. They provide instrumental care but anticipatory, protective, reconstructive and preservative care. **Reaching the end**: this does not mean that carers cease to care. It might indicate the service providers in the community felt that carers are no longer need their help or another form of care is substituted.. **A new beginning**: it means that when the patient was reaching to be institutionalised at a time, the carers were sometimes felt difficult to withdraw the caring role, especially for the long-term carers.	**Changing nature of relationship**: carers were aware that their relationship between the cared-for persons did not like before. They were aware of their identity change. **Reassurance**: a form of support necessary to the family carer throughout the duration of the caring journey. **Being there**: a commitment of marriage or a familial bond of loyalty. **Walking in the dark**: this refers to carers were 'thrown in at the deep end' with little preparation for what was about to happen to them. **Getting on with it**: carers had progressed from 'walking in the dark' to a more controlled and methodical means of managing their caring. **Looking forward to future**: the end of this caring journey. It comprises a positive outcome for the majority of the carers and the cared for people. **The essence of caring**: at the start the carer is a person in their own right carrying out various roles within the bond of their relationship with the person who becomes ill. At the very beginning of the journey it is obvious that the person becomes predominantly a carer. At the end, the carers return to being a person.