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Meeting the challenge : The female carers' perspective of managing dyspnoea

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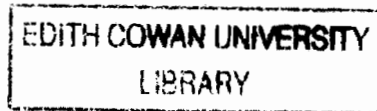
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**MEETING THE CHALLENGE:
THE FEMALE CARERS' PERSPECTIVE
OF MANAGING DYSPNOEA**



A thesis submitted in partial fulfillment of the requirements
for the award of
Master of Nursing

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Declaration

“I certify that this thesis does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in text”.

Kim Angela Skett:  _____

Date: 4th July 2004.

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The researcher wishes to thank the participants of this research project for permitting her to share their experiences of providing care to their family members. Many of these experiences were personal and had not been discussed previously; therefore, I would like to acknowledge the difficulty that each participant expressed in regards to talking on tape but also to thank them for overcoming this and allowing taping to occur. Each participant believed that they would not have any “worthwhile” experiences to discuss, but the researcher left each interview astounded by the amount of information provided and overwhelmed by the effort that the carers made to enable the family member to remain at home.

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Abstract

The aim of this descriptive, explorative study was to describe the lived experience of informal carers providing care within the home, to a family member who has lung cancer and the symptom of dyspnoea. Many studies have highlighted the stressors associated with care provision, but no studies have focused on the experience associated with caring for a family member who is dyspnoeic.

Ten carers were interviewed regarding their experiences of providing care to the family member during the palliative phase of the illness and while the family member was experiencing the symptom of dyspnoea. Analysis of the initial data highlighted differences in issues identified by nurses and carers, therefore, two Registered Nurses were interviewed to determine how the perceptions of the carers needs differ between the carer and the nurse.

Data was collected using unstructured, in-depth interviews which were audio-taped. All data was analysed and common themes identified. Three key themes emerged from the data: developing skills, sustaining the carer and meeting the challenge. In addition to these themes, “developing relationships” emerged as the underpinning concept that supports the themes.

The double ABCX model of adaptation and adjustment was used to determine how the carers’ perceptions of the stressor and their coping resources influence the process of adaptation. Recommendations have been developed from the findings and are directed towards clinical practice issues, education of carers and areas for further nursing research.

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CHAPTER ONE

Introduction

Increasing numbers of individuals requiring palliative care are receiving complex and time consuming care within their homes, with care provided by informal carers (Addington-Hall & McCarthy, 1995; Beck-Friis, 1993). These carers are often family members who may have received little or no training in delivering this care (Ramirez, Addington – Hall & Richards, 1998; Teno, Casey, Welch & Edgman-Levitan, 2001). Informal carers who provide care to a family member receiving palliative treatment may experience many stressors that impact on the carer's own physical and psychological wellbeing (McCorkle & Pasacreta, 2001; Hinton, 1994). The aim of this study was to identify and explore the experiences of the informal carer when providing care to a family member with lung cancer who has the symptom of dyspnoea.

Prior to the 20th Century care was provided within the home, but changing trends in health care delivery led to an emphasis on care provision within the hospital setting. The current emphasis on palliative care is to provide care within the community setting. This chapter will explore the historical perspective of palliative care and incorporate how the changes in health care provision impact on the wellbeing of the informal carer. The significance of the study on the provision of care within community palliative care nursing will be discussed.

Included within this chapter are the aims and objectives of the study, which are discussed in relation to the research question. Definitions of terms used within the study are provided.

Background

The concept of hospice can be traced back to times when religious pilgrimage was made to the holy waters of the Ganges, when the Indian Emperor Asoka (273 – 232 BC) ensured that provision was made for the pilgrims and their families (Simpson, 1989). During the following centuries many groups established hospices and significant literature was written in relation to thanatology (Simpson, 1989). The early beginnings of what is often referred to as ‘modern hospice’ can be traced to the late 19th century with the establishment of hospice as a place where the impoverished and sick went to die (Saunders, 1998). Simpson (1989) suggests that the progress of palliative care worldwide ceased following World War Two. During the 1960s the modern hospice and palliative care movement was developed to address the issues that were causing suffering during the dying process (Ferris et al., 2002).

The program of care that hospice provides is based on the understanding that dying is part of the normal life cycle. The modern concept of hospice utilises this understanding to develop an alternative model of care to the traditional curative model (Egan & Labyak, 2002). The definition of palliative care formulated by the World Health Organisation (WHO) encompasses how the model of care used by hospice has expanded the traditional curative model of health care. Palliative care is defined by the WHO (2004) [<http://www.int/hiv/topics/palliative/care/en/print.html>]:

“...an approach which improves the quality of life of patients and their families facing life threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems”.

This goal is attained by the provision of optimal symptom management and support for both the family member and carer.

Historically, hospitals were primarily used to provide care for the poor with this focus of care shifting during the early 20th Century (Kirk & Glendinning, 1998). Hospitals began to dominate health care provision due to advances in medicine promoting curative treatment rather than relief of suffering (Izquierdo- Porrera, Trelis-Navarro & Gomez-Batiste, 2001). During the latter part of the 20th Century the emphasis was once again placed on care provision within the community setting (Kirk & Glendinning, 1998).

The declaration of Alma Ata in 1978 by the WHO encouraged governments to place primary health care as a focus within the health care systems. Since this time care within the community setting has increased, however, Kirk and Glendinning (1998) argue that this shift of focus has been driven by an increased health care expenditure, changing patterns of illness and medical technology developments. The changing patterns in health care have led to the emphasis on providing care in the community for family members with end stage disease (Payne, Smith & Dean 1999). It is also recognised that the majority of individuals prefer to receive care within their homes (Brockbank, 2002; Higginson et al., 2002). Many treatments that would have been given in an inpatient setting are now provided on an outpatient basis with the expectation that on going care will be maintained at home (Barsevick, Much & Sweeney, 2000; Carter & Chang, 2000, Chan & Chang, 1999, Ferrell, 1999; McCorkle & Pasacreta, 2001; Ramirez, Addington-Hall & Richards, 1998; Raveis, Karus & Seigal, 1998; Weitzner, McMillan & Jacobsen, 1999). This shift in location of care has often resulted in the burden of care being relocated to the informal carer (Kirk & Glendinning, 1998; Payne et al., 1999).

From an Australian perspective, research was undertaken during the 1970s and 1980s to gain an understanding of the need for palliative care services. This has led to the provision of palliative care within general hospitals, free standing hospices and within the community setting (Harris & Finlay-Jones, 1987). Specialist palliative care within Australia is recognised as a specialised field of health care, but currently is not available to all Australians. To further develop access to palliative care services the National Palliative Care Strategy was formulated during the year 2000. This strategy upholds the principles of palliative care and recognises that “generally people prefer to die with the support of family and friends within their local community, be this in their own homes or an in patient environment” (Kirsner, 2000 p.2).

Importance of community support services

As previously discussed the focus of care has shifted from inpatient settings such as teaching hospitals to the community with increasing numbers of informal carers choosing to provide care at home for family members (Hull, 1992). These informal carers provide care which would previously have been attended within a hospital or hospice environment. This care ranges from the provision of physical care such as hygiene assistance to ensuring that medications are taken at the correct times to the carer giving injections of medications. To enable this care provision community nursing services have become an integral part of health care delivery.

A significant aspect of the role of the community palliative care nurse is to provide support to the informal carer. The importance of this aspect of the role increases as the length of stay in hospitals decreases and the requirement for assessment of needs within the home increases (Wilson, Pateman, Beaver & Luker, 2002). Community

palliative care nurses' can assist the carer to identify and implement coping strategies which will enhance the ability to provide care, while meeting the carers own physical and psychosocial needs (Hull, 1992).

Impact of care provision on informal carers

Informal carers play a major role in providing care to the family member receiving palliative care within the community setting with studies identifying that the majority of these informal carers are female (Pasacreta, Barg, Nuamah & McCorkle, 2001; Shyu, 2000). The study by Shyu (2000) suggests that many informal carers will experience competing demands on their time because they may be required to continue paid work as well as provide care to the family member.

A barrier to care provision within the home is the management of symptoms that are perceived by the carer as difficult. Dyspnoea is viewed as a difficult symptom and is related to increased hospital admissions (Bradshaw, 1993). Therefore, to promote management in the home and prevent hospital admission it is important that the palliative care community nurse understands the experience of the carer who is providing care to a family member experiencing dyspnoea.

Cancer affects all family members both physically and psychologically (Chan & Chang, 1999; Ferrell, 1999; McCorkle & Pasacreta, 2001; McVey, 1998; Payne, 1998; Weitzner et al., 1999; Williams, 1999). As the physical condition of the family member deteriorates the emotional and physical stressors associated with provision of care increases (Carter & Chang, 2000; Fakhoury, 1998; Kristjanson, Leis, Koop, Carriere & Mueller, 1997; Payne et al., 1999; Shyu, 2000). The emotional and physical stressors can be related to unmet needs that arise when the carer undertakes

provision of care for the family member. These needs may impact on the carer's physical and / or psychological wellbeing and ultimately on the ability of the carer to provide care to the family member.

Research undertaken in this area has identified various needs, which if unmet, may create difficulties for the informal carer when providing care to a family member in the home. These needs encompass communication, education and information. Communication incorporates both communication issues within the family and between the carer / family member and health care professionals (Addington – Hall & McCarthy, 1995; Davies, Reimer & Martens, 1994; Kristjanson et al., 1997; Lecouturier, Jacoby, Bradshaw, Lovel & Eccles, 1999; Pasacreata et al., 2000; Shyu, 2000). Education assists the carer by providing knowledge regarding the tasks that need attending and information permits understanding of the physical and emotional demands this role will place on the carer (Carter & Chang, 2000; Fakhoury, 1998; Hinton, 1994; Holing, 1986; Kristjanson et al., 1997; Pasacreata et al., 2000).

Other needs that have been discussed in the research literature include: lack of support from both formal and informal networks (Davies et al., 1994; Pasacreata et al., 2000; Payne et al., 1999) and financial difficulties that may be experienced by the family (Addington-Hall & McCarthy, 1995; Hinton, 1994). Further consideration needs to be given to the previous ill health of the carer as this may impact on the ability of the carer to continue providing care to the family member (Addington-Hall & McCarthy, 1995; Hinton, 1994; Pasacreata et al., 2000).

These needs, if unmet, may produce many negative effects on the carer's mood, ability to interact with others, ability to provide appropriate care to the family

member and management of the carer's own health needs (Carter & Chang, 2000; Fakhoury 1998; Kristjanson et al., 1997; Payne et al., 1999; Shyu, 2000). No studies were found that specifically addressed the needs of the informal carer of a family member with the diagnosis of lung cancer and the symptom of dyspnoea.

It is also necessary for health care professionals to understand and demonstrate sensitivity towards cultural issues that may cause difficulties for the carer when providing care to a family member (Oliviere, 1999). Cultural issues may impact on all aspects of palliative care including symptom control and bereavement issues (Chan & Chang, 1999; Lin 2001; Oliviere, 1999).

Epidemiology

Between the years of 1997 and 2000 there were 512,945 registered deaths in Australia (Australian Bureau of Statistics, 2002) and of this figure, approximately 28% of deaths were caused by cancer (Najman, 2000). Of the total number of deaths in Australia a proportion would have received care and died at home, with many of those individuals who died within a hospital or hospice settings receiving care within the home until the last week or days of life. Lung cancer remains the leading cause of cancer related deaths in Australia (Nobbs, Smith, Smith & Wood, 2000).

Statistics available from Silver Chain Hospice Care Service (SCHCS) show that a large percentage of those individuals with a cancer diagnosis and receiving home care have a diagnosis of lung cancer. During the year 2001, SCHCS provided in home palliative care to a total of 2050 clients. Of this total 656 clients had end stage lung disease, with 557 clients having a diagnosis of lung cancer or metastatic disease and 99 with individuals with a non cancer diagnosis of end stage respiratory disease.

These statistics show that approximately 32% of clients who received home care from SCHCS have either a primary diagnosis of lung cancer or a disease process that impacts on respiratory function. It can be postulated that 60% of individuals with this diagnosis may experience significant symptoms of dyspnoea with the risk of some being classified as having unresolved dyspnoea at the time of death.

Lung cancer will be the fifth highest cause of mortality worldwide, by 2020 (Edmonds, Karlsen, Khan & Addington – Hall, 2001). Within the context of Western Australia, Threlfall (1997) reports that while the incidence of some cancers may fall it is expected that there will be an increase in the case numbers of cancers such as colorectal and lung cancer. Many cancers, such as lung cancer will occur more frequently in people over 64 years of age, than in other age groups (Threlfall, 1997). Cancer of the lung also has poor relative survival rates in comparison to other cancers. The one year survival rate is 34.6% for males and 37.6% for females (Australian Institute of Health and Welfare [AIHW], 2001)

Silver Chain Hospice Care Service (SCHCS), which is one of the agencies that provides care to this population, assists families to manage this treatment at home. At any given period of time the number of families cared for in this way by SCHCS is approximately 400. The requirement of care provision for individuals requiring palliative care by family members and community health services will continue to grow due to the projected increase in cancer and cancer related deaths.

Statistics obtained from SCHCS show that approximately 32% of family members receiving in home care from SCHCS have either a primary diagnosis of lung disease or have a disease process that impacts on respiratory function. This figure does not

include other disease processes, such as Motor Neurone Disease and congestive cardiac failure, which are also known to cause dyspnoea. This leads to a potentially large family member group who will experience dyspnoea at some stage of their disease process. As informal carers play a significant role in caring, research that explores the experience of providing care to this group of family members must be undertaken. This will enable relevant education/nursing interventions to be provided that will support the carer and ultimately improve provision of care to the family member.

Research question and objectives of the study

The literature review demonstrated a lack of qualitative research that focused on the experience of informal carers when providing care to a family member who has lung cancer and is dyspnoeic. Therefore, the following research question was used to guide this study:

What are the experiences of informal carers of palliative care family members with lung cancer who are experiencing the symptom of dyspnoea?

The following objectives were developed from the research question:

- To explore and describe the experience of care provision from the perspective of the informal carer who is providing care to a family member with lung cancer who has the symptom of dyspnoea classified as unresolved,
- To identify and describe how interaction with supportive networks affects the informal carers ability to provide care to the family member who is experiencing dyspnoea.

A further objective was incorporated following the initial analysis of the interview transcripts:

- To identify and explore the stressors impacting on the informal carers' ability to manage the care of the family member within the home setting from the perspective of the Registered Nurse.

Purpose and significance of the study

The rise in the projected number of lung cancer related deaths shows the necessity for health care professionals working in palliative care to have an understanding of how the experience of providing care to a family member with lung cancer impacts on the physical and psychological wellbeing of the informal carer. In the Perth area it is recognised that a number of family members whose needs are related to palliation of symptoms rather than seeking curative treatment are cared for in their own homes by family members. Silver Chain Hospice Care Service (SCHCS), which is one of the agencies that provides care to this population, assists families to manage this treatment at home. At any given period of time the number of family members cared for in this way by SCHCS is approximately 400.

Approximately one third of the informal carers of family members who are receiving care from SCHCS will be providing care to a family member who has the diagnosis of lung cancer. The family member will potentially develop the symptom of dyspnoea. This study will assist palliative care nurses and community nurses to understand the experiences and associated needs of the informal carer who is providing care to a family member who has the symptom of dyspnoea. Understanding the experience of providing care from the carer's perspective will enable nurses to provide appropriate interventions and education strategies, which will enable the carer to provide appropriate care to the family member while maintaining the carers own wellbeing.

Definitions of terms

- Cancer:** a malignant, invasive cellular neoplasm that has the capability of spreading throughout the body or body parts (Marieb, 1989).
- Dyspnoea:** the unpleasant awareness of difficulty in breathing (Woodruff, 1999).
- Family:** "...those individuals considered as family by the patient". (Ferrell, 1998).
- Family stress:** a state that arises from an actual or perceived demand-capability imbalance in the families functioning and which is characterised by a multi-dimensional demand for adjustment or adaptive behaviour (McCubbin & Patterson, 1983, p.9).
- Formal carer:** formal carers are paid health care professionals, such as doctors or nurses, or volunteers who are associated with an organisation that provides care to individuals (Derby & O'Mahoney, 2001).
- Hospice:** a system of family-centered care designed to assist the chronically ill person to be comfortable and maintain a satisfactory lifestyle through the terminal phase of dying (Glanze, Anderson & Anderson, 1990, p.576).
- Informal carer:** Informal carers may be any individual, not associated with an organisation, who does not receive financial gain for providing care (Derby & O'Mahoney, 2001).
- Palliative care:** "...an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2001).

Stressor: a life event or transition impacting upon the family unit which produces or has the potential of producing, change in the family social system (McCubbin & Patterson, 1983, p. 8).

Thesis organisation

This thesis is organised into seven chapters. Chapter one introduces the research topic, incorporates the background of the study and discusses the significance of the problem. Chapter two presents the literature review, which provides an overview of stressors that impact on a caring relationship. Chapter three discusses the use of the double ABCX model of adaptation and adjustment from a nursing context. Chapter four discusses the methodology used to guide the study. This chapter incorporates recruitment into the study, methods of data collection and analysis. The fifth chapter describes the findings of the study. Chapter six contains the discussion of the studies findings in relation to other research and the conceptual framework. The final chapter, chapter seven, contains the study's conclusions, implications for nurses and carers and recommendations for further research. Limitations of the study are also discussed in chapter seven.

CHAPTER TWO

Literature Review

Introduction

The aim of this study was to identify and explore the experiences of carers when providing care to a family member with lung cancer who has the symptom of dyspnoea. To achieve this aim it was necessary to develop an understanding of the role of the informal carer in palliative care and how the change in the ways in which health care is delivered have altered this role. It was also necessary to understand the stressors that could be encountered on a day-to-day basis by the informal carer when providing care to a family member. A further aspect which required exploration was how these stressors impacted on the physical and psychological wellbeing of the informal carer.

An important aspect to acknowledge in association with the aim of this study was the prevalence of lung cancer and the percentage of those individuals diagnosed with lung cancer who would experience the symptom of dyspnoea. In conjunction with this it was necessary to determine how the perception of the severity of dyspnoea differs among health care professionals, informal carers and the individual who is experiencing this symptom. This chapter contains a review of the literature related to these areas.

Lung cancer

Lung cancer is recognised as a disease that has a high incidence and a high mortality rate (Krishnasamy, 2000; O'Driscoll, Corner & Bailey, 1999; Yardley, Davis & Sheldon, 2001) and is acknowledged as being the most common cancer worldwide

(AIHW, 2001). It is projected that worldwide, lung cancer will be the fifth highest cause of mortality by the year 2020 (Edmonds, Karlsen, Khan & Addington-Hall, 2001). Within Western Australia the overall incidence of lung cancer is predicted to increase (Threlfall, 1997). It is estimated that more than 80% of those individuals diagnosed with lung cancer will die within one year of diagnosis (Yardley et al., 2001). The mean survival time is six months and there is a less than 10% survival rate after five years for both males and females (Krishnasamy, 2000). When discussing care of the client with lung cancer, White (1987) observes that when there is a relapse following completion of active treatment the time prior to death is short. Lung cancer is the second most frequent diagnosis of clients receiving care within their own homes; therefore, the relatively short survival time has many implications for family members who may be required to provide care to the individual with lung cancer (White, 1987).

The study undertaken by Bradshaw (1993) suggests that individuals with a diagnosis of lung cancer were more likely to be admitted to an inpatient facility to receive care during the terminal phase of the illness. This study compared admissions between three palliative care services in Perth, Western Australia. Bradshaw (1993) found that the increase in admission to inpatient services may be related to the stage of the illness when the individual was initially referred to the community palliative care organisation or the financial implications of managing the individual at home.

Dyspnoea

The word dyspnoea is derived from the Greek dys (bad) pneo (breathing) (Ahmedzai, 1999, p. 586) and is reported to be the most common symptom in patients with advanced cancer by many authors (Ahmedzai, 1999; O'Driscoll et al.,

1999; Roberts, Thorne & Pearson, 1993; Woodruff, 1999). The published prevalence rates of dyspnoea vary between 25% and 75% (Ahmedzai, 1999; Woodruff, 1999).

Dyspnoea is reported to occur most frequently in those individuals who have a primary diagnosis of lung cancer (Dudgeon, 2001; Wilcock et al., 2002; Woodruff, 1999). In their study, which aimed to investigate non-pharmacological interventions for individuals who have a diagnosis of lung cancer and the symptom of dyspnoea, O'Driscoll and colleagues (1999) observed that between 10% and 15% of individuals experience the symptom of breathlessness at the time of diagnosis with the prevalence of dyspnoea rising to 65% during the illness trajectory. The outcome of the study revealed that 85% (N=44) of participants experienced dyspnoea intermittently. A limitation of this study was that a structured assessment tool was not used with the researchers relying on self report information provided by the participant.

Dyspnoea is acknowledged as being a frightening experience (Ingle, 2000) and may precipitate admission to an inpatient facility (Bradshaw, 1993). Therefore, it is necessary for health care professionals to develop an understanding of the impact of dyspnoea on the physical and psychological wellbeing of clients who have a cancer diagnosis and their informal carers.

Prior to suggesting interventions that will assist the carer and the individual experiencing dyspnoea it is necessary to understand the possible causes of the symptom. To achieve this it is necessary to understand the physiology of respiration.

The physiology of respiration involves a complex interplay of processes that result in the physical movement of air into and out of the lungs, gas exchange and transport of oxygen to body tissues (Martini, 1995). Lung cancer, which involves epithelial cells, mucous glands or alveoli, often restricts airflow into the lungs and therefore causes alteration to the respiratory process. Treatment regimes for either palliative or curative measures in lung cancer may also disrupt the respiratory process that can lead to the experience of shortness of breath.

There are a number of potential causes of dyspnoea in clients who have lung cancer (Table 2.1). The causes of dyspnoea are multifactorial and could be associated with factors that lead to ventilatory and / or mechanical problems (Dudgeon, 2001; O'Driscoll et al., 1999; Ripamonti & Bruera, 1997). These causes may incorporate a complex interplay of factors involving physical, psychological, emotional or functional elements, which lead to the feeling of breathlessness (O'Driscoll et al., 1999; White, 1987). This interplay of factors makes dyspnoea a symptom that is difficult to relieve completely (Twycross & Lichter, 1999). While acknowledging that dyspnoea occurs in relation to various causes Woodruff (1999) and Bredin (1999) suggest that anxiety is the most frequent component.

A series of studies undertaken by Tanaka, Akechi, Okuyama, Nishiwaki and Uchitomi (2002) assessed the prevalence of dyspnoea and the medical and psychosocial factors associated with the symptom of dyspnoea. Prevalence of what is described by the authors as "clinical dyspnoea" was reported to occur in 55% (N= 86) of the participants. Clinical dyspnoea is defined as "dyspnoea interfering with any daily life activities" (Tanaka et al., 2002, p. 484). Use of the Cancer Dyspnoea Scale and the Hospital Anxiety and Depression Scale in conjunction with

clinical data confirmed that the symptom of dyspnoea is multifactorial (Tanaka et al., 2002).

Table 2.1: Potential Causes of Dyspnoea

Mechanical (Obstructive) Cause	Ventilatory (Restrictive) Causes
Tumour erosion of lung tissue	Thrombo emboli
Pleural effusion	Tumour emboli
Airway obstruction (e.g. asthma; COPD)	Radiation
Inspiratory muscle weakness	Chemotherapy
Lymphangitis carcinomatosa	Metabolic sources
Superior vena cava obstruction	Psychological factors (e.g. anxiety)

Perceptions of dyspnoea

Dyspnoea is described as a subjective feeling of breathlessness (Ahmedzai, 1999; Jolley, 2000; Ripamonti & Bruera, 1997; Woodruff, 1999) that involves the individual’s perception of the event and the reaction to that sensation (O’Driscoll et al., 1999; Ripamonti & Bruera, 1997; Roberts et al., 1993; Wilcock et al., 2002). Because of the subjective nature of the symptom it is necessary to obtain relevant information regarding the severity of the episode of dyspnoea from the client (Dudgeon, 2001; White, 1987). An overview of studies that have assessed dyspnoea in individuals with lung cancer is shown in Table 2.2.

The perceptions of the severity of dyspnoea have been found to differ among groups. Although Edmonds and colleagues (2001) suggest that health care professionals may not acknowledge the severity of the psychological impact of dyspnoea, Ahmedzai (1999) states that individuals experiencing the symptom and carers (both

informal and formal) have differing views on the severity and experience of dyspnoea but does not describe these differences in opinions.

Table 2.2: Studies Assessing Dyspnoea in Clients with Lung Cancer

Author and date	Participants	Results	Limitations
Allard et al., 1999	33 terminally ill clients, 22 diagnosed with lung cancer	Supplementary doses of up to 25% of usual opioid regime reduces dyspnoea intensity	No discussion regarding the possible cause of the dyspnoea episode
Edmonds et al., 2001	Interviews post bereavement with 449 carers of lung cancer clients and 89 chronic lung disease clients (CLD)	Breathlessness was more common and more distressing in those individuals diagnoses with CLD	Symptom distress was identified by carers, some of which were professional carers
Tanaka et al., May 2002	171 clients with advanced lung cancer	Dyspnoea interfered with Activities of Daily Living (ADL) in 55% (N= 94) dyspnoea rated one out of ten interfered with ADL's in 13% of the participants	Participants were classed as "in good physical condition" (p. 421) The interference questions have not been validated for use with symptoms other than pain.
Tanaka et al., June 2002	157 participants with advanced lung cancer	Use of the cancer dyspnoeic scale and dyspnoea numeric scale indicate that in 55% (N= 86) of participants dyspnoea impacts on physical and / or psychological activities	The interference questionnaire was designed to assess pain and validity was not confirmed for use with other symptoms
Tanaka et al., June 2002	171 clients with advanced lung cancer	Dyspnoea is multifactorial	Participants were ambulatory: People with severe dyspnoea which excludes attending out patient clinics were not incorporated into the study
Wilcock et al., 2002	131 participants with lung cancer 130 participants with a non malignant diagnosis	The experience of breathlessness varies dependent upon the cause in both groups of participants	Use of American terminology in an English population

Studies that assess the individual's perception of the dyspnoeic episode included the use of descriptors to describe the quality of the experience of breathlessness (Wilcock et al., 2002) and completion of dyspnoea scales (Tanaka et al., 2002). The study by Wilcock et al., (2002) suggests that due to the subjective nature of the symptom, the descriptor chosen could be used to describe various sensations associated with different causes. A limitation of this study may be associated with the use of American terminology in an English population.

Completion of dyspnoea scales were used in several studies by Tanaka and colleagues. The studies suggest that using the cancer dyspnoea scale and dyspnoeic numeric scale in conjunction with medical information provides relevant information relating to the physical and psychological impact of the episode of dyspnoea (Tanaka et al., 2002). The study by Tanaka et al., (2002) that assessed the prevalence of dyspnoea in clients with advanced lung cancer determined that of the 157 participants, 55% (N= 86) experienced dyspnoea which impacted on their daily lives.

Edmonds and colleagues (2001) compared the experience of dyspnoea between individuals with lung cancer and those with chronic lung disease, as assessed by their informal carers post death of the family member. Seventy-six percent (N= 62) of the carer respondents who had provided care to a family member with chronic lung disease rated dyspnoea as "very distressing" compared with 60% (N= 201) of carers of individuals who had lung cancer. In-depth analysis regarding the difference was not discussed, but the authors point out that 91% of individuals who have chronic lung disease experienced dyspnoea in the final week of life compared with 69% of those who have lung cancer.

No research was found that investigated the informal carers' experiences when providing care to a family member with dyspnoea. Studies that sought information post bereavement were assessing the carer's perception of the family member's experience of dyspnoea, but did not consider the carer's experience.

In relation to interventions that may be useful to alleviate the symptom of dyspnoea, the focus of this literature review was not intended to assess appropriate intervention methods. There are many interventions that may be used to alleviate the symptom of dyspnoea, dependant upon the cause. Some of these interventions would necessitate initial treatment within an inpatient facility or out patient clinic with on-going care provided within the home. These interventions may include radiotherapy or drainage of a pleural effusion. Examples of interventions that would be carried out within the home incorporate the use of medications, oxygen therapy or use of nebulisers. No literature was found that assessed the informal carer's experience of providing this care.

Informal carers

The primary focus of the literature reviewed was in relation to informal carers of family members who are receiving palliative care. Although many studies were found that determine events that can contribute to difficulties when providing care no studies were found that assessed how the experience of caregiving impacts on carers of family members with a particular disease and symptom such as lung cancer and dyspnoea. Table 2.3 provides an overview of studies that have assessed the needs of informal carers.

Table 2.3: Assessing needs of informal carers: study results

Author and date	Participants /Design	Results	Limitations
Addington-Hall and McCarthy 1995	Qualitative interview 2074 family members of clients deceased during 1990.	To support informal carers and prevent unnecessary admission to inpatient facilities it is necessary to understand the social and health needs of family members.	While acknowledging the need for more effective symptom management the study did not provide details of the management of the client's symptoms or information provided to the carers.
Aranda and Hayman-White 2001	Descriptive data presented from 42 caregivers Correlational data presented from 33 caregivers	To support the informal caregivers it is necessary for appropriate nursing interventions to be formulated	Co-morbid medical conditions were not assessed. Impact of caring role on financial needs was not assessed
Bradshaw 1993	Retrospective study comparing 176 client records	More clients diagnosed with cancer of the lung required admission to inpatient facilities than those with other diagnoses.	Reasons for admission to inpatient facility was not explored
Chan and Chang 1999	Cross sectional survey of 26 caregivers of terminally ill cancer clients admitted to a hospice in Hong Kong	Development of physical and psychological problems are associated with the educational level of carers and the duration of experience of care provision	Low response rate of 52% (N=26) with no discussion regarding the 48% of participants who did not complete the questionnaire
Chan and Chang 2000	Cross sectional survey of 29 caregivers of clients admitted to a hospice in Hong Kong	The age of the family member and the caregiver impacts on the experience of the family	Occupational status not discussed in association with the impact of the experience of providing care in those carers under 50 years of age
Hinton 1994	Prospective study incorporating interviews of 23 clients and co-resident caregivers	Maintaining standards which meet the emotional and physical needs of the carers incorporates the availability of inpatient facilities in conjunction with home care.	No discussion within the article regarding the amount and type of medical input and the effect this has on the carer outcomes
Holing 1986	Qualitative interview of 14 caregivers- clients deceased within previous 12 months	Caring during the palliative phase was more emotionally demanding than physically demanding.	Nursing interventions used with these carers not discussed

Table 2.3 (contd.)

Author and date	Population/Design	Results	Limitations
Jarrett et al., 1999	18 clients and 11 relatives participated in qualitative interviews	Client and carer expectations of a palliative care service are limited to psychosocial support and symptom control	Differences between the patient and carer expectations are not explored.
Kristjanson et al., 1997	72 participants across 3 palliative care settings participated in a correlational study	Length of illness, family functioning and relationship status impact on carer satisfaction with care provided by palliative care services	No discussion regarding professional input received to those receiving home care
Pasacreta et al., 2000	Longitudinal study in which 187 caregivers attended the family caregiver cancer education program	Provision of education programs for carers improve confidence in care provision, perception of own health and ability to manage care.	No discussion regarding possible difficulties observed by the facilitators
Payne et al., 1999	39 carers participated in cross sectional study	Younger carers and female carers may be in need of additional support.	Authors are aware that selection bias occurred therefore clients with advanced disease not included which may affect results
Weitzner et al., 1999	Comparative study of 267 caregivers of clients receiving curative treatment & 134 caregivers of clients receiving palliative treatment	Comparisons between carers of individuals receiving palliative care or curative treatment demonstrates carers of palliative care clients experience worse physical health and report a poorer quality of life.	Quality of life was assessed but the study did not incorporate factors such as supportive resources and the carer's co-morbid medical conditions that can impact on quality of life.

As provision of health care moves away from inpatient settings to the home more responsibility is being placed on the family carer to provide care that may be complex and time consuming. Studies that have investigated the needs of informal carers point out that the carer may be responsible for continuing procedures or treatment that previously would have been attended within an inpatient setting (Addington- Hall & McCarthy, 1995; Carter & Chang, 2000; Chan & Chang, 1999; Weitzner et al., 1999). The carers may be required to give medication, attend to

physical care of the family member and assist the family member to make decisions regarding treatment options. The authors agree that it is necessary for the health care professionals providing support to this population of informal carers to understand the impact of this care provision on the quality of life of the carer.

Caregiving can be a physically and emotionally demanding role, but it is acknowledged there are both positive and negative aspects to this role. The study by Hinton (1994) assessed the effectiveness of home care provided by palliative care staff in supporting the carer to provide care to the family member. The results of the study determined that the carer experienced more emotional suffering than the family member in the last months due to the physically tiring role with the preference for home care falling from 100% (N=77) to 54% (N=41) of clients and 45% (N= 34) of carers. In this study 25% (N=19) of carers were found to become severely tired or exhausted. This is confirmed by several studies that describe how the emotional and physical stressors associated with provision of care increases as the physical condition of the family member deteriorates (Carter & Chang, 2000; Kristjanson et al, 1997; Payne et al 1999; Shyu, 2000). Given the complexity and often physical nature of caregiving, caregivers need to be informed of the physical and emotional aspects related to the provision of care (McCorkle & Pasacreta, 2001; Weitzner et al., 1999).

While acknowledging the negative implications of caregiving Pasacreta et al., (2000) and Aranda and Hayman-White, (2001) suggest that there are a number of positive elements involved in caregiving. The positive elements include pride in ability to maintain the caring role and the reinforced feelings of attachment between the family member and carer (Aranda & Hayman-White, 2001; Pasacreta et al, 2000). Positive

aspects also include decreased feelings of guilt, maintenance of family ties and feelings of closeness between the family member and carer (Holing, 1986; Payne et al., 1999; Wiles, Payne & Jarrett, 1999). Addington-Hall and McCarthy (1995) and Aranda and Hayman-White (2001) propose that despite the negative effects caregiving may have on the carers' quality of life, many carers report that caregiving is rewarding. The study by Addington-Hall and McCarthy (1995) reports that 53% (N= 1099) of carers found caregiving rewarding.

Stressors associated with care provision

This review of the literature demonstrates that informal carers may encounter many stressors, which if unmet, may impact on the carer's physical and/or psychological wellbeing (Table 2.4). These stressors, if not managed effectively, may also ultimately impact on the carer's ability to provide care to the family member.

Table 2.4: Potential Stressors Associated with the Caregiving Role

Stressor	Need
Lack of knowledge	Information Education
Lack of support resources	Professional resources Lay resources Spiritual support
Negative effect of caring role on carers' wellbeing	Health issues of carer to be met Psychological support
Other	Financial needs

Psychological needs.

A number of studies conclude that that cancer has a physical and psychological impact on all family members (Chan & Chang, 1999; McCorkle & Pasacreta, 2001;

McVey, 1998; Payne, 1998; Weitzner et al., 1999; Williams, 1999). Few studies are found that assess the impact of caring for a family member receiving palliative care (where the family member has a diagnosis of depression or anxiety) on the psychological wellbeing of the informal carer.

Many authors have assessed the incidence of depression and anxiety in family members receiving palliative care who have advanced cancer (Fincannon, 1995; Kissane, 2000; McVey, 1998; Payne, 1998; Williams, 1999; Woodruff, 1999), but do not present a cohesive argument when assessing the prevalence rates of depression and anxiety in palliative care family members due to the different methods and criteria used for assessment (Carter & Chang, 2000; Payne, 1998; Williams, 1999). Rates of depression were reported to vary between 4.5% and 58% by McVey (1998) and up to 69% by Payne (1998). Waller and Caroline (1996) suggest that the rate of depression in palliative care family members is not different to that of individuals with non-cancer medical disorders who are receiving palliative treatment.

It has been argued that the cause of depression and anxiety in individuals who have a cancer diagnosis is related to the knowledge of having cancer and symptoms that are poorly controlled (Kaplan & Saddock, 1998; McVey, 1998; Woodruff, 1999). Symptoms of depression and anxiety in family members receiving palliative care are often undetected by health care providers (Payne, 1998). Payne (1998) suggests that this is related to the perception that the symptoms of depression and anxiety are a normal transition through the grief process. No literature was found that suggests utilising a uniform assessment across palliative care services that would assist in the diagnosis of depression and anxiety in this population.

When discussing symptoms with family members and families, Ramirez and colleagues (1998) point out that carer anxiety is rated as one of the most significant problems. The prevalence of anxiety and depression among carers has been found to be high. In the year prior to the death of the family member 46% of carers experienced anxiety and 39% depression (Ramirez et al, 1998). Psychological distress experienced by the carer is also reported to increase as the family member approaches the terminal phase of the illness (Carter & Chang, 2000; Chan & Chang, 1999; Pasacreata et al., 2000; Raveis et al., 1998; Weitzner, et al., 1999). The increased needs of the family member requiring care at this time were found to be a significant factor in causing the distress experienced by the carer. McCorkle and Pasacreata (2001) suggest that provision of effective support within the home setting by health care professionals can significantly reduce the psychological distress experienced by carers.

Limitations of these studies were that the researchers did not measure variables such as socioeconomic status and cultural needs in their findings. Nurses working in the community palliative care area have observed that the socioeconomic status of the family receiving care impacts on the actual care received by the family. Nurses suggest that families perceived to be of a lower status received less support from the wider health care community with the nurses believing that this lack of support increases psychological stressors experienced by the family (personal communication (R. Pickerell, H. Green 26th September 2001). No literature was found that specifically assessed the support received by this population of family members and carers, although it is acknowledged that psychological stressors increase in the lower socioeconomic sector of society (Wilkes & White, 1998).

A number of studies conclude that there are many issues involved in the caregiving role that impact on the psychological well being of the caregiver (Pasacreata et al., 2000; Chan & Chang, 1999; McCorkle & Pasacreata, 2001). The age of the caregiver and that of the family member has been shown to be related to increased psychological needs (Chan & Chang, 2000; Payne et al., 1999). Younger caregivers were found to experience more psychological morbidity with the age cut-off to describe this varied between studies from 50 years of age (Chang & Chan, 2000) to 60 years of age Payne et al (1999).

Several studies have investigated family carer's risk of developing depression and anxiety (Barsevick, Much & Sweeney, 2000; Carter & Chang, 2000; Chan & Chang, 1999; Given et al., 1993; Kurtz, Kurtz, Given & Given, 1995; McCorkle & Pasacreata, 2001; Raveis et al, 1998; Weitzner et al, 1999). The studies assessed the relationship between caring for a depressed or anxious family member and the carer developing depression and anxiety. Raveis and colleagues (1998) point out that situational factors determined the psychological outcome for the carer whereas studies by Given et al., (1993) and Kurtz et al., (1995) concluded that the levels of depression were determined by the optimism shown by the family member and caregiver. None of the studies found a relationship between the family member's psychological symptoms and those of the carer. Variables such as supportive networks and cultural differences were not included in the results. Small sample size and low response rate are also limitations of many of these studies.

Educational needs

The educational aspects of providing care to family members within the home has been identified as a pivotal need, which will assist the carer in providing care. Fifty

percent of caregivers experienced difficulty in providing care to the family member due to the carers not being provided with relevant educational information (Holing, 1986). Providing the caregivers with education relevant to their needs decreases the burden of care provision (McCorkle & Pasacreta, 2001; Pasacreta et al., 2000). Fifty percent of carers who participated in a structured educational program report an increased sense of confidence in their ability to provide care (Pasacreta et al., 2000). Low participation rates were a limitation to the study by Pasacreta et al., (2000), but the outcomes suggest a need for education provision for caregivers. Many carers are unable to participate in education programs due to various reasons related to caregiving; therefore, “interventions should be tested that can reach large numbers of caregivers, including those who are uncomfortable with the group setting or homebound” (Pasacreta et al., 2000, p. 302).

Informational needs

Many authors argue that caregivers do not receive the information they require to provide optimal care and for informed decision making (Addington – Hall & McCarthy, 1995; Kristjanson et al., 1997; Lecouturier et al., 1999; McCorkle & Pasacreta, 2001). Burns, Dixon, Broom and Smith (2003) point out that understanding the disease trajectory and changes in the focus of treatments offered are important aspects of the caring role. Burns and colleagues (2004) determined that 48% (n = 65) understood that treatment was not curative. A limitation of this study is that although suggesting that client care may be hampered by the carers lack of understanding, Burns and colleagues did not explore the content of information provided to the caregivers.

It is suggested that between 40% (Addington – Hall & McCarthy 1995) and 47% (Lecouturier et al., 1999) of carers do not received the information required to provide care. Carers experience difficulty in receiving information from health care professionals (Kristjanson et al., 1997; McCorkle & Pasacreta, 2001). Jarrett and colleagues (1999) suggest that palliative care nurses were an appropriate source of information. A limitation of the study by Jarrett et al., (1999) was that the information provided to the carer was in relation to symptom control with other possible concerns of the carer not being discussed.

Receiving relevant information enables the carer to provide appropriate care and make informed decisions (Ramirez et al., 1998). Ramirez and colleagues (1998) also suggest that when carers are provided with information relative to their needs anxiety that may have been provoked by uncertainty and unnecessary fears was also reduced. Fakhoury (1998, p.173) when discussing what promotes satisfaction with palliative care services states that informed carers “...have different sets of expectations compared to those who are kept in the dark about the patients imminent death”.

These studies have shown the need for carers to receive relevant information to enable care provision and decision making.

Support

The most common reason for palliative care clients to be admitted to inpatient facilities is related to the carer not having the ability to continue providing the care necessary for the family member to remain at home (Payne et al., 1999; Wiles et al., 1999). Support needs of the carers vary due to the changes in role that may be necessary when a family member has a terminal illness. The primary carer may find that increasing amounts of physical, emotional and spiritual support will be needed

to maintain his/her own health status. It is therefore necessary for health care professionals to have an understanding of the support networks that the family has in place.

Payne and colleagues (1999) determined that support for the informal caregiver was available from three different groups. These are family, friends and health care professionals. It was also suggested that although support was available caregivers valued self-reliance and independence. In contrast to this Pasacreata and colleagues (2000) suggests that caregivers have difficulty eliciting help from family and friends. Davies and colleagues (1994), when assessing palliative care programs that are based on the premise of the family as a unit of care, report that family functioning influenced the utilisation of resources. Families who accepted support from informal networks were satisfied with the outcomes, whereas those families who were reluctant to accept support were dissatisfied with any support that was accepted (Davies et al., 1994).

The studies reviewed did not specify the agencies that would be appropriate to provide support to families receiving palliative care. An avenue of support that may be under utilised is that provided by social workers. Luff and Blanch (1998) and Monroe (1999) argue that social workers as members of the interdisciplinary team, can provide support to the caregiver and family members and information on agencies that are available to assist with their requirements.

Payne et al., (1999) and Lecouturier et al., (1999) differed in their findings regarding health professionals. Payne et al., (1999) found that the support provided by health care professionals was appreciated, but Lecouturier and colleagues (1999) reported a

lack of emotional support from health care professionals. Doyle (1999, p. 961) suggests that if families are not supported effectively by healthcare professionals the result may be “poorer quality of care for the family member, increased family strain and unnecessary hospitalisation of the family member”.

Financial difficulties

There was little reference found in the literature to the financial difficulties related to the care of palliative care family members. In the study by Aranda and Hayman – White (2001) the Caregivers Reaction Inventory was used. This contains a dimension that relates to the impact of caring on finances. For the purpose of the study by Aranda and Hayman-White (2001) this dimension was not used.

Hinton (1994, p.188) suggests that most financial problems were often focused on “heating bills and debts sometimes eased by advise or, crudely effective, money”. The study by Addington-Hall and McCarthy (1995) supported this and found that between 23% and 31% of respondent’s required financial assistance. Further study needs to be conducted in this area and should include variables such as socioeconomic status and availability of agencies that are able to provide assistance and costs to the families associated with purchasing assistance.

Ill health of caregiver

Although few studies were found that discussed the previous ill health of caregivers in relation to the stressors that affect the caregiver, Hinton (1994, p.188) concedes that many caregivers are “elderly, frail or sick”. In studies by Addington –Hall and McCarthy (1995) and Pasacreta et al., (2000), between 30% and 37% of caregivers have health problems that affected their ability to provide care. Pasacreta and

colleagues (2000, p. 295) offered 187 caregivers a psycho-education program that addressed “symptom management, psychosocial support and resource identification”. A positive outcome in the study by Pasacrete et al., (2000) was that 33% (n = 62) of the caregivers reported improved physical health during the educational program.

Communication and family functioning

The way in which the family has functioned prior to the illness of the family member impacts on their coping strategies both during the palliative care phase and during bereavement (Davies et al, 1994; Kristjanson et al, 1997; Pasacrete et al 2000; Shyu, 2000). Family interactions are based on long term relationships and communication patterns; therefore families differ in the ways they provide support. Some families may adopt flexible roles to ensure care is provided to the family member and also the caregiver (Davies et al, 1994; McCorkle & Pasacrete 2001); whereas others may remain static in current roles and not adapt to the situation (Davies et al, 1994; McCorkle & Pasacrete, 2001; Pasacrete et al., 2000).

Studies that discuss communication within the family suggest that communication was difficult (Payne, 1998; Davies et al, 1994) and that collusion to protect the family member receiving care should be avoided (Ramirez et al, 1998). Although the literature reviewed suggest that communication patterns impact on care provision, a cohesive argument is not forthcoming in relation to the impact of poor communication and the effect this may have on the family unit.

When discussing communication between the informal carer and health care professional Payne et al., (1999) observes that carer’s may experience difficulty

when discussing their own needs unless this was spoken about away from the family member. A lack of understanding of the role of health care professionals and not knowing how to request assistance was suggested by Jarrett and colleagues (1999) as a hindrance to effective communication. This is supported by Wiles et al., (1999) who report that the needs of the carer remain unmet unless the carer requests help.

Culture and ethnicity

No studies were found that assessed nursing knowledge related to the provision of culturally sensitive care to those carers of family members from non-western cultural backgrounds now living in western cultural settings. When discussing the care of Chinese family members Chan and Chang (1999) point out that the Chinese cultural values of self-sacrifice and tolerance would prevent caregivers from requesting assistance and advice. Further to this, it is suggested that the informal carer's would provide care that may interfere with their existing responsibilities from a sense of duty to the family member (Chan & Chang, 1999).

Lin (2001) points out that because family members were usually the primary carer and the cultural assumption that Taiwanese families are close, decision making was often the responsibility of the caregiver. This study, which assessed the congruence between family members and caregivers' pain perception, found that family members often would not report symptoms to caregivers for several reasons. These reasons include the family member having the "desire to be a good patient" (p.19). It is suggested by Lin (2001) that inaccurate information may be given to the health care professional due to the family member's reluctance to provide the carer with accurate information. This study concludes that the quality of life and mood of both the family member and the caregiver was disrupted due to cultural beliefs related to

symptom control. This study demonstrates that it is necessary to give education to both the family member and caregiver regarding the need for symptom control to maintain quality of life.

Studies also need to be undertaken in western cultures where many people from other cultural backgrounds are living in order to determine their cultural needs. Appendix A demonstrates the cultural background of SCHCS family members in the Perth Metropolitan area from July to October 2001.

Summary

This review of the literature has shown that lung cancer is the most common cancer worldwide with a high incidence of the symptom of dyspnoea. Dyspnoea is known to cause distress to both the carer and client, but no research was found which explored the experience of the carer when providing care to a family member who has lung cancer and the symptom of dyspnoea.

It was suggested that clients with the diagnosis of lung cancer have a higher incidence of hospitalisation. Few studies were found which provided information relevant to teaching carers of clients with lung cancer ways of managing the symptom of dyspnoea within the home.

The main problems encountered by carers are associated with a lack of information, education and support by professional and lay resources. This highlights the need for health care professionals to understand the specific requirements of the family to enable development of an appropriate plan of care which will support the carer and enable the client to receive care within the home.

CHAPTER THREE

Conceptual Framework

Introduction

Quality of life is an important factor for the carer in being able to maintain the palliative care family member at home. To enable the carer to continue with provision of optimal care to the family member, it is crucial for service providers to increase support when necessary. As discussed in chapter two, when the burden of care increases, the level of support required to enable the carer to maintain an appropriate quality of life also needs to be increased.

When providing palliative care it is necessary to maintain a family focus in accordance with the goal as stated by Gezairy (2004) "...to provide the best quality of life for patients and their families". To enable the caregiver to assist with provision of care it is essential that healthcare providers are able to provide support and interventions that meet the carers' needs.

Tate (1977) when discussing the care of the dying person finds that it is a nurse's responsibility to maintain the highest standard of care, while respecting the family members and families wishes and protecting their values. Tate (1977, p. 81) states that

"the measures used to provide assistance should enable the family member to live with as much comfort, dignity and freedom from anxiety and pain as possible. The family member's nursing care will determine to a great degree how this final human experience is lived and the peace and dignity with which death is approached".

When conducting studies on the ability of caregivers to provide the care necessary to maintain a family member at home, it is important to utilise a conceptual framework that has its basis in family functioning. The use of a conceptual model will permit consideration of the psychosocial needs of the family. This is achieved by utilising the concepts that are involved in a family systems model. Conceptual frameworks, which assess how the family functions as a system, demonstrate that it is necessary to understand that "...the setting determines what happens inside it, and that the parts can only be understood in relation to the whole" (Alexander, 1999, p. 188). In addition to this, Friedman (1992) suggests that the use of a framework will enable the healthcare professional to find meaning in the data.

Family stress theory

Several authors have found that the ways in which the family has functioned prior to the illness of the family member impacts on their coping strategies both during the palliative care phase of the illness and during bereavement (Davies et al., 1994; Kristjanson et al., 1997; Pasacreta et al., 2000; Shyu, 2000). Family interactions are based on long term relationships and communication patterns; therefore families differ in the ways in which they provide support. Some families may adopt flexible roles in order to ensure care is provided to the family member and also the main carer whereas other families may remain static in current roles and not adapt to the situation (Davies et al., 1994; McCorkle & Pasacreta, 2001; Pasacreta et al., 2000). Tomlinson (1986) suggests that the use of a family stress theory will provide health care professionals with assistance in determining the needs of families providing care for a family member with an acute or chronic illness. In support of this Green (1982), Gulla (1992) and Mays (1988) recognise the necessity of family assessment in a health care system that now acknowledges the importance of the family in

obtaining positive health care outcomes. Gulla (1992) proposes that an evaluation of family functioning should be incorporated into the assessment of families where an individual is receiving palliative care. Gulla (1992) and Mays (1988) agree that utilising a family assessment and therefore understanding the way in which the family functions, its perceived stressors and coping responses will enable the health care professional to implement a service that promotes effective care and outcomes for the family as a whole.

Byock (1999, p. 84) suggests that when determining the appropriate model for use, the selected model should complement "... the nature of the scientific enquiry or the goals of the specific endeavor". Further to this, Byock (1999, p. 85) states that the most appropriate model would "recognise meaningful distractions and qualities of human experience". The model would also permit understanding of all aspects of suffering rather than taking a medical model focus that relates to physical symptoms and disease progression (Byock, 1999). Neabel, Fothergill-Bourbonnais and Dunning (2000) also point out that the model should incorporate behavioural, cognitive and affective domains.

One such theory, which is of use when working with families caring for a family member with a chronic illness, is the Double ABCX model of adjustment and adaptation. McCubbin and Patterson (1983) suggest that the Double ABCX model provides a framework by which the impact of the stressor, families coping resources and their perception of these influence the process of adaptation.

Double ABCX model

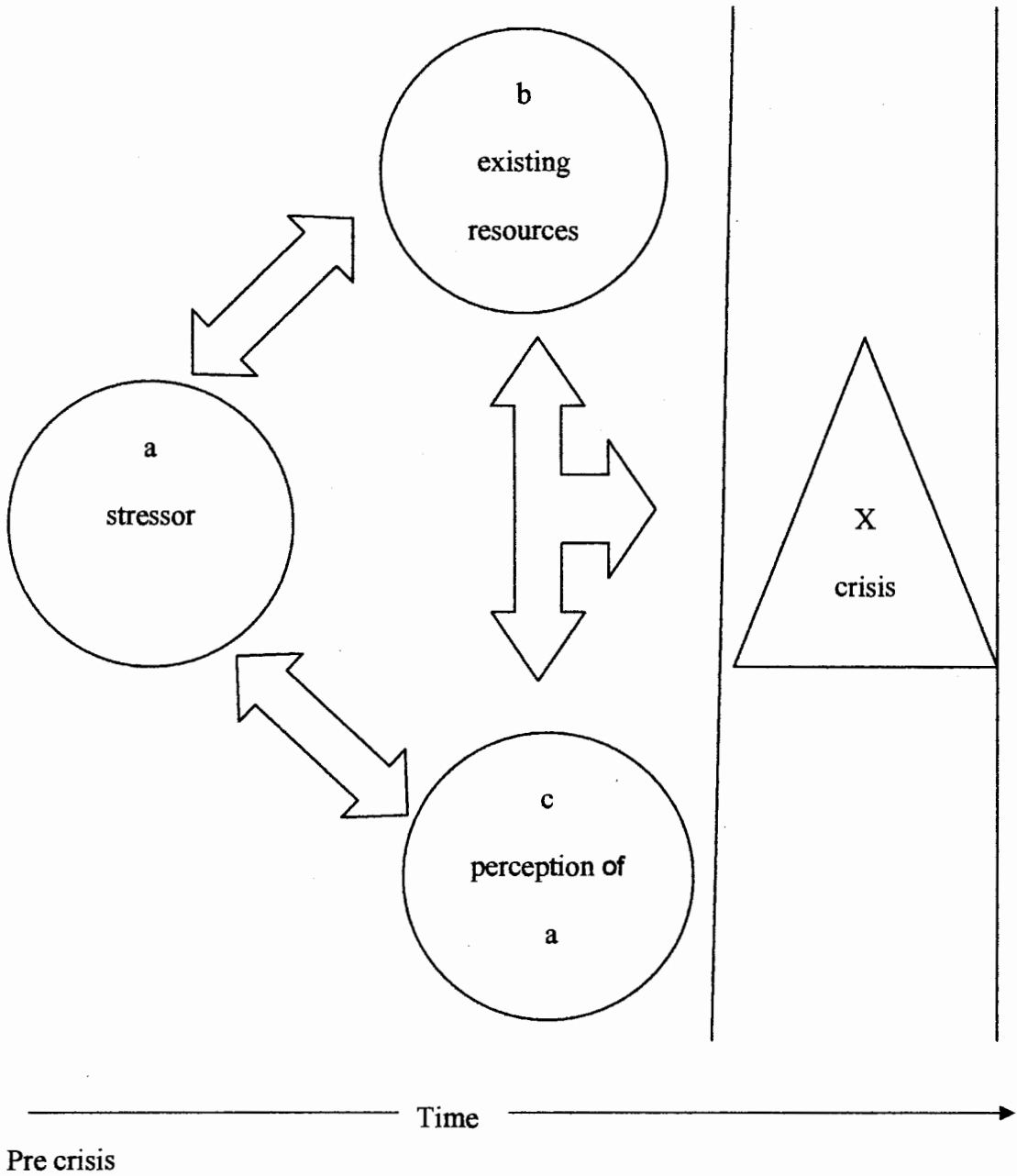
The ABCX family crisis model was first proposed by Ruben Hill in 1949. At that time it was used to describe factors that produce crisis or non-crisis in families (McCubbin & Patterson, 1983; McDonald, 2002). McCubbin and Patterson (1983) explain that when assessing these families the model was used to determine pre-crisis variables, their interaction and outcome for the family (Figure 3.1). The model was extended during the 1980s by McCubbin and Patterson to become the Double ABCX model of adjustment and adaptation. Adapting the model permitted incorporation of the differences in family adaptation during the post crisis period (Figure 3.2).

The Double ABCX model of family stress and adaptation considers factors that may precipitate a crisis in one family but not in another. These factors are involved in both the pre-crisis and post-crisis time. The way in which the family manages during the pre-crisis will impact on family functioning and adaptation in the post-crisis period. Adjustment of the family to stressors is a result of the interaction of both pre-crisis and post-crisis variables (Mays, 1988).

The factors involved in the pre-crisis period are identified as a, b, c and x. Factor a incorporates the actual presence of the stressor whereas factor b assesses the resources and coping mechanisms that the family use. When discussing factor a, McCubbin and Patterson (1983) outline the difference between a stressor and family hardships by pointing out that the stressor produces change within the family system which may result in hardships for the family unit. These hardships relate specifically to a stressor. Interventions to assist with the management of the stressors and

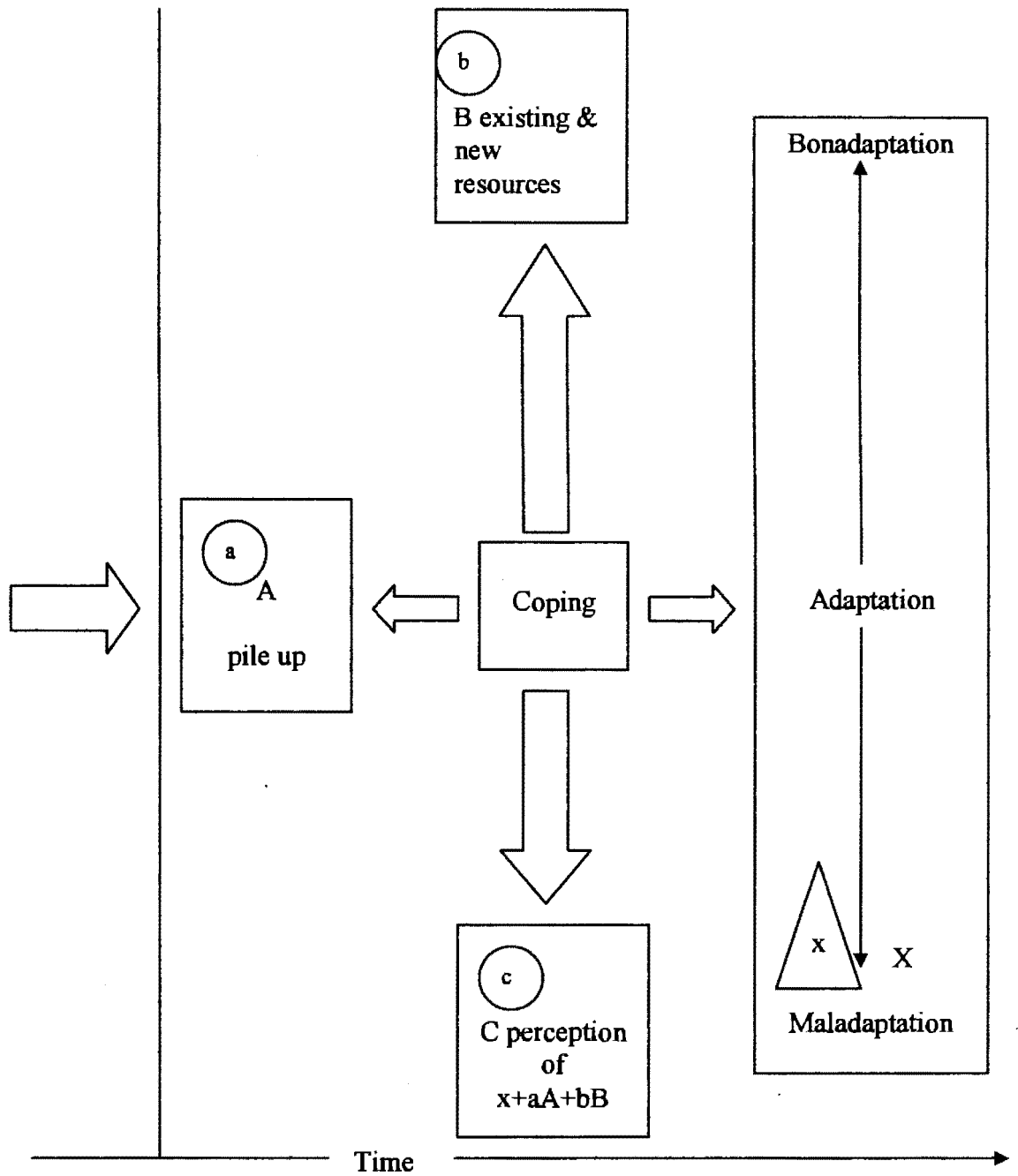
resulting hardships need to be formulated to assist with promotion of family functioning (McCubbin & Patterson, 1983).

Figure 3.1: Double ABCX model of adjustment and adaptation



McCubbin and Patterson 1983, p.12.

Figure 3.2: Double ABCX model of adjustment and adaptation



Post crisis

McCubbin and Patterson 1983. p. 12.

Factor b is described by McCubbin and Patterson (1983, p.8) as the factor that determines the families use of resources to meets the demands of the stressor or hardship. When used, the resources enforce the family's capacity to avoid a crisis situation from occurring. Friedman (1992) when discussing factor b, determines that if the family do not utilise the resources they have available, the outcome is the same as if the family did not have any resources. Friedman (1992) elaborates on this by discussing issues regarding intervention in families who have unused resources. Friedman (1992, p.320) states "...it is less difficult to assist families to utilise past coping patterns than it is to help families learn new ways of responding". McCubbin and Patterson (1983) suggest that resources incorporate factors that promote family cohesion such as mutual goals, ability to adapt as a family and the capability to meet the physical and emotional requirements of the family members.

The final factor in the pre-crisis period is factor c. Factor c is the family's perception of the stressor, associated hardships and the way in which the family is affected (McCubbin & Patterson 1983). McCubbin and Patterson (1983) report that the meaning the family gives to the stressor reflects the family's values and prior knowledge of ways in which to manage potential crisis events. Friedman (1992) points out that factor c is an important element as families who frequently define situations as threatening, will encounter factor "a" more often. Friedman (1992) suggests that those families who encounter more events perceived as crises do not have the coping resources available to manage these events.

Factor x is described by McCubbin and Patterson as the demand for change. The outcomes from the previous factors influence the crisis or x factor. McCubbin and Patterson (1983) consider the ability or inability of the family to manage the initial

stressor by utilising resources and the families' definition. It is suggested that in those families' who are able to use adaptive resources to manage the stressor event and maintain family stability the stressor may not culminate in a crisis situation.

The post crisis period incorporates factors which are identified as aA, bB, cC and xX. Factor aA is described by Friedman (1992, p. 320) and Mays (1986, p. 54) as "the pile up of stressors". McCubbin and Patterson (1983) point out that the pile up of stressors is associated with the stressors and demands that the family has coped with previously. In addition to this McCubbin and Patterson (1983, p. 11) report that the stressors may originate from "individual family members, the family system and/or the community of which the family and its members are part". Mays (1986, p.54) elaborates on this to suggest that involved in factor aA are the initial stressor, prior stressors, consequences of the families efforts to cope, normative transitions and ambiguity of the family, both intrafamily and social (Mays 1986, p. 54).

Factor bB is described by McCubbin and Patterson (1983) as the utilisation of adaptive resources which may be utilised to meet the demands caused by the stressor. Mays (1986, p.53) states that "these resources may already be part of the families repertoire or they may be developed and strengthened in response to the demands of the event or other aA factors".

There are several elements to these resources and the resources may incorporate personal characteristics such as self-esteem and knowledge, characteristics of the family unit such as communication patterns and characteristics of the community. McCubbin and Patterson (1983) suggest that usually there are two types of adaptive resources. These are classified as "existing resources and expanded family

resources” (McCubbin & Patterson 1983, p. 14). When discussing existing resources McCubbin and Patterson (1983) observe that these resources are the ones that are or have been previously utilised by the family. Within factor bB existing resources are incorporated within b. Existing resources may be individual, family or community focused (McCubbin & Patterson, 1983). Expanded family resources that are incorporated within factor B constitute new resources which have emerged to assist with managing the current situation. As with factor b the resources may also develop from the individual, family or community supports.

McCubbin and Patterson (1983, p. 15) point out that “one of the most important resources comprising the bB factor is social support”. McCubbin and Patterson (1983) explain that social support promotes the families sense of wellbeing and belonging this in turn enables the family to develop resistance to crisis and the ability to restore constancy within the family system.

McCubbin and Patterson (1983) explain that factor cC incorporates the positive and negative interpretations of the stressor. Included in this factor are the family's perceptions of the event, the family's definition of all the factors that are placing demands, the stressor meeting resources and the action to be taken to achieve balance and functioning (McCubbin & Patterson 1983). Further to this, McCubbin and Patterson (1983, p. 16) observe that the family's definition of a situation and ability to provide it with meaning becomes a “...critical component of family coping”.

Coping is the concept that bridges the factors bB and cC. Coping incorporates both cognitive and behavioural components. Friedman (1992) suggests that the interaction

between bB, cC and coping determine the family's state of adaptation, xX. McCubbin and Patterson (1983, p.16) expand on this to explain that there are five elements involved within the concept of coping. These elements are associated with the use of resources to manage the stressor and associated hardships, maintain family functioning whilst adapting to the situation and development of new resources. McCubbin and Patterson (1983, p.17) define coping as "...not stressor specific, but involves efforts to manage various dimensions of family life at the same time, realizing that a 'perfect' solution is never possible".

Three units are discussed in association with factor xX, individual, family and community. Each of these units has their own demands and capabilities. McCubbin and Patterson (1983, p.18) point out that "family adaptation is achieved through reciprocal relationships, where the demands of one of these units are met by the capabilities at another, so as to achieve a 'balance' simultaneously at two primary levels of interaction". When considering the impact the individual may have on the family system McCubbin and Patterson (1983) observe that the individual may place demands which the family as a unit is not able to meet. In addition to the demands that the individual may place on the family, there may also be discrepancies between the family and community commitments that cause an imbalance within the family. It is then necessary for the family to achieve a balance between family and community commitments in accordance with the capacity of the family to meet and manage these commitments.

Within the xX factor there is the continuous variable which is known as adaptation. Adaptation ranges from positive or bonadaptation to negative or maladaptation. McCubbin and Patterson (1983, p. 19) define adaptation as "...the central

concept...used to describe the outcome of family efforts to achieve a new level of balance in family functioning which was upset by a family crisis". Adaptation is a continuous variable as it is dependent upon how the families' needs are met.

When seeking to determine how the experience of providing care to a family member with lung cancer who has the symptom of dyspnoea impacts on the informal carers well being it is necessary to understand how the carer manages situations which potentially can lead to crisis situations. The double ABCX model of adjustment and adaptation provides a framework which permits understanding of the ways in which individuals manage potentially stressful situations, utilise previous experiences and move towards adaptation. The double ABCX model of adjustment and adaptation will be discussed in relation to the findings of this study in chapter six.

CHAPTER FOUR

Research Plan

Introduction

To achieve the aims and objectives of the study it was important to utilise a research design that permitted exploration of the participants' experiences. This chapter will discuss the research design utilised in this study. Recruitment into the study will also be described as will the method of data collection and analysis.

Research design

As discussed in chapter two, no studies were found that specifically addressed the needs of informal carers who were providing care to a family member with lung cancer who has the symptom of dyspnoea within the home care setting. No measurement of the severity of dyspnoea experienced by the family member was recorded for this study but all participants were providing care to a family member with dyspnoea classified as unresolved.

The focus of the study was to gain insight into the experience of caregiving to a family member with dyspnoea and how that experience affects the physical and psychological wellbeing of carers. To gain this insight it was necessary to select a research design that would provide information from the participant's perspective. To enable exploration of the experience a qualitative, explorative, descriptive method was chosen to guide the research. By using this method, the participant's were able to discuss their own experiences of providing care to a family member with lung cancer.

Explorative, descriptive methodology

Qualitative research is described as a methodology that facilitates understanding of the phenomena being studied by utilising the lived experience of the participants (Benoliel, 1984; Holloway & Wheeler, 1996; Leininger, 1985; Pollit & Hungler, 1989; Streubert, 1999). This benefits the discipline of nursing because the researcher is able to generate an account of the phenomena by studying statements critically. This then provides insight into the participant's reality. This insight generates new knowledge and understanding, which impacts on care provision.

Leininger (1985) points out that qualitative research is appropriate for use when a new perspective is required. Holloway and Wheeler (1996) and Patton (1990) expand on this view and suggest that qualitative, explorative research is relevant for studies where there is limited knowledge of the problem being investigated. Qualitative enquiry produces detailed information that can be studied in depth (Holloway & Wheeler, 1996; Patton, 1990). Benoliel (1984) argues that the qualitative method is appropriate for use in health research to expand knowledge in several areas including exploration of how individuals adapt when diagnosed with a chronic illness. Therefore, the focus of qualitative, explorative research is to determine the elements of the phenomenon being studied.

Descriptive designs are able to be used in both qualitative and quantitative methodologies (Burns & Grove, 1993; Roberts & Taylor, 2002). For the purpose of this study the descriptive design was utilised within the qualitative methodology. The purpose of a qualitative, descriptive design is to describe "what it is like to have a certain experience" (Roberts & Taylor, 2002, p. 176). Therefore, by using a qualitative, exploratory, descriptive design to guide the study, the researcher was

able to determine the experiences of the informal carer when providing care to a family member with lung cancer who has the symptom of dyspnoea. The researcher was then able to utilise this information to determine how the care could be guided towards adaptation within the double ABCX model of adjustment and adaptation.

Participants

The research focused on the carers of palliative care family members who had a diagnosis of lung cancer with the symptom of dyspnoea being classified as unresolved. The participants were eight informal carers who were providing care to a family member and receiving palliative care through Silver Chain Hospice Care Service (SCHCS) during the period October and November 2002.

Participants were identified by nurses as carers that were concerned about the dyspnoea the family member was experiencing. During data analysis discordance between the issues identified by the nurses and the carers was highlighted. Carers did not focus on dyspnoea as a specific concern or as a barrier to providing care. The study protocol was revised and following ethics approval a further two carers were recruited into the study, leading to a total of ten carers.

Interviews were also held with the primary nurses of those carers who had participated in the study following revision of the protocol. These interviews were conducted to assess the perspective of the Registered Nurse in relation to the needs of the carer and to identify any discordance between the needs identified by the carer to those identified by the Registered Nurse.

Inclusion and exclusion criteria

To be eligible to participate in the study the carer was required to be the primary carer for a family member who had a diagnosis of lung cancer with the symptom of dyspnoea being classified as unresolved. The carer needed to be over 18 years of age and able to give written, informed consent to participate in the study.

Informal carers who were caring for a family member who was judged to be in the final stages of the illness were excluded due to the risk of participating in the study increasing burden to the carer.

The Registered Nurse was required to be the primary nurse for the family of the informal carer who was participating in the study.

Recruitment

Convenience sampling was chosen to allow the researcher to identify as many potential participants as possible. The researcher planned to recruit six to ten carers who were receiving care from Silver Chain Hospice Care Service during a three month period. Initial interviews were undertaken with eight participants during the months of October and November 2002. Further interviews were conducted when ethics approval of changes to the study was obtained. These additional interviews were conducted between May and July 2003 with carers and registered nurses. Following ethics approval the research nurse attended meetings at three SCHCS service delivery centres where information was provided to Registered Nurses regarding the study. Posters outlining the purpose of the study were displayed at the service delivery centres (Appendix B).

The Registered Nurse distributed the information sheet to potential participants; the information sheet outlined the purpose of the study, the nature of participation and invited informal carers to participate. When the informal carer expressed interest in participating in the study the SCHCS Registered Nurse sought permission to give contact details to the researcher. The researcher then contacted the carer clarifying the purpose of the study and answering any questions. Following agreement to participate, an interview was arranged, which was held at a time and place convenient to the participant. All interviews took place in the participant's home. However, an alternative, private location in the researcher's workplace was available if the participant preferred this setting.

Registered Nurses, who were providing care to clients with a diagnosis of lung cancer and were receiving care from an informal carer within the home, were provided with an information sheet that invited participation in the study. Participation involved a short interview which was conducted after the interview with the informal carer. As was the case with the informal carers the interview was held at a time and place convenient to the Registered Nurse. Two Registered Nurses agreed to participate with both requiring the interview to be conducted in their work place.

Data collection

Tollefson, Usher, Francis and Owens (2001, p.260) define interviews as a "conversation to gain information". Tollefson and colleagues (2001) suggested that when the interview is undertaken retrospectively, particularly following a prolonged period of time, the interviewer may only obtain information considered important to the participant. When interviews are to be undertaken it is necessary to structure the

interview to ensure the original aims are met (Tollefson et al., 2001). For the purpose of this study, the aim was to obtain information relating to the current experience of the participant. Following transcription of the interview tapes it became apparent that with some participants, events surrounding the initial diagnosis were continuing to affect the participant's current experience and ability to provide care.

Conducting interviews is an important element of research when it is necessary to elicit information pertaining to the carers concerns and to assist in identifying unmet needs (Chan & Chang, 1999). A further aspect that required consideration in this study was that the family member's condition is a factor that must be considered when conducting interviews (Jarrett et al., 1999). Wiles and colleagues (1999) expand on this to suggest that researchers should be sensitive to the family member's and caregivers' physical and emotional state so that distress and discomfort are not caused. It is believed that this will reduce the burden for the participants. Therefore, the time taken to conduct the interview is an important factor to consider. For the purpose of this study, carers of family members who were in the terminal stage of their illness were excluded and the length of time taken to conduct the interview was estimated to be approximately 60 minutes. The actual time taken for the interviews ranged from thirty to ninety minutes.

The data obtained from the informal carer was collected using an unstructured interview. The interviews conducted with the Registered Nurse followed a structured format (Appendix C) because these were used to specifically seek information in response to analysis of the carer's interview.

The interview with the informal carer commenced following the use of an initial question (Appendix D) that encouraged the participant to describe the illness trajectory from time of diagnosis to the time of the interview. This was to assist the researcher to develop a rapport with the carer and also to gain an understanding of the issues associated with the initial diagnosis. Following this question, an opening probe was used that encouraged the participant to describe the experience of providing care to the family member during the palliative phase of the illness. From the participant's response the researcher encouraged the participant to expand on the experience using prompts and probing questions. The duration of the interview varied between 30 and 90 minutes. Prior to commencing the interview participants were informed that a second interview may be required to clarify information; this was not necessary.

Verbal and non-verbal probes were utilised, as was recapitulation. Recapitulation was used as when the participant returns to the beginning of the experience it is often found that new details are included. Silence was used to establish a comfortable pace as this also encourages the participant to tell the story in his or her own way (Sorrell & Redmond, 1995).

Interviews conducted with the informal carers were audio taped for accuracy and transcribed verbatim by the researcher using a word processing package (Microsoft word XP). Interviews conducted with Registered Nurses were hand written by the researcher and checked by the Registered Nurse for accuracy prior to being transcribed by the researcher using the word processing package. All identifying features were removed during transcription.

Data analysis

Roberts and Taylor (2002) identify that by using an analysis method that produces themes and sub-themes a descriptive interpretation of the participants experience will emerge. To ensure that thematic analysis is achieved, it is important for the researcher to maintain the original aims and intentions of the research study (Roberts & Taylor, 2002). By doing this the researcher will recognise themes, both specific and implicit, as they emerge. The data was analysed using the method outlined by Colaizzi (1978).

1. Following the interview all tapes were listened to prior to transcription. Following transcription the researcher listened to the tapes while reading the transcript to ensure completeness and accuracy.
2. The researcher read and reread the written transcripts to acquire a feeling for and familiarity with each participant's stated or implied meanings. At this point the researcher also began to extract significant phrases from the transcripts.
3. The transcripts were read again and analysis of the individual statements began. At this stage the researcher reread the field notes appropriate to the transcript to determine underlying meaning to statements.
4. For each interview significant statements were identified and temporary themes applied.
5. Comparison of transcripts occurred and further themes identified. The supervisor of the researcher also reviewed sections of transcripts to ensure themes were not excluded.
6. During analysis the original aims and intentions of the study were reviewed to ensure that all possible themes were identified. Twelve provisional themes were identified which were then reduced to the final three. A further underlying concept was found which underpins the themes.
7. Informal carer participants were not requested to review the descriptions but at the time of interview the researcher had used paraphrasing and recapitulation to

ensure understanding of the experience described. The descriptions provided by the Registered Nurses were confirmed at the time of the interview with no data changes being necessary.

Rigour

The aim of qualitative research is to explore the experience of phenomena from the participant's perspective (Sandelowski, 1986; Roberts & Taylor 2002; Holloway & Wheeler, 1996). Further to this Sandelowski (1986) points out that reliability and validity are crucial in quantitative research. It is therefore necessary to establish guidelines that will ensure that qualitative research results meet methodological rigour testing.

Contrasting views exist on the format that needs to be followed to establish rigour in qualitative research. It is suggested by Holloway and Wheeler (1996) that establishing trustworthiness is the important element in rigour. Holloway and Wheeler (1996) point out that to achieve this, the researcher must provide a decision trail that can be followed by other researchers. Credibility, fittingness, auditability and confirmability are suggested by Sandelowski (1986, p. 29) as appropriate methods to achieve rigour in qualitative research.

Credibility is achieved when the phenomena studied are recognised by others as similar to their own experience (Roberts & Taylor, 2002; Sandelowski, 1986). To achieve fittingness the findings of the study should be pertinent to other settings. By ensuring that the decision trail can be followed by other researchers enabling them to reach the same or similar conclusion, the study will achieve auditability (Roberts & Taylor, 2002).

Confirmability is said to be the “criterion of neutrality in qualitative research” (Sandelowski, 1986, p. 34). To achieve this it is essential that credibility, fittingness and audibility are accomplished. To fulfill this criterion the participants should be able to recognise the study findings as their own lived experience without finding that the researchers own bias has impacted on the outcome (Roberts & Taylor, 2002; Sandelowski, 1986).

By utilising this approach the research will provide a decision trail that will enable participants to recognise the results as their own lived experience. Ultimately, other researchers will be able to follow the trail and determine that the results arose from the data obtained during the study.

Audit trail

Rogers and Cowles (1993) suggest that it is necessary to incorporate into the audit trail any decisions made by the researcher related to conducting the study. The audit trail should also include the reasons leading to the decisions made by the researcher involving the relationships between the various aspects that emerged from the interviews (Rogers & Cowles, 1993). In addition to this Rogers and Cowles (1993) suggest that the methods pertaining to data collection and analysis and how participants were included in the study should be incorporated into the audit trail.

For the purpose of this study the audit trail comprised of a methodological set of notes. These notes incorporated field notes, which included aspects of the interview such as the setting, non- verbal behaviour of the participants and any distractions during the interview process. Aspects of the field notes were incorporated into the

data collection during transcription of the interviews to provide the researcher with information pertaining to specific incidences that occurred during the interviews.

Bracketing

The primary goal of the researcher is to understand the meaning of the phenomena. It is therefore necessary to recognise how the researchers' own preconceptions may impact on the research. Currently there is debate among qualitative researchers how and if this can be achieved. Rew, Bechtel and Sapp (1993, p. 300) discuss the importance of delineating the roles of researcher and nurse to avoid role confusion during the interview. It is also necessary for the researcher to understand the reasoning related to why the chosen area of research was selected. This in turn impacts on the need for rigour in qualitative research.

As a Registered Nurse working within the community palliative care setting the experience of the researcher was that many carers were unable to manage the symptom of dyspnoea. This study was therefore undertaken to determine the experience of carers of family members who have lung cancer and the symptom of dyspnoea, which will enable a relevant education and support program to be established to assist this population. The researcher understood that her own preconception of the study would be related to establishing that no carer would be able to manage the symptom of dyspnoea. The researcher also recognised the need to avoid role confusion between nurse and researcher during the interview process. Strategies surrounding delineation of roles were discussed with the supervisor prior to interviews commencing. The researcher had also previously undertaken a role of research nurse and was able to utilise this experience within the current study.

To ensure that researcher bias did not occur, the interview utilised a semi-structured format. The primary intention of the study was to obtain information related to providing care to a family member experiencing dyspnoea. Opening questions and probes were structured to ensure this information was obtained. The interview structure was also planned to reveal other symptoms or areas of concern that impact on the caregiving experience.

Ethics

To uphold the principles of research ethics it is important that informed consent is obtained from the participants (Appendix E). This included ensuring that the participants were aware of the purpose of the study, participation is voluntary and that withdrawal could occur at any time without prejudice. The participants were informed that code numbers or pseudonyms would be allocated to maintain privacy. Participants were also advised that five years following the study data would be destroyed by shredding. Tapes were wiped and destroyed following transcription and checking by the researcher for accuracy. All data will be stored in a locked office for the five-year period in accordance with NHMRC guidelines.

Participants were informed that if he / she became distressed at any time during the interview the research nurse would cease the interview. The participant was then given the option of continuing after a break, continuing on another occasion or withdrawing from the study.

One participant became distressed during the interview and did not want to continue to talk on tape but requested that her discussion following cessation of taping was used in the study. All participants were offered the opportunity for referral to free of

charge counselling services at completion of the interview but no participant took up this offer.

The study commenced following ethics approval from the Edith Cowan University Ethics Committee and Silver Chain Hospice Care Service.

CHAPTER FIVE

Findings

Introduction

Analysis of the interviews undertaken with the carer will be discussed in this chapter. The main focus of these interviews was to discover the experience of the carer in providing care to a family member with lung cancer who has the symptom of dyspnoea classified as unresolved. In the context of this study the experience of the carer encompassed how the effects of caring for a family member impacts on the carers wellbeing and ability to provide care.

This chapter will also present the analysis of the interviews undertaken with the Registered Nurses providing care to the participant and family member. The main focus of the interview with the Registered Nurses was to determine what issues the Registered Nurse perceived to be causing concern to the carer and how these compared to the information gained from the carer. A secondary aim was to determine the information the Registered Nurse had provided to the carer to assist with care provision. By obtaining this data the researcher was able to compare the findings from the interviews conducted with the carer and the Registered Nurse to determine if the information provided to the carer by the Registered Nurse was utilised.

When discussing the themes that emerged from the analysis of the interviews, the informal carers will be identified by pseudonyms. Pseudonyms will be used for any family members or health care professionals identified during the interview.

Themes

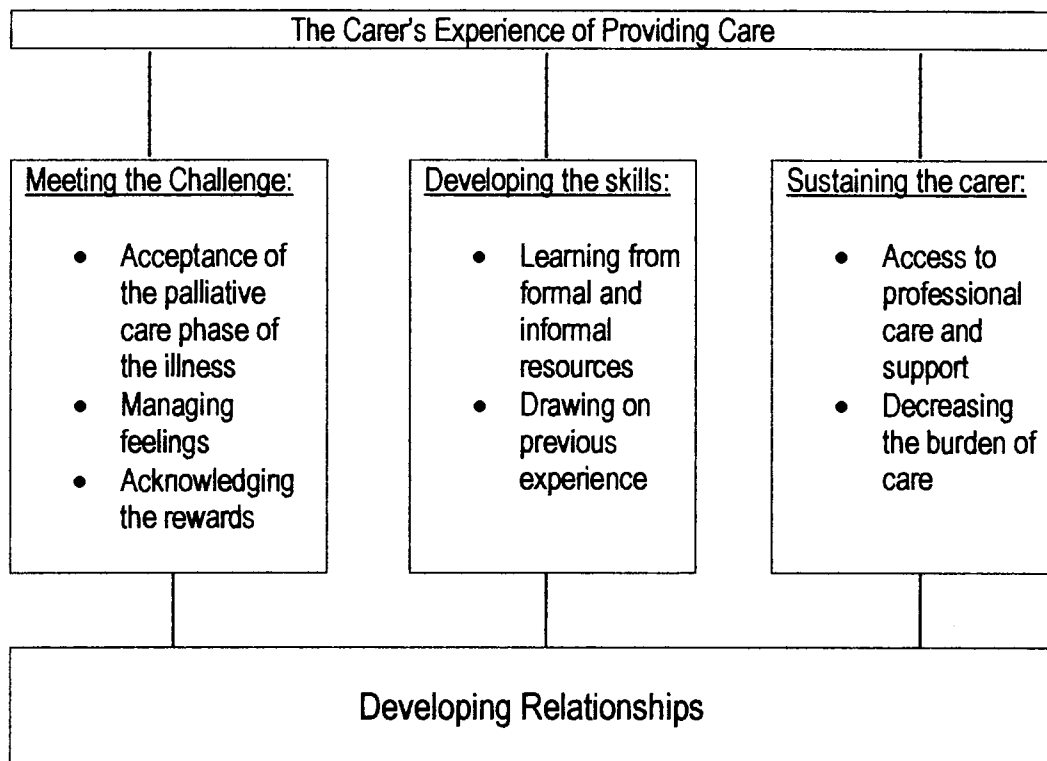
Three major themes that describe the carers experience emerged from the analysis.

- meeting the challenge
- developing the skills
- sustaining the carer

Within each major theme several sub themes were identified and are outlined in Figure 5.1. Each theme will be discussed in turn. At the end of each major theme a carer's story of their experience is presented to provide an overview of how the theme and sub theme relate.

In addition to the three major themes, the theme *developing relationships* emerged from the data. The data suggests that *developing relationships* is the underpinning concept that supports each of the three themes. The ability of the carer to manage the care of the family member at home is dependant upon the relationships that evolve between family members and other sources of support, both formal and informal. Although the theme, *developing relationships* is integral to each major theme it will be discussed separately. This will enable the researcher to describe the importance *developing relationships* has to the overall experience of providing care.

Figure 5.1: Managing Dyspnoea: The Informal Carer's Experience. Themes and Sub Themes.



Meeting the challenge

The theme *meeting the challenge* of providing care was evident for all of the participants' interviews. Caring for a family member was a daunting experience particularly when it was known that the family member was going to die. This theme incorporates recognition that caring is a challenge that can appear daunting, entails dealing with the unknown and provides a sense of achievement when the challenge is met. For the carer, *meeting the challenge* was about "doing it right" and ensuring that the family member received the best care possible. *Meeting the challenge* involved the carer developing the confidence to provide care and most importantly, the ability to continue to provide care. *Meeting the challenge* also encompasses the carer's intimate knowledge of the family member receiving care, understanding the difficulties

involved when providing care, but also acknowledging the rewards associated with caring for a family member within the home. Understanding of and the ability to manage the symptoms associated with lung cancer was part of this challenge. However, dyspnoea did not feature as a significant barrier to care provision, or as a specific area of concern for the participants.

No matter how difficult it was to provide care, the primary focus of the carers was to manage the care of the family member at home. While acknowledging their concerns and fears in “caring”, participants emphasised that they wanted to care for their family member at home. For example, Gwen who had previously discussed how she was unsure of her ability to provide care, and then stated, “I say all the time I can do it we will keep him here”. Within the context of this study the experience of the carer when *meeting the challenge* is one of achievement in being able to assist the family member to remain at home by providing support and care.

Carers acknowledge that providing care to a family member is challenging. *Meeting the challenge* of providing care and assisting the family member to remain at home is achieved by:

- the ability of the carer to adapt to the changing situation,
- developing confidence to provide what is perceived to be professional care,
- acknowledging the emotional aspects of the experience,
- recognising the rewards associated with providing care.

Carers acknowledged that providing care at home could be difficult, but the participants of this study were determined to continue to provide care to the family member within the home:

(Carol) "...it is never nice [watching someone die] and all those sort of things that's hard [emotional impact on all family members] but we're [the family] very happy that he is here and we would not want it any other way..."

(Fran) "...we are so lucky having a big family...if we did not have a big family we would definitely need somebody to come in helping. It is a huge undertaking really."

Three sub themes identified were acceptance of the palliative care phase, managing feelings and acknowledging the rewards. Each sub theme will be explained in detail and a brief overview is provided.

To enable the carer to meet the challenge of caring for the family member at home there were many aspects to be considered. Acceptance of the palliative care phase, which incorporated understanding that the outcome of the disease will be the death of the family member was a core sub-theme identified in enabling the carer to meet the challenge of providing care. For many of the participants it was this recognition that provided them with the framework in which they functioned, but also increased the challenge as they dealt with their personal feelings of loss and sadness.

While wanting to provide care at home and accepting the immediacy of death, the initial response of some carer's was to initially attach importance to understanding or determining the cause of the disease. Gwen's response following her husband's diagnosis of lung cancer was typical of other participants:

(Gwen) "but I think it was all the chemicals...he was ill when we laid that black stuff [mulch] you put on the garden over here."

The carers were then able to redefine the situation and obtain information from health care professionals to assist with the carer's understanding of the severity of the disease and prognosis:

(Carol) "...about two weeks ago they [doctors] started trying to find the cause of the shortness of breath because it was increasing...he has really been clinging onto that hope that it was an infection or...fluid there again...the last resort being that the tumour was in the good lung and that has only come...affirmed diagnosis two days ago when he had the x-ray...there is only a small 200ml of fluid there...so that's not what's causing it...so face the reality that it's tumour in that lung..."

By obtaining this information the carer was able to understand that the outcome of the disease process would be the death of the family member. Having a clear understanding is important for carers. A shared understanding between the family member and the carer helped carers focus on *meeting the challenge* of caring. The following exemplars reveal how in some situations the outcome of the disease process was also accepted by the family member:

(Carol) "...he [family member] has said ...dying is a part of living and it's a very important aspect to share, that it affects your own life. It's precious."

(Barbara) "...they're the cards I'm [family member] being dealt so I will just have to deal with it. So we are dealing with it...and we are managing really good I feel."

Within other families the carer accepted the outcome of the disease process but the family member remained in denial. This increased the burden on the carer. The following exemplar describes how the carer understands the need for her husband to maintain the hope that his condition will improve:

(Di) "I don't think he realizes how ill he is...he will keep saying to me I'll kick this...but I think if you are as ill as that you will grab onto anything."

When the carer found it difficult to accept the prognosis caring was more difficult. Eve, who was providing care to her husband, discussed how although he was psychologically prepared for the outcome of the disease she was not able to accept that death would occur in the near future as evidenced by:

(Eve) "I think if you have a strong heart and...your kidneys are alright ...why can't he live a few years...I can't see why he can't make it."

Maintaining normality and independence for the family member was viewed by the carers as integral to accepting the palliative care phase of the illness. Carers "know" the family member. They used this knowledge to stay true to the person when providing care. Carers worked within the limits of the situation. They took on aspects of the professional nurse role such as providing medications, use of equipment and physical care. By incorporating their knowledge of the person with the provision of care, carers provided holistic care to the family member.

Maintaining normality was achieved in various ways, which included goal setting:

(Barbara) "...we just set ourselves a goal and we just go for it. Then we suddenly realised we've just reached that goal, let's set another one..."

Carol's approach was to plan day by day:

(Carol) "...it's all day by day. You don't look to far ahead and you take a day at a time and go from there really."

As the family member's physical condition deteriorated carer's developed strategies to enable the continuation of care provision within the home while assisting the family member to maintain normality and independence as far as

possible. The following exemplar describes the consideration given to enabling the family member to continue to leave the home environment despite the limitations imposed by the symptom of dyspnoea. Alice required equipment that would enable the family member to move outside the immediate home environment:

(Alice) "if we go anywhere she has to go in her wheelchair because she just can't walk very far at all she gets short of breath."

Difficulties were also recognised by the nurses and carers regarding the use of equipment. Analysis of the data revealed that difficulties related to space available within the home and reluctance of the client to accept the need to use equipment.

The following exemplar describes consideration by the nurse regarding space available:

(Nurse: Sue) "...ensuring that equipment was in at the right time, not too soon as they lived in a small house, was very important."

Difficulties are also encountered when the family member receiving care is reluctant to accept assistance in the form of hospital equipment:

(Nurse: Tracey) "I offered a hospital bed, he was using a lounge in the family room so declined it."

(Ivy) "Sue [nurse] organised a shower chair...the only thing she [family member] uses it for is to stack her clothes on when she changes."

Managing feelings emerged as a pivotal component of *meeting the challenge*.

Managing feelings is achieved by establishing an awareness of the challenges involved in caring for a family member with lung cancer and the symptom of

dyspnoea. This includes understanding the disease process and acknowledging the physical and psychological impact the experience of providing or receiving care will have on the individuals involved.

There are many emotions that may be experienced by both the carer and the family member receiving care during an illness trajectory. Acknowledging these emotions and understanding the impact on the caring experience and managing these feelings, was highlighted by the informal carer as an important component in *meeting the challenge* of providing care. Managing feelings relates to how the carers manage their own feelings of distress, helplessness, frustration and guilt as well as assisting their family member during times of frustration and loss of dignity.

Caring does not occur in a vacuum. While meeting the physical and emotional needs of the family member, carers' are dealing with their own feelings of loss and stress.

(Barbara) " ...I used to change his dressing three times a day [to radiation skin reaction]...I would say... look at all the new skin around there, 'cos he could never see it and I would say you have got all this new skin today...and on the third day I would say its practically gone. I can't believe it and then that was all behind us then. Which was a good thing, because it was a really traumatic thing [changing the dressings] because I took all the gauze and all the medication off it and as soon as the air got to it he was just about screaming in pain so that's all behind us now thank goodness...before that I could not even look at a scabby sore or anything like that...And I did not even have to think about it [whether or not to do the dressing] I just started doing it and probably because it was Mark [family member]."

(Alice) "It's just very sad to see somebody [you care about] going down hill and knowing that really you can't do much to help her [family member]. I can care for her needs and everything but there is nothing much I can really do. I think it is probably worse for me than it is for her."

As the general condition of the family member deteriorated the carers developed an understanding of the situation from the family member's perspective and also developed strategies which assisted the carer with *meeting the challenge* of providing care. An important aspect of managing feelings was revealed as knowing the person. Knowing the intricacies of the family member permitted the carer to manage the feelings of distress and loss of dignity which accompanies the loss of independence:

(Di) "...it's in the morning he is bad tempered and I think it is all to do with the showering and shaving everything like that...this is a terrible disease you lose all dignity and so forth... I have to shower and shave him. It is very humiliating to him."

(Fran) "...so that was a big change for her going into the hospital bed, giving up her own bed."

Knowing the person also demonstrated to the carers that they were able to provide care that is important in maintaining the family member's psychological wellbeing. Providing this care assisted the carer and the family member to feel better:

(Fran) "... [mum] still has her make up on...doing her hair and setting it for her...ironed nighties and things like that. I think it helps her self esteem. I think it is very important."

(Eve) "...his trousers did not sit so nice anymore and I had to take in from all his trousers a big piece at the back."

Understanding the importance of maintaining normality and independence of the family member can also be achieved when the carer was able to preempt the family member's needs. Carol ensured that the family member did not become over exerted and therefore short of breath, by ensuring that all necessary items were within reach:

(Carol) "...if I know he is going outside I'll carry the things ...get his medications so he does not have to make that trip."

When the family member who is now receiving care has previously provided care to an individual with a terminal illness, that experience may impact on the current care. This is an important aspect that requires consideration by both the informal carer and health care professionals. From the perspective of the informal carer difficulties may be encountered if the family member's experience provides a barrier to care provision. Analysis of the transcripts revealed that managing the feelings of the family member while acknowledging the difficulties this previous experience imposed on the current care requirements resulted in emotional conflict for the carer.

Ivy acknowledged the difficulties facing her mother in law in relation to the use of medications. The following exemplar describes how the previous experience of providing care to a family member influenced Ivy's mother-in-law's own symptom control needs.

(Ivy) "...she nursed her daughter with cancer 10 years ago in England and Freda [daughter] was completely under the influence of morphine from the time mother got there. So to her morphine means she is going to take to bed and that's the end. So there is no way she is going to have the morphine so it's hard for her."

This difficulty was acknowledged by the visiting nurse:

(Nurse: Sue) "I suggested morphine for her breathing but that was very difficult as she [client] was very reluctant, it took a lot of persuasion."

The following exemplar describes the action taken by the family to meet this challenge and improve symptom management:

(Ivy) "...Sue [Registered Nurse] is going to talk to her about [use of morphine]...she [nurse] did talk to her last week...it was no, no way. We've all [family] spoken to her about it this week...[we have explained] it's not to put you [asleep], it's to manage your lungs, clear your airways..."

Carers suppress their own emotions and needs while continuing to ensure that the physical and emotional needs of the family member are met. This was discussed by Fran, who has a nursing background and found that although she had a theoretical understanding of the changes that were taking place, emotionally this was very difficult:

(Fran) "...she decided not to eat anymore...decided to drink sustagen three times a day, that was hard for me ...it's very hard for me to pull back and say this is what she wants...I just had to let it go really."

Other carers developed different strategies that involved continuing to provide care while suppressing their need to express their feelings. The following exemplars describe how the strategy used by Hilda and Di was to internalise emotions and not to discuss negative aspects of the family member's behaviour:

(Hilda) "...just try to keep my cool...not get agitated, sometimes I feel like snapping back but I try not to. Keep things on an even keel."

(Di) "...you can't tell him these things, you just have to keep it to yourself...I think you just have to be very brave."

In contrast to this, the strategy used by Alice is to undertake physical exercise:

(Alice) "...I can go and do forty laps of the pool...it completely relaxes me mentally."

Hilda described her feelings of helplessness when her husband insisted on driving home (approximately 50 kilometers) while experiencing a severe episode of dyspnoea:

(Hilda) "...he insisted on coming home, driving the car home ...It was scary ...I did not know whether to let him drive or not. I don't drive."

Situations that evoked feelings of guilt varied from responding negatively to the family member, belief that actions by the carer had increased symptoms or the use of respite. As discussed previously carers may suppress their own emotions but analysis of the interviews revealed that when a carer verbally responded the result was a feeling of guilt. An example of this is provided by Hilda, who discussed a conversation when she had told her daughter about an argument that she had with the family member:

(Hilda) "...I really wanted to shout at your dad, we had an argument and now I'm feeling guilty for doing it..."

Alice, who had been providing care for her friend for seven months, organised a period of respite to make it possible for herself to attend a family wedding. Alice described her feelings of guilt following a visit with her friend at the hospice:

(Alice) "... [friend] makes me feel mean and nasty as if why can't I really have her home."

Di who was trying to provide nourishing foods to her husband believed that her actions had increased the symptom of dyspnoea:

(Di) "I should have known...I should not have given him cream."

Analysis of the interviews revealed that a further aspect of managing feelings involved the carers continuing to provide care while feeling that they did not have the knowledge to do so. Helplessness emerged as a major issue in the carers perception *meeting the challenge* of caring. Carers described how they felt helpless when observing the family member during an episode of dyspnoea. The carers' explained that they believed they were unable to do

anything constructive to relieve the symptom. The following exemplars describe how the observing the family member during a period of dyspnoea increases the feeling of helplessness:

(Hilda) "...it makes you feel upset and wondering what you can do to help. There is nothing much you can do apart from giving him the medicine and getting things for him..."

(Carol) "...it is not nice to see...bodies fighting for air. It's not nice to watch".

(Eve) "...but it's hard to see when he gets out of breath."

Helplessness may also be experienced by carers if they do not have the knowledge or confidence to provide the family member with the appropriate information. Di, who is providing care to her elderly husband, discussed how he is unwilling to accept that he has a terminal illness and discusses any symptoms in relation to arthritic pains. The following exemplar describes Di's response to questioning by her husband regarding the cause of his back pain:

(Di) "...he does not understand his disease...I'm not a nurse and he keeps asking me questions and I keep telling him lies. I know I should talk to nurse..."

The feeling of frustration was revealed to be closely associated with the feeling of helplessness. Frustration emerged at those times when the carer wanted to request assistance from a formal source of support, but the family member was reluctant to accept this:

(Carol) "...I think we should ring Silver Chain or...ring the hospital and most of the time Paul was saying it's not necessary... The difficulty is overriding that, that very difficult thing to the wishes of the person and then what we are looking at that's a very difficult thing".

Throughout the interview Ivy, who was providing care to her mother-in-law, related the experience of providing care to the feeling of frustration and helplessness. This was discussed in relation to the family member's refusal of

treatment, reluctance to share the experience of symptoms and wanting to maintain her status as the family matriarch. The following exemplar describes emotions experienced by the carer in relation to lack of knowledge regarding the disease progression and symptoms that are being experienced:

(Ivy) "She's 88 years of age so refuses all treatment so really it's very hard because I find we are assuming a lot of things because she is not having updates on her treatment or x rays ...anything different she's getting we are automatically putting down to the cancer...so I find that's the hardest part actually because she is not inclined to tell us everything that is happening...I think that is the worse part of it even if you are just taking them for treatment or taking them to the doctors you feel as if you are doing something, whereas now we just feel as if we are just sitting watching her."

Acknowledging the rewards associated with providing care and assisting the family member to remain at home also emerged as a key sub-theme associated with *meeting the challenge*. As with each of the themes identified from the analysis of the interviews, underpinning all aspects involved with *meeting the challenge* is the theme *developing relationships*.

The primary purpose of the carer is to manage the care of the family member at home. Acknowledging the rewards associated with providing care to the family member was revealed as important to the carers. In many ways this enabled the carers to "meet the challenge" of being a carer. The rewards encompassed acknowledging the carers ability to provide care by adapting the carers own lifestyle, identifying abilities that had previously been unknown and changes in the carer / family member relationship that encouraged togetherness.

Within the context of the research question "what are the experiences of informal carers of palliative care family members with lung cancer who are experiencing the symptom of dyspnoea" and incorporated within the sub theme

of acknowledging the rewards are the positive aspects of the relationships that develop between the carer and the family member.

Carol, who was providing care to her brother in law, described the changes in the relationship between her brother in law and the other family members involved in care provision when he became comfortable in asking for help:

(Carol) "You try to maintain independence and all of that...do everything that you can to hang onto everything you can do. Whereas now he is happy to ask and realise that I am, the kids are, happy to do this, get that."

Barbara discussed how her relationship with her husband developed and they used the time remaining to undertake activities together such as buying Christmas presents for their grandchildren while her husband was still able to leave the home.

(Barbara) "...he used to play bowls...but this year we have done all the Christmas shopping together...it was really good. Good sense of feeling."

Fran, who had spoken about how important her relationship with her mother is to her, discussed the positive aspects of providing care in relation to ensuring that her mother remained in the care of the family:

(Fran) "It is a wonderful gift to be given that time to repay your mum for everything that she has done."

In relation to *meeting the challenge* and acknowledging the rewards adapting the carer's lifestyle to accommodate the needs of the family member was described in a positive manner. The rewards associated with the caring experience were related to the carer's ability to undertake the task. Joan discussed how she has adapted her own sleep pattern to enable her to continue

to provide the medications for her husband that he requires during the night to assist with the symptom of dyspnoea by:

(Joan) "...yesterday we got a nebuliser for him so I have to set that up and that was what I was doing at 11 o'clock [pm] and four o'clock this morning."

Acknowledging the carer's own ability to manage a situation which previously would have resulted in increased stress further strengthens the carers resolve when *meeting the challenge* of providing care. Barbara identified that her husband would not be willing to have physical care attended by people that he does not know so undertook the twice daily dressings that he required which resulted in her own feeling of achievement:

(Barbara) "...I was really proud of myself, the way I handled that [dressings] because if somebody had have told me that a week prior that I would be doing that I would have said no way..."

Acknowledging the rewards of caring was for one carer associated with the importance the family placed on the family member's status within the family unit. Ivy disclosed that her mother in law was viewed as the matriarch of the family. Ivy described her mother in laws behaviour and her own concerns regarding the families' ability to manage during the bereavement period by comparing her family with a fictional family shown in an English television series:

(Ivy) "We've got a good family, we are very lucky, it's just I don't know what will happen when it does occur, because did you ever see Eastenders well my daughter calls her Lou Beale. She says Nan you think you are Lou Beale. You are still telling me dad what to do and he's 67..."

Carol's experience

Carols experience is typical of the experience of the other carers who participated in this study. Carol's primary purpose was to manage the care of

her brother-in-law at home for the duration of his illness while continuing in the traditional roles of mother, home maker and wife.

Carol is married and has nine children whose ages range from one year to 17. Carol is also the primary carer to her brother-in-law who has lung cancer and bone metastasis. Carol's discussion of providing care to her brother-in-law incorporated her spiritual beliefs, her knowledge of the care that a friend had required and her understanding of the needs of her children. She was not able to seek assistance with care from extended family as they lived interstate. Carol's brother-in-law had previously lived in Victoria, but moved to Western Australia following a marriage breakdown. He had developed few friendships during this time.

Although it was evident that her brother-in-law's condition was deteriorating, Carol presented as a person who was confident that she could continue to manage his care at home. Her focus was on the positive aspects of meeting the challenges involved in care provision by utilising previous experience, interaction between herself, her brother-in-law and health care professionals, support resources from family and spiritual beliefs. While accepting the immediacy of the death of her brother-in-law, Carol also focused on *developing relationships* between herself, her family and her brother-in-law to ensure optimal care provision and a positive experience for all involved.

Acceptance of the palliative care phase of the illness, managing feelings and acknowledging the rewards are important sub themes involved with *meeting the challenge*. Incorporated within each of these sub themes is the carer's

acknowledging that they want to manage the care of the family member at home. Acceptance of the palliative care phase, managing feelings and acknowledging the rewards assisted the carers to achieve the goal of providing care to the family member within the home.

Developing the skills

To be able to provide care to a family member with lung cancer and the symptom of dyspnoea within the home care setting carers' identified that they needed to develop new skills. The carers did not describe dyspnoea as a specific symptom that hindered their ability to develop the skills required to meet the physical and psychological needs of the family member. Again, dyspnoea did not focus strongly, it was less of a focus than managing medications or physical care.

In relation to the research question "what are the experiences of informal carers of palliative care family members with lung cancer and the symptom of dyspnoea" the theme *developing the skills* reflects that the carers take on aspects of the professional carer role and as a result rapidly learn technical skills. This is not viewed by the carers as a source of stress; however, the carers described feelings of uncertainty, nervousness and helplessness when initially developing the skills required to provide care to the family member.

Two aspects were identified as pivotal to assisting the carers develop the skills to enable the provision of care. These aspects were learning from formal and informal resources and drawing on previous experience. Analysis of the transcripts reveals that the focal areas of *developing the skills* were in relation

to knowledge of medications and provision of physical care. These skills were gained by the carer by learning from formal and informal resources. Carers developed these skills through education and observation.

Learning from formal and informal resources was an important aspect in developing the skills necessary to provide care to the family member. Communication between the carer and the resources assisted the carer with *developing the skills* when the information provided was tailored to the carer's specific needs. In some situations poor communication hindered skill development. Barbara's experience, which will be outlined at the end of this sub theme, demonstrates how effective communication between the carer and formal resources can promote the carer's ability to provide effective and appropriate care.

Sources of knowledge varied. The following exemplar describes how Barbara was having difficulty understanding the personality changes her husband was experiencing in relation to medications until she discussed this with a friend who had experienced a similar situation:

(Barbara) "He [husband] was on dexamethasone and it just completely changed his personality and I just couldn't deal with it. He was swearing and yelling out ...he has never even raised his voice to me... ...she [friend] looked after her brother with cancer ...her brother was on the dexamethasone and he got to the stage where he was calling her [swearing] ...Mark was swearing...words that he would never use and this other person said the same thing ..."

In contrast to Barbara's experience, Alice accepted the mental state changes which were affecting her friend as part of the disease process:

(Alice) "She gets very disorientated, yet she does not seem to notice it. It's very distressing for somebody you know. She comes out with stupid things, you

have got to try and think of an answer that does not make it look as though she is stupid..."

When seeking information in relation to either the provision of physical care or information regarding medication, carers also utilised the knowledge from professional resources. This may be through indirect activities such as by discussion with health care professionals or observation of nurses who are providing care.

Although wanting to manage care provision at home, analysis of the interviews identified carers with no previous experience of providing care felt less secure in their ability to manage this role. Barbara's experience demonstrates how confidence in ability increased when assistance was sought from other sources. Barbara described how receiving positive reinforcement from an outpatient facility enabled her to develop confidence in her ability to provide care:

(Barbara) "I believed that I would never do it [dressings] and it was really nasty [radiation skin reaction] and everybody commented at the hospital and they said you know you have done such a good job."

Di and Gwen, who were providing care to their elderly husbands, discussed how they were unsure of their ability to provide care as evidenced by:

(Di) "Last year we had to go to Scotland because my sister in law was dying of lung cancer...but no I have never nursed anybody...I don't know how good I am."

(Gwen) "...me and my sister are both entirely different people and she helped my mum and dad when they were ill. The things that she done [personal care] I could never have done."

Skills can also be developed by the carer through direct activities such as when the carers are encouraged to provide physical care in conjunction with the nurse who is attending to the care.

Barbara observed dressings being attended to her husband's severe radiation skin reactions and modeled her care on her observations:

(Barbara) "...I watched them [hospital nurses] and then I came home and did it..."

A major component of learning from formal and informal resources is the ability for all individuals involved to communicate effectively. Information which is provided to carers may be of a technical nature therefore it is necessary for this to be communicated to the carer in a meaningful way to ensure the carer understands the care to be given. An exemplar of communication in relation to ways of decreasing dyspnoea experienced by the family member during showering was discussed by Fran:

(Fran) "The nurses have told me everything that we have to do. They [nurses] suggested saturating her system with oxygen before going to the shower...using morphine syrup and morphine tablets which gave her coverage..."

However, analysis of the interviews highlighted differences in understanding between the nurse and the carer regarding symptom management. The following exemplars demonstrate the differences in relation to managing dyspnoeic episodes.

Tracey, the Registered Nurse, explained the options that she believed had been understood by Joan:

(Nurse: Tracey) "I talked about the shortness of breath and suggested staging activities... equipment to make doing activities easier...using a fan to blow air...to get air movement around his face when he was short of breath. I also talked to him [family member] and his wife [Joan] about finding a comfortable position to sit in which would help when he is short of breath."
"

Joan's interpretation however, was very different:

(Joan) "...I tried as the silver nurse said waft a paper, make a draft in front of him to try to help. Only it does not help 'cos he gets aggravated..."

When discussing medications, Joan explained that following discussion with the home visiting nurse she was aware of the use of morphine to assist with management of dyspnoea:

(Joan) "...He was on one millimeter [milliliter] now...he can have either two or four depending on his need. So now he is having two...if he has too many attacks I will put it up..."

In contrast to this Di, who was unsure of symptom management, was also unsure of the information that she received from the visiting nurse:

(Di) "...I don't know what to give him [for dyspnoea and pain relief] so we talk to the nurse but I don't think she knows. She might up his morphine again, that's the only thing."

Analysis of the transcripts revealed that carers underrate the significance of their role and care provided which can result in feelings of inadequacy.

Although providing care which enabled her mother-in-law to remain at home Ivy did not believe that the practical assistance she was providing was beneficial:

(Ivy) "...nothing that is helping her in the illness...looking after her, cooking for her, washing, cleaning whatever but we are not doing anything that is beneficial in my eyes to her..."

Negative aspects of communication, which makes *developing the skills* difficult, were also discussed by the carers. Carers identified that they did not receive all the information necessary for care provision as evidenced by:

(Hilda) "...there was nothing about that [side effects of treatment] [told to us]. We only knew what we had heard from other people [non-professional]."

Alice related this as associated with not directly being related to the person she was caring for:

(Alice) "I would like to know [prognosis] for her sake. What I'm really nursing is it just the same or has it advanced to other cells...Maybe I want to know too much, I don't know."

Communication in the three-way relationship amongst the carer, family member and health care professional can be complex with differing views on disclosure. Reluctance by the family member to share what is happening with both the carer and the health care professional could result in the carer not having access to the technical information that will assist with managing the care effectively.

The following exemplar describes how Sue, the Registered Nurse, identified that the reluctance by the family member to disclose to both the health care professional and the carer what is happening, impeded the carer's ability to provide care. Within this family the elderly family member was determined to continue managing her own care despite increasing frailty, shortness of breath and falls without the use of medications, equipment and assistance from others.

(Nurse: Sue) "Everything was a problem because she [family member] would not comply with taking medications or any suggestions to help."

Ivy, the carer, highlighted the difficulties when the carer's view on disclosure to health care professionals differs to that of the clients:

(Ivy) "...when Sue [nurse] is here she will ask her [family member] a question and sometimes it is not always the truth that she's answering and looks go on and she [family member] looks at me as if to say don't tell her and Sue looks at me as if to say is that right...and I will say you have got to be honest with them otherwise they can't help."

Drawing on previous experience was also associated with *developing the skills* required to provide care. Analysis of the interviews reveals that previous experience may help or hinder the development of skills. When carer's utilised knowledge and strengths gained from previous experience and adapted this knowledge to the current situation of providing care to a family member. The following exemplars describe how past experiences may not be related to direct care provision but provided an understanding of the impact of the disease process for the carers:

(Hilda) "...[my] granddaughter had a tumor behind her ear ...so we knew all about what had happened in her case."

(Carol) "...it helped that I had a girlfriend who died of the same thing [lung cancer]....I think that has really helped me see the natural progression of it."

A family who had successfully managed a similar situation previously was able to adapt the knowledge gained from that experience to the current situation as shown by:

(Fran) "I have a nursing background and also we have nursed our father at home 14 years ago...we have just got into the same thing as we did then."

In contrast to this Ivy, who had previously experienced providing care to a family member could not relate that experience to the current situation. Previously the care had been provided to a family member who had a

head/neck cancer with visible tumour growth. This family member continued to visit specialists throughout the duration of the illness. Ivy found the current situation difficult as there was no visible evidence of tumour growth and the family member had declined treatment:

(Ivy) "That was totally different because you could see Jacks [nephew] it was on the outside [gestured to face and neck] and Albert [husband] used to take him to the specialist so we knew exactly what was happening with him."

The Registered Nurse providing care to this family identified that Ivy and Albert were continually comparing the current experience of care provision with their previous experience. This past experience had the impact of hindering the development of skills. The following exemplar demonstrates the Registered Nurses understanding of the situation and the approach taken to assist the family at this time:

(Nurse: Sue) "I let them [Ivy and Albert] talk about their anxieties related to a previous experience. Then I was able to reassure them that they were not making the same mistakes. There was something about a pressure sore so she [family member] got rubbed frequently."

Although expressing difficulties in associating this caring experience with a previous experience drawing on previous experience was possible for Ivy when planning for the terminal stages of her family member's illness. Analysis of the interview highlighted the importance of communication between all family members involved in providing care when planning for future occurrences. Ivy lives in a granny flat situated in the garden of her daughter's home. The family member receiving care has a bedroom in the main house. The following exemplar describes how Ivy and her family have made changes and planned for when the family member's health deteriorates further:

(Ivy) "...we have only got one bedroom so what we did was took a window out of my daughters place and put in a door so that is mothers room, but when things get worse we intend swapping rooms and one of us will stay in here with her."

Learning from informal and formal sources assisted the carers in *developing the skills* required to enabled care to be provided within the home. Learning could be achieved in various ways but effective communication between all individuals involved in the caring experience was revealed as the essential component which assisted the carer in *developing the skills*. Drawing on previous experience and adapting this experience to the current situation assists the carer to further develop skills.

Barbara's experience

Barbara had been married to Mark for 42 years and prior to the diagnosis of lung cancer both had enjoyed good health. Barbara had never worked outside the home. Her role was that of housewife and mother to their three children. Mark had always maintained the traditional male role in the marriage and had relieved Barbara from undertaking any situations that she may have found difficult.

Barbara's discussion of her experience of providing care to Mark focused on her need to "draw strength" from Mark and her perception that she was "weak" because she "had not had any bad things happen" prior to Marks diagnosis of lung cancer. Barbara described Mark as a perfectionist who had "spoilt" her for the duration of their marriage. This perfectionist attitude was demonstrated when at the beginning of the interview Mark organised the tape recorder and conducted a test to ensure that the interview could proceed effectively.

Although Barbara's focus was on her perceived weaknesses she also described how she had changed from a person with minimal confidence in her ability to manage any caring skills, to one who could "manage any aspect" of caring. Barbara described how she had developed these skills by observing nursing staff and mirroring their practice and also by discussing issues that concerned her with health care professionals and informal support networks such as friends.

Sustaining the carer

Maintaining physical, psychological and spiritual wellbeing has been discussed by many authors (Carter & Chang, 2000; Hinton, 1994; McCorkle & Pasacreta, 2001) who have studied the impact of providing care on informal carers. Analysis of the interviews revealed that within this population of carers, providing care to a family member who has lung cancer and the symptom of dyspnoea, sustaining the carer emerged as an important theme. The informal carers did not identify the symptom of dyspnoea as a specific concern, but were generally concerned about symptom management as a whole. Dyspnoea was identified as being a symptom that required intervention by health care professionals and was not the responsibility of the informal carer. Therefore *sustaining the carer* is an important theme that involves interactions between the carer and health care professional to promote and develop the ability of the carer through provision of education and information to manage the symptom of dyspnoea as opposed to the carer waiting for and relying upon professional assistance.

Sustaining the carer occurred in two distinct ways. Access to professional care and support emerged as a sub-theme that demonstrated the importance of receiving assistance from professional resources. A second sub-theme, decreasing the burden of care, incorporated understanding of the situation by informal resources such as family, friends and the use of professional services that provided advice and respite. Within the theme of *sustaining the carer* three distinct supportive networks were identified. These were formal, informal and spiritual. Formal networks discussed by the carer comprised home care agencies, in-patient facilities and general practitioners. The informal sources were other family members and friends. Spiritual support was identified as involving the carer's own beliefs and also from religious institutions such as the local church attended by the carer. The importance of access to formal support when providing care at home was viewed by the carers in two ways. These included allaying concerns and supportive actions.

Pivotal to the support for carers was confidence and knowledge that professional attention could be obtained promptly if required. The following exemplars describe how access to professional care and support allayed concerns expressed by carers who were concerned about a family members well being.

Alice, who has attended Dr Smith's general practice for many years found that as Dr Smith knew the carer and family member, he understood the situation and was able to provide assistance when necessary and at short notice:

(Alice) "...we took her over to Dr Smith who's our normal doctor. He is always willing to put [fit] us in, you know, under the circumstances...."

The formal source may be a home visiting service as shown by:

(Hilda) "...so I rang the nurse and she came..., it did not take very long. She thought it may be an infection he had got because he had a temperature as well, like flu symptoms it was actually. She gave him an injection well she rang the doctor first and the doctor said give him an injection and he slept the rest of the day and then he was alright again. Well a lot better than he had been."

In contrast, when professional care was difficult to access the carer's uncertainty and distress increased. This did not help sustain the carer. The need for prompt medical attention extended to the carers', who recognised the need for their own health to be maintained. In contrast to the experience of Alice, Joan had concerns regarding the support available from her local general practitioner service because it was difficult to obtain appointments with him / her. Joan discussed this in relation to her concern regarding spread of infection from herself to her husband.

(Joan) "I had to wait a week for an appointment because I had a chest infection...dad [husband] goes for chemotherapy and I was worried about giving him the infection..."

Although the home visiting service was identified as a crucial support for carers' analysis of the transcripts revealed that this service was not always accessed. There was a reluctance to call on services outside of regular hours.

Joan described an instance when although concerned about the family member, the home visiting service was not accessed until the following morning:

(Joan) "I did not phone her [nurse] through the night [because] I did not like disturbing them [nurses]...he was bad with his coughing, really bad I thought I was going to lose him."

The carer then explained that if she was concerned in the future she would contact the home visiting service:

(Joan) "...after what she [nurse] told me I would call them out because then they could give him an injection to help..."

Analysis of the data revealed that that some carers do not have the self confidence to request advice from health care professionals. The following exemplar describes how Di, who had met several of the home visiting nurses, did not believe that she had been able to develop a relationship with any of the nurses, that permitted her to contradict the information the nurses were receiving from her husband.

(Di) "If I say anything the nurse might think well she's a liar."

In contrast to Di's experience, Carol was receiving support from one nurse but did not have the confidence to discuss her concerns with the visiting nurse:

(Carol) "...the whole aspect too of you don't want to bother people. Are they going to say well bad luck mate you're going to have to put up with it..."

The importance of continuity of care within the home setting was highlighted by participants and nurses. One family was experiencing difficulties in providing care because the family member would not discuss symptoms with the carer. This carer utilised the relationship between the family member and the nurse to reinforce symptom management:

(Ivy) She [family member] has really taken to Sue [nurse] she [family member] thinks she [Sue] is absolutely wonderful so tends to talk to Sue more [than to us]...I even had to ring Sue [to ask] was it alright for her to take a lemsip as well as her ordinary medications...she won't take it [medications] unless we get proof [that it will not cause harm]..."

The nurse providing care to Ivy's family recognised the difficulties that were being experienced. The nurse discussed her impression of how continuity of care enabled Ivy to continue to provide care:

(Nurse: Sue) "I think that continuity of care was also very important as only one other nurse went into the home. The family said that they did not always phone as they...were able to anticipate what I would have said in that situation..."

Analysis of the interviews highlights the importance placed upon access to professional care and support. Supportive actions accessed from formal sources and identified by carers, varied from home visits by volunteers to hygiene assistance and provision of supplementary foods:

(Alice) "Silver Chain has got carers and one comes in Mondays and Fridays for three hours so that I can go off [to meet with friends]..."

(Fran) "...and the care nurse who come to shower her and sponge her have been wonderful."

(Eve) "But there again Silver Circle (sic) came in and brought him some cans of ensure and he did quite like them."

Family carers reported the importance of the roles played by formal and informal resources in *sustaining the carer* by decreasing the burden of care for the informal carer. Informal support, from family and friends decreased the burden of care provision when they demonstrated understanding of the situation. This understanding was demonstrated by assistance with care and nonjudgmental listening.

The following exemplars describe incidences when family members and friends received the information about the family member's stage of illness and were able to provide the primary carer with assistance with care. Respite, either for a few hours or days, was identified as pivotal for sustaining the carer.

Volunteers, family and friends were supportive in enabling the carers to have a break from care provision.

Periods of respite were also obtained for carers when family members who lived overseas visited and remained in the home with the family member, enabling the carer to attend to business outside of the home.

(Joan) "...the family rallies round. I went to the casino one day and he had to go down to his daughters in Safety Bay and stay there."

(Alice) "... [sister & sister in law] came over from Holland. It was just about getting to that stage where I needed a break..."

(Gwen) "... [The doctors stated that] they can't do any more for him, so I told them [sister & sister in law living in England] and they came out...so that gives me a break."

Fran, who was providing care to her mother, organised a roster to ensure that all family members assisted with the care provision.

(Fran) "...my family and I all look after mum, so all of us chip in...we have a roster...we set up a communication book and communication board so we all read those."

(Joan) "...his granddaughter comes in for lunch every day while she is at work and his daughter comes at half past three and the other daughter phones and his son phones from Shark Bay. The family is all coming for dad, even if they are far away."

Although this may be viewed by some carers as integral to *sustaining the carer*, rosters are not always well received by the family member:

(Ivy) "We are frightened of her falling and that's why there is always somebody here. But she gets irate about that...she says you should not be staying with me. I'm not a baby."

To alleviate the situation, a compromise was discussed and Ivy's mother-in-law accepted the use of a monitor, which permitted her to remain in the house alone and therefore maintain independence.

In addition to the carer receiving support from family members, carers also viewed their role as supporting or protecting other family members who had a close relationship with the family member receiving care. Ivy, who viewed her family as the main support source discussed how she was attempting to protect the family by relating to a previous experience when she had to leave her brother who later died:

(Ivy) "...we thought mother was getting worse rather quick. Paul [grandson, living in Sydney] said do you think I should come over [to Perth]...I said I can't tell you...I know what it is like to...have to leave [a family member who is dying]...he [Paul] arrived here Thursday night...He is her favorite. But my daughters are really good with her [family member] ...We have got support but...we tend to shield the girls the same as she is doing with us."

Discussing the prognosis with the carer can cause difficulties for health care professionals and at these times it is essential that the information is provided in language that is easily understood. The following exemplar describes the Registered Nurses' concerns following discussion of the prognosis with the carer. While understanding the families need to be with the client during the terminal stages of the illness the Registered Nurse advised the family of the prognosis and was then concerned that the family had misinterpreted the information:

(Nurse: Sue) "I advised them about getting the favourite grandson over from Sydney, twice. I made a mistake the first time. You know you have the talk and they thought I meant to get him over immediately, but he was here when she [client] died."

The interviews highlighted the pivotal role played by family and friends in decreasing the burden of care by listening to the carers' concerns and fears without providing advice and/ or comment.

(Fran) "...I can just go and cry in front of them [friends] and just blabber on. They understand and it's just wonderful."

(Hilda) "...she [daughter] stayed with me that night because I just went to pieces..."

(Alice) "...she [friend] provides a lot of support...I can sort of unload to her."

The importance of informal support in relation to decreasing the burden of care was also highlighted when it was not available. Gwen discussed how she and her husband had migrated from England to live close to their only child in Australia and provide support for their daughter and grandchildren. Since migrating to Australia the relationship had not developed as expected and now Gwen's husband was in the palliative care phase of his illness. Gwen considered the actions and statements by her daughter to be affecting her own wellbeing:

(Gwen) "The only time she [daughter] helps because she works near the hospital...she's not much company not for us."

Gwen described herself as "hard" and not able to express emotion in relation to her husband's illness. In contrast to this when discussing the relationship with her daughter she stated "I do shed a tear over her though", at this point of the interview Gwen became very emotional and the interview ceased.

Barriers to decreasing the burden of care were associated with the carer's reluctance to utilise available services or the family member's concern that assistance from others may result in hospitalisation. The carers acknowledged

the availability of formal respite as a resource that could assist to sustain them in their role as carer. However, for some, this was not a viable option.

The following exemplars highlight the burden these carers carry while wanting to provide optimal care for the family member regardless of the cost to their own health and wellbeing. Di would not consider the option of inpatient respite and provided two reasons for this. The first reason related to her concerns regarding being separated as Di and her husband had been married for 53 years:

(Di) "Nurse has said that to give me a break they can take him into hospital for a couple of days but I 'cannay' even see that. I don't think I would let them you know we have been together too long."

The second reason was discussed in relation to the psychological impact that she believed respite would have on her husband:

(Di) "...he would think he is worse than what he is. You know you are walking on eggshells. No I'll carry on until I can't."

Alice, who was providing care to her friend, initially decided not to use respite because she felt it would be perceived as abandoning her friend whose relatives had recently returned to Holland:

(Alice) "...there was no way I could put her into respite having lost her sister and sister-in-law whom she loves so dearly. They [sister and sister-in-law] had just gone back [to Holland]. There is no way I could say you go out to [hospice]..."

During a discussion with her mother-in-law, Ivy found that a major concern was related to the prospect of going into hospital:

(Ivy) "...her greatest fear was to be put into hospital so we have sorted that one out. She is not going unless it is absolutely vital."

Ivy discussed this with both her mother-in-law and the visiting Registered Nurse. The nurse observed that Ivy and her husband were becoming exhausted from providing care so did not offer in-patient respite but offered in-home respite which was declined. To enable continuation of care within the home and relieve the burden from the primary carer the nurse organised a family roster:

(Nurse: Sue) "...she [family member] lived longer than we thought she would, so I [RN] organised shifts that involved all the family".

Volunteer services, which can assist in decreasing the burden of care, are available to visit family members within their homes thereby enabling carers to attend to business outside of the home. Hilda who had discussed her frustration in relation to being with her husband twenty four hours a day was offered this service but declined as she believed her husband would not be receptive to this:

(Hilda) "I don't think so I don't think he would be very keen. I suppose if I had to go somewhere he'd have to but I don't think he would really, well not at this stage anyway."

In contrast to Hilda, Joan preferred not to use volunteer support from a formal agency, which was offered by the visiting Registered Nurse, but to continue using the support from family members:

(Joan) "There was a lady came round. She was a relief sitter and I haven't needed her because I don't go out anywhere. My daughter takes me shopping...one of the kids come round with her and they stay with dad [client] until I come back."

The final supportive network associated with *sustaining the carer* is spiritual support. Spiritual support was revealed to encompass both sub themes associated with *sustaining the carer*. The participants revealed that the offer of

assistance for all aspects of caring were available from the religious institutions to which they belonged. No participants had accepted physical assistance from this supportive resource. As previously stated, Alice utilised her own spiritual beliefs and those of the family member to assist with sustaining her during this time.

(Alice). "It is a wonderful faith...she [family member] has even got to the point of saying if he [God] does not heal me down here he will heal me in heaven any way, so there is some truth in that."

Carol utilised religious beliefs to explain to her children what was happening to the family member:

(Carol) "...we believe in God and that is an enormous foundation of where you start looking at the whole suffering, death, life, eternal life that whole process."

In contrast to this Di, whose husband did not openly acknowledge any specific spiritual belief used her own beliefs to assist her during this time:

(Di) "...I don't think I'll get by without praying."

Supportive networks are an essential component in enabling the carer to provide care to a family member within the home. Support can be obtained from various sources which include home visiting services, general practitioners and friends. The importance of support provided by either professional lay or spiritual resources emerged from the data as core components of sustaining the carer and enabling them to maintain their own wellbeing.

Analysis of the interviews in relation to sustaining the carer shows that Alice's experience of care provision was typical of all participants. Alice has previous experience in providing care to a friend with a terminal illness was able to reflect on the past experience to assist with the current situation. In the current situation, Alice was again providing care to a friend and was able to utilise formal and informal resources to assist with care provision. Alice also drew on her own and her friend's spiritual beliefs to support her during this time.

Alice's experience

Alice a widow in her 70s has one daughter living in the Northern Territory and had been providing care to her friend of twenty years, Pru. Following Pru's initial admission to hospital where she received the diagnosis of lung cancer and cerebral metastasis, Alice offered to provide care to Pru for one month. It was expected that at the end of the month Pru would be able to return to her own home. Pru did not improve so remained at Alice's home. Alice had been providing care to Pru for seven months, but had placed Pru in a local hospice three days prior to the interview to provide Alice with two weeks respite. At the time of the interview Alice was feeling very angry towards Pru, as Pru had requested to return home while knowing that Alice was going on holiday the following day.

While presenting as very confident in her ability to provide physical care to Pru, Alice was aware of her need to obtain support from formal and informal sources which would enable her to continue to provide care. Alice had utilised support provided by her General Practitioner, SCHCS and friends. Alice also described the importance of spiritual beliefs, which were highlighted during

the interview when Alice referred to how Pru “lived her life according to Isaiah 51 – 54” and that she encouraged this to continue.

Developing relationships

Developing relationships emerged from the data as the underpinning theme that supports each of the three major themes. The ability of the carer to provide and maintain care of a family member at home is dependent upon the relationships that develop throughout the caring experience and/or relationships that have developed previously. These relationships occur amongst the carer, formal and informal resources. The relationship that the carer has with the family member receiving care and other members of the family unit will also influence the caring experience.

Interactions with formal sources of support begin at the time of diagnosis. This interaction may assist or provide a barrier to the carer’s ability in developing a relationship with the health care professional and will therefore influence the caring experience. Of the major themes identified from this study, *developing relationships* was revealed to be a pivotal component of each of the sub themes (refer to Figure 5.1, p. 60).

Health care professionals have a key role in promoting provision of care by informal carers. By enabling the carers to develop a trusting relationship through open and empathetic communication, the carers are able to feel supported and therefore able to seek assistance during times of need.

Carers established relationships with health care professionals, which permitted the expression of the carers' own emotion. Barbara had developed a relationship with the palliative care consultant that enabled her to express her feeling of helplessness. Barbara had been struggling to understand the behavioural changes exhibited by her husband:

(Barbara) "...doctor said how have you been going Mark...and I just stood up and said...we are not going great we are going just terrible because I couldn't cope."

Developing relationships that promoted a learning environment assisted the carer to provide care that met the physical and psychological needs of the family member. Carers also highlighted the feelings of helplessness when observing a family member experiencing dyspnoea. Although stating that management of dyspnoea was the responsibility of health care professionals Carol had developed a relationship with the visiting palliative care nurse and was able to obtain advice regarding management of dyspnoea:

(Carol) "...whatever they've [nurses] said to do we've made sure we do [use of medications and oxygen]...to make his breathing easier...the nurses are the experts."

In contrast to Barbara's and Carol's experiences, Eve's initial interaction with a health care professional was not one that she identified as beneficial. The following exemplars from the interview with Eve described her feelings of rejection following a meeting with one health care professional, but following a second opinion, her hope was restored:

(Eve) "We [Eve and family] came there thinking that they [radiation oncologist] was going to give him radiation treatment...he [radiation oncologist] just sends us home and sorry [claps hands] we can't do nothing for you...I did not expect that...[it was] too hard, too hard."

(Eve) "...they [radiation oncology team] told us that he [radiation oncologist] can't guarantee anything but he [radiation oncologist, second opinion] told us he was going to have a try."

Developing relationships with providers of supportive services not previously accessed by the carer or family often occurred at a time known to cause increased carer stress and at a time when the family member was psychologically vulnerable and physically weak. The ability of the health care professional to assist with *developing relationships* between the health care professional and family members provides the health care professional with an understanding of family interactions and concerns of each of the family members. This understanding challenges the way in which health care professionals offer supportive services. The importance of developing a trusting relationship that provided support while also promoting independence of the carer was discussed by the Registered Nurse:

(Nurse: Sue) "I also believe that by not being there all the time, letting them know I believe in what you are doing ...letting them know I trust their judgment."

The following exemplar describes how the Registered Nurse was able to utilise the understanding of how the family interacts to offer appropriate assistance to the family. Sue, the Registered Nurse providing care to Ivy's mother in law acknowledged that to offer respite within an in-patient facility would be inappropriate for this family:

(Nurse: Sue) "I [Registered Nurse] knew she [family member] was adamant that she would not go back into hospital. If I had suggested respite it would just have alienated them [family]."

Relationships that have developed during the carers' lifetime were also viewed as an important component of the caring role. The relationship between carer

and family member was so important that one carer ceased work outside the home. Fran discussed how her relationship with her mother, (the family member receiving care) impacted on her decision to provide the care within the home:

(Fran) "...I gave up work to look after mum...It was so important to be with her."

Developing relationships has been revealed as an essential component in enabling the carer to provide care to a family member who has lung cancer and the symptom of dyspnoea. Relationships can be developed between the carer and family members and / or formal or informal sources of support. These relationships will permit exploration of the carers own needs, the family members needs and the needs of other family members involved in care provision. By exploring these needs the carer is able to develop strategies that will enable these needs to be met and therefore assist the care to manage the care of the family member within the home.

Summary

"What are the experiences of informal carers of palliative care family members with lung cancer and the symptom of dyspnoea" was the research question used to guide analysis of the interviews. The analysis shows that the focus of care was the family member and the carers were willing to provide any care to enable the family member to remain at home. The experience of the carers highlighted three main themes. These themes were *meeting the challenge*, *developing the skills* and *sustaining the carer*. Within each of these themes, sub themes were identified which assisted carers to continue managing the care at home.

Carers were able to take on aspects of care which are frequently considered to be the domain of health care professionals. While the carers often reported that they were not able to provide care which was beneficial to the family member, analysis of the interviews shows that they used skills in conjunction with their knowledge of the person to provide holistic care. Dyspnoea was not highlighted by the carers as a barrier to providing care, but a feeling of helplessness was experienced when observing the family member during a dyspnoeic period.

Developing relationships was revealed as the theme that underpins all other themes and sub themes. The relationships that the carer developed while providing care and those relationships developed previously were identified as pivotal components to the caring experience.

CHAPTER SIX

Discussion

Introduction

This study sought to describe the experiences of the informal carers of palliative care family members with lung cancer and the symptom of dyspnoea. Dyspnoea was envisaged by the researcher as being a barrier to providing care within the home. It was expected that the informal carers would focus on the management of dyspnoea as an integral part of their experience. However, participants of this study did not identify dyspnoea as a barrier to providing care to the family member. Although acknowledging the feeling of helplessness when observing a family member experiencing dyspnoea, participants did not focus strongly on the management of the symptom, all symptoms evoked concern. Dyspnoea was viewed as a symptom that required intervention by health care professionals and management of this symptom was not the responsibility of the carer.

When analysing the transcripts from the study, in association with the research question, three themes emerged each of which incorporated sub themes. A fourth theme emerged, which was considered to be a theme that underpins all other themes (refer to Figure 5.1, p. 60).

Differing aspects of the phenomena associated with providing care to a family member who has lung cancer and the symptom of dyspnoea are incorporated within the three major themes. The themes include *meeting the challenge*, *developing the skills* and *sustaining the carer*. *Developing relationships* was the underpinning theme

that influenced all themes. Within this chapter, the findings from the study are discussed in relation to each of the themes and further expanded to incorporate the sub themes. The themes and sub themes are discussed in relation to the relevant literature. Within each theme page numbers are provided to assist with cross referencing to chapter five, findings.

This chapter also incorporates discussion in relation to the conceptual framework, the Double ABCX model of adjustment and adaptation. A further intention when discussing the findings in relation to the conceptual framework was to promote discussion regarding the application of existing nursing knowledge within the Double ABCX model of adjustment and adaptation to this population of informal carers.

Meeting the challenge

Lung cancer is recognised as having a higher mortality than any other type of cancer (O'Driscoll, Corner & Bailey, 1999) with Yardley and colleagues (2001) suggesting that more than 80% of these individuals die within one year of diagnosis. Although it is acknowledged that individuals who have lung cancer experience more symptom distress than those with other cancer diagnoses (Tanaka et al., 2002), lung cancer is also considered to be an illness that is manageable within the home setting (Costantini et al., 1993; Grande, McKerral & Todd, 2002). Further to this, Thomas (2000) points out that most people want to receive care within their homes. The participants of this study all wanted to provide care to the family member and stated that the family member wanted to remain at home.

The findings of this study revealed that the pivotal component of *meeting the challenge* was related to the carer's ability and willingness to continue to provide care to the family member on a daily basis (p.61). In support of this Ida, Uemura, Osakama and Tajitsu (2002) emphasised that the most influential factors in home care incorporate enthusiasm of the carer to provide the necessary care and the desire of the family member to receive this care.

Carers meet the challenge by developing the confidence to provide the care, physically managing practical aspects of care, understanding the difficulties and acknowledging the rewards associated with care provision. Also involved in *meeting the challenge* was the carer's ability to utilise the intimate knowledge the carer has of the family member to provide care tailored to the family members needs.

Analysis of the interviews revealed that there were many aspects to be considered when providing care to a family member within the home. The sub themes that emerged from the theme *meeting the challenge* were acceptance of the palliative care phase of the illness, managing feelings and acknowledging the rewards. Within these sub themes various concepts were identified which require consideration by health care professionals who assist carers with *meeting the challenge* of providing care to a family member receiving palliative care.

Acceptance of the palliative care phase of the illness

Meeting the challenge of providing care involved the carers recognising that the family member was in the palliative care phase of the illness and that the outcome would be the death of the family member. Acceptance of the palliative care phase of

the illness also involved the carer recognising the impact of care provision on their own wellbeing.

Not all participants of this study were able to accept the immediacy of death of the family member, but all participants described their acceptance of the palliative care phase of the illness (p.63). For some participants importance was attached to determining the initial cause of the illness, whereas for others the question 'why has this happened' was the focus. Following acceptance of the immediacy of death carers were able to redefine the situation, then formulate and plan strategies that assisted the carer with *meeting the challenge* of providing care.

The participants' interpretations of the ways in which information was provided at the time of diagnosis initially influenced the carer's ability to effectively manage care within the home (p.63). Feeling inadequately prepared for the caring role and difficulty in receiving information from health care professionals was common among the participants of this study. Many authors argue that carers do not receive the information required to provide effective care and permit informed decision making (Addington-Hall & McCarthy, 1995; Bonevski, Sanson-Fisher, Hersey, Paul & Foot, 1999; Kristjanson et al., 1997; Lecouturier et al., 1999; McCorkle & Pasacreta, 2001; Meredith et al., 1996; Ramirez et al., 1998). Nolan and Grant (1989) point out those communication difficulties that occur between carers and health care professionals may result in many carers being unable to receive the support required to continue providing effective care within the home.

Participants identified that they were required to be available twenty four hours a day to ensure that the family member's needs were met (p.73). Aranda and Hayman-White (2001) and Carter and Chang (2000) point out that being available to provide 24 hour care may have a negative impact on the physical and psychological wellbeing of the carer. In contrast, participants in this study discussed the implications of providing 24 hour care and the need to adapt their lifestyle to maintain their own health. This often involved resting at the same time as the family member. Participants who discussed their pre-existing health problems explained that the family member was the focus of care and caring was not negatively impacting on their wellbeing. No participants described providing 24 hour care as a barrier to continuing to provide care within the home.

Maintaining normality and independence was revealed as a crucial component of acceptance of the palliative care phase of the illness (p.64). Participants described maintaining normality and independence as a method of decreasing the emotional burden of the illness for the family member. The methods used by carers to maintain normality also assisted the participants with *meeting the challenge* of providing care. Maintaining normality promoted strengthening of the relationship between the carer and family member. Goal setting (p. 64) was revealed as common to all participants and often involved the carer and family member doing things together which previously would have been attended by the carer only. Using equipment such as wheelchairs to assist the family member with achieving these goals was viewed by the participants as important component of assisting the family member to maintain normality and independence.

Analysis of the interviews revealed the emotional investment associated with providing care (p.66). Participants acknowledged the frustration experienced by the family member when the symptoms experienced or disease progression prevented the family member from continuing to manage their own activities of daily living (p.64). The losses incurred by the family member were also felt by the carer. The feeling of empathy was expressed towards the family member, demonstrating understanding of the losses. Participants discussed ways in which they planned caring strategies that assisted the family member to remain as independent as circumstances permitted. Strategies incorporated the use of equipment (Alice), positioning of furniture to provide “rest stops” (Joan) and ensuring that items were within reach to prevent exertion (Carol). These strategies were viewed by the carers as ways to assist with decreasing the occurrence of episodes of shortness of breath. Using these strategies led to a feeling of achievement for the carers. This “knowing the person” led to a holistic approach to providing care.

Managing feelings

All participants of this study wanted to manage the care of the family member at home without regard to the difficulties encountered during care provision. Previous experience had no impact on this desire. The symptom of dyspnoea was not identified as a significant barrier to enabling the carer with *meeting the challenge* of providing care; however, the participants described feelings of helplessness when observing the family member experiencing dyspnoea. Managing feelings was identified as crucial to their ability to meet the challenge of providing care.

Managing feelings involved the carer not only being aware of their own feelings, but also assisting the family member to manage the feelings of frustration associated with loss of dignity (p. 66). The carers who participated in this study described feelings of distress, helplessness, frustration and guilt.

The participants in this study did not distinguish dyspnoea as negatively impacting on the overall experience of providing palliative care to the family member. However, a feeling of helplessness was described by participants when observing the family member experiencing an episode of dyspnoea. The feeling of helplessness was related to the carer's perception that they were unable to do anything beneficial to alleviate the symptom distress experienced by the family member (p.70). This feeling of helplessness occurred despite the carer having provided supportive measures as advised by health care professionals. Participants acknowledged the impact dyspnoea had on the family member's physical and psychological wellbeing but did not view dyspnoea as impacting on their own wellbeing, although several participants described waking during the night to provide medications for dyspnoea. Few participants discussed management options that would assist with alleviating the severity of dyspnoea other than the use of morphine.

Dyspnoea, which is commonly associated with many cancer diagnoses is described as being most prevalent in those individuals who have a primary diagnosis of lung cancer (Cooley, 2000; O'Driscoll et al., 1999). Tanaka and colleagues (2002, p.488) point out that even low dyspnoea scores "one on a scale of zero to ten" can have an impact on activities of daily living". Dyspnoea restricts all activities of daily living and therefore has a negative impact on quality of life for the family member (Tanaka

et al., 2002; Roberts et al., 1993). It is therefore necessary for health care professionals to provide information to the informal carers of lung cancer patients who have the symptom of dyspnoea, which will enable the carer to effectively manage this symptom and therefore reduce the carers own feelings of distress.

Many described the emotional conflicts experienced while providing care for the family member at home. Analysis of the interviews revealed that the participants often suppressed their own emotions while continuing to meet the emotional needs of the family member (p.69). The participants revealed that when the carer did respond in a negative manner towards the family member or believed an action they had taken caused an exacerbation of symptoms the result was a feeling of guilt by the carer.

Carers identified feeling guilty (p.70) and frustrated (p.71). Frustration was identified as a component from both the carer's and the family member's perspective. Symptom management and disparity between the carer's understanding of management and the disease process and those of the family member were identified as a major cause of communication difficulties that resulted in a feeling of frustration for the carer and family member.

The data revealed that when discussing frustration from the participant's perspective, the feeling of frustration was related to the family member's reluctance to share the experience of symptoms with the carer, therefore, the carer was unable to assist with the management of symptoms. A crucial component of care, providing the carer with

the feeling of achievement, was identified by Wilkes and White (1998) as symptom management.

The feeling of frustration also emerged at those times when the carer wanted to request assistance from a formal source and when the family member was reluctant to share the experience of the symptoms (p.71). The reluctance by one family member to request assistance from the home visiting service during an episode of dyspnoea resulted in admission to hospital for symptom control. The family member had experienced a gradual increase in shortness of breath with the carer being unable to manage the symptom without professional advice. The carer explained that she was aware that the hospital admission could have been prevented if access to the home visiting service had been permitted. Thomas (2000) and Beck-Friis (1993) point out that home visits to clients assist with preventing hospital admissions.

Frustration was revealed to be closely associated with the feeling of helplessness. Participants described a sense of being unskilled. They revealed feelings of frustration and helplessness when explaining that they did not have the knowledge or confidence to provide appropriate information to the family member (p.71). This information included information regarding symptom management and the ability to explain to the family member that the symptoms experienced were associated with the cancer diagnosis.

Changes in the role of both the carer and family member were identified as having positive and negative implications (p.72). When changing roles, carers were required to contend with the loss of their previous role while accepting that this role would

continue to evolve during the caring experience and imminent bereavement. Changes in the role for carers often incorporated taking on extra responsibilities; however, this was viewed as part of the caring experience. Negative implications occurred when the change in role of the carer was not accepted by the family member receiving care (p.71). No carers identified changes in the role as a barrier to continuing to provide care or as having an impact on their quality of life. In contrast, the literature suggests that role change interferes with the carer's current responsibilities and therefore adversely affects the quality of life (Chan & Chang, 2000; Kozachick et al., 2001; McCorkle & Pasacreta, 2001; Shyu, 2000).

Knowing the person and utilising previous relationship strengths assisted the carers in understanding the emotional impact experienced by the family member that resulted from the change of roles (p.66). The participants did not disclose any negativity felt towards the family member, but empathised with the emotions the carers believed the family member to be experiencing. Carers recognised the need to support the family members in this process. The participants of this study did not relate role change, undertaking new or extra responsibilities as increasing the burden of care or adversely affecting their quality of life.

There are many potential stressors associated with the caregiving role which may increase carer burden (refer to Table 2.4, p. 24). Many authors conclude that increase in caregiver burden can adversely affect the carer's quality of life (Addington-Hall & McCarthy, 1995; Chan & Chang, 1999; Kristjanson et al., 1997; McCorkle & Pasacreta, 2001; Meyers & Grey, 2001; Pasacreta et al., 2000).

The reluctance of the family member to relinquish their hierarchical role within the family unit was found to impact on the effectiveness of communication between the carer, the family member receiving care, other family members and health care professionals. One participant described the family member as “obstinate” (Ivy). Analysis of the transcript identified differing views on disclosure between the carer and the family member in relation to progression of disease and symptoms experienced (p.68, p.72). Support and advice was provided by the Registered Nurse to the carer that assisted with management of this aspect of the caring experience.

Communication problems can intensify during times of increased stress such as the palliative care phase of a terminal illness. Findings of this study revealed that communication problems did exist amongst the participants, family members and members of the family unit. Participants differed in the ways in which they managed the problems. Discussing and resolving the problems within the family was the approach used by a few participants, others sought advice from health care professionals. Some participants suppressed their emotions (p.69) while continuing to provide care to the family member. Communication problems did not deter the carer from wanting to continue to provide care within the home. Several authors have argued the importance of the role of the nurse in palliative care in assisting carers to identify issues that are related to communication problems and develop ways in which to manage this (Barsevick et al., 2000; Duhamel & Dupuis, 2003; Holing, 1986).

Acknowledging rewards

A pivotal component which assisted the carer to meet the challenge of providing care was acknowledging the rewards. These rewards encompassed strengthening of relationships and acknowledging the carers own ability to provide the care. The participants of this study acknowledged the changes to their lifestyle. These changes were not described as impacting negatively in their quality of life, but emphasised as positive aspects of the caring experience. As the carers recognised their ability to provide care their determination to continue with providing care at home strengthened.

Feelings of closeness and togetherness were described by several participants when discussing the relationship changes that had occurred since the family member's initial diagnosis (p.73). Participants revealed that although it was necessary to plan activities around the ability of the family member, they were doing more together than prior to the illness. The literature reveals that during the course of the illness the feelings of attachment between the carer and family member are often reinforced (Aranda & Hayman-White, 2001; Pasacreta et al., 2000; Wilkes & White, 1998).

Disruptions to sleep patterns (p.73) were highlighted with carers explaining the need to attend to medications and personal care during the night. One participant identified the feeling of frustration when awakened to empty a urinary drainage bag at night. All participants who discussed disruptions to their sleep pattern explained that they understood the reasons why the family member woke them. A positive correlation was revealed in the study conducted by Carter and Chang (2000) between carers sleep problems and symptoms of depression. While discussing sleep problems

such as quality of sleep and duration, no participant in this study discussed feelings of depression.

Developing the skills

In relation to the research question “what are the experiences of informal carers of palliative care family members with lung cancer and the symptom of dyspnoea” the theme, developing the skills describes how the carers were required to develop and perform many skills. The participants of this study often undervalued the significance of their role in assisting the family member to remain at home (p.80). At times they described feelings of inadequacy in being able to manage practical and complex care provision. Carers did not recognise that they had taken on aspects of the professional role and therefore learnt technical skills. These skills included physical care, use of equipment and medication management. Performing the skills that assisted the family member to remain at home was not viewed by participants of as stressful because they did not see themselves as “skilled” in that context. The carers did reveal feelings of uncertainty and nervousness when initially learning skills.

This study revealed that carers wanted to manage the care of their family member within the home. Learning from formal and informal resources and drawing on previous experience emerged as core sub themes within the theme of *developing the skills* that assisted the carer to achieve this aim.

When discussing the management of dyspnoea the carers who participated in this study described feeling helpless, but dyspnoea was not viewed by the carers as a

significant barrier to care provision. This group of participants differs from those in a previous study conducted in Western Australia, which revealed that dyspnoea was a significant factor in hospitalisation of individuals with a diagnosis of lung cancer (Bradshaw, 1993). Many authors argue that lung cancer is manageable within the home setting, but did not expand on this to consider the informal carers experience of providing care or whether dyspnoea was a factor in any hospitalisation that may have occurred (Constantini et al, 1993; Grande et al, 2002; White, 1987).

Learning from formal and informal resources

Learning from formal and informal resources was identified as crucial to the carer's experience. The focal areas of learning were related to the use of medications for symptom control and managing the physical care of the family member. These skills were learnt through education and observation.

A major component of learning that assisted with *developing the skills* was effective communication (p.78, p.81). Participants described communication between the carer and formal resources as a key factor that influenced their caring experience. Communication is described as being the basis of all human interaction, involving the transmission of verbal and non verbal messages between two or more people (Ellis, Gates & Kenworthy, 1995; Sundeen, Stuart, Rankin & Cohen, 1989). Communication is also considered to be a core component in the development of therapeutic relationships (Glanze, Anderson & Anderson, 1990). The central role of communication in cancer or palliative care has been highlighted in numerous studies which describe effective communication as involving provision of information tailored to meet the individuals needs (Dean, 2002; Griffie, Nelson-Marten &

Muchka, 2004; Jarrett et al., 1999; Payne et al., 1999; Wallace, 2001; Wiles et al., 1999). The National Health and Medical Research Council (1999) recognise the central role of communication in the experience of the individual and have developed guidelines to assist the health care professional in effective communication techniques.

Participants of this study described communication within both positive and negative context. The participants described how effective communication which assisted with learning increased their self confidence and therefore assisted with *developing the skills* which permitted the delivery of care (p.78). Learning from formal and informal resources was revealed as occurring through both verbal and non verbal interactions. Effective communication whether provided through verbal or non verbal interactions involves ensuring the carer understands information and the care to be given. Analysis of the interviews revealed that learning occurred when the information provided was tailored to the individual's needs.

That dyspnoea was not a focus for carers was an unexpected finding. One key reason for this is that the management of dyspnoea was considered to be the responsibility of the health care professional. As stated by Carol (p.98), "they are the experts". In contrast, the Registered Nurses who participated in this study described how they provided the carers with information which would assist the carers with management of dyspnoea (p.79). This information incorporated use of medications, use of aids and posturing of the client. Analysis of interviews demonstrated that carers provided with this information did not always comprehend the information they were given. The literature points out that when providing information to carers it must be

congruent with the recipient's beliefs and delivered in language which is easily understood (Duhamel & Dupuis, 2003; Payne, 2002; Yardley et al., 2001).

Non verbal interactions included the participant observing physical care provided to the family member by Registered Nurses. The participant was able to mirror the care observed and had developed the confidence to complete the procedure in the home. Padberg and Padberg (2000) suggest that the majority of information stored in the brain results from observation. Therefore, the visual component of any teaching strategy is of great importance (Padberg & Padberg, 2000).

Verbal interactions with health care professionals enabled the participants to develop skills that incorporated understanding of physical and psychological symptoms. One participant described her pride in her ability to manage the caring tasks and observed that this was further reinforced when nursing staff provided positive feedback (p.78).

Poor communication between the carer and formal resources hindered skill development for some participants (p.81). Communication has been viewed as problematic for carers with lack of information being identified as a major block to development of effective caring skills (Payne, 2002; Thomas, 2000). The study by Lecouturier and colleagues (1999) that assessed carer satisfaction with community palliative care services reported that only 27% (n=42) of respondents were very satisfied with information provision. Although the participants of this study did not discuss dissatisfaction with any service accessed during the palliative care phase of the illness, issues relating to communication were highlighted.

One participant of this study revealed her belief that not being directly related to the person she was caring for negatively impacted on communication between herself and some health care professionals and therefore her ability to provide effective care (p.81). This participant discussed the inability to elicit information from health care professionals regarding the disease progress and associated symptoms that were expected to occur. Communication issues that develop between informal carers and health care professionals can be attributed to the perception by the health care professional of the role of the carer. Payne (2002, p. 113) points out that these perceptions influence the “quality of information” given to the carer. Twigg (1989) suggests that carers are considered as resources, co-workers or co-clients. When viewed as resources, the care provided relates to the needs of the family member without regard to the needs or wishes of the carer. As co-workers, informal carers are acknowledged but assumptions are made regarding the role. The aims of the health care professional may not be congruent with those of the carer. The third category, co-client, acknowledges the role of the carer and incorporates the carers needs and views in relation to ongoing management of the family member (Payne, 2002; Twigg, 1989). In support of this Kristjanson, Sloan, Dudgeon and Adaskin (1996, p. 18) suggest that when acting as carers of terminally ill clients, the carer should be considered as a “pseudo-client” to ensure their needs are met.

Payne (2002) outlines a fourth category in which the carer is described as an expert. When viewing the carer as an expert the health care professional utilises the knowledge and skills of the carer in the management of the client. Payne (2002) suggests that the quality of the service provided to the carer is dependent on the category to which the carer is allocated. Although it is not within the scope of this

study to identify the role of the carer as perceived by the health care professional, it can be postulated that the experience of the participants relates to the way in which the role is viewed by the health care professional. This study highlights knowing the family member influenced the carer's ability to provide care and it appeared to increase the focus on holistic care.

A major component of learning is associated with the ability of individuals to communicate effectively. This study highlighted differing interpretations of management of dyspnoea between the carer and the Registered Nurse. Analysis of the transcripts revealed that when the interpretation differed the management of the symptom was not effective. For one participant this resulted in the family member becoming "aggravated" (Joan p.80). When communication is not effective care provision increases in difficulty (Thomas, 2002). Effective communication incorporates transfer of information between health care professionals, relevant information provided to the carer and client and use of terminology appropriate to the carer and client (Payne, 2002; Thomas, 2002). Poor communication may result in the carer and/or the client feeling helpless and confused.

Discussion with friends and other family members was also revealed to be an important component of *developing the skills* (p.77). Discussion assisted the carers to draw on the experience of others and utilise this information when providing care to the family member or during interaction with health care professionals.

Although dyspnoea was not viewed as a symptom that caused specific management difficulties, managing the psychological care of the family member was reported by

several participants as impinging on their ability to communicate effectively with the family member. Two participants observed that changes in the mental status of their family member were symptoms with which they had difficulty coping (p.77). These participants differed in their approach to alleviating their concerns. One participant initially discussed concerns with a friend and then used this information to discuss management of the symptom with the health care professional whereas the second participant utilised previous experience to accept the change as being connected with the disease progression. This is supported by Hull (1992) who points out changes in the mental state of the family member often caused difficulty for carers. Carers who are able to rationalise the changes in mental state as associated with disease progression are able to accept these changes and manage the situation (Hull, 1992).

Drawing on previous experience

This study identified that drawing on previous experience in a caring role either helped or hindered the carer's ability in *developing the skills* applicable to providing care to the family member. Each participant emphasised concerns regarding symptom management and physical care of the family member, but dyspnoea did not feature as a major concern.

Drawing on previous experience enabled several participants' to recognise and develop skills that assisted in *developing the skills* necessary to enable management of the care of the family member within the home. The main skills utilised from previous experience were communication, caring and organisational skills. Communication skills were used when interacting with the family member and supportive resources. Caring skills were used to provide physical and psychological

care of the family member with organisational skills being used to encourage sharing of the care within the family unit.

Analysis of the interviews revealed that drawing on previous experience assisted some participants to develop plans that would assist with the continuation of providing care within the home when the family member's physical condition deteriorated (p.82). Participants were able to draw on previous experience to develop plans of care which ensured that the family members' needs were met while also ensuring that the needs of the family as a unit were achieved.

This study revealed that past experience may not have been associated with direct care provision. Knowing others who had received care at home assisted the participants of this study to understand the positive aspects of caring and also the difficulties that may be encountered when providing care within the home.

Drawing on previous experience was not achieved by all participants (p.82). Barriers to utilising previous experience were associated with the carer not being able to recognise similarities in the experience or being unable to adapt previous knowledge as the extent of the disease progression was unknown.

Sustaining the carer

Integral to the experience of providing care to the family member within the home was maintenance of physical, psychological and spiritual wellbeing. To achieve the maintenance of these components for the carer, analysis of the interviews identified three distinctive support networks. These support networks comprise of professional,

lay and spiritual resources. When utilised, these support networks interacted to provide the carer with a sense of psychological wellbeing through access to professional care and support and also assisted with decreasing the burden of care for the carer.

In support of the literature which reveals that the preferred place of care for an individual who has a terminal illness is within the home (Hinton, 1994; Mitchell, 2003) all participants of this study wanted to provide care for the family member within the home. Dyspnoea was not identified as a specific concern; however, participants were concerned about symptom management as a whole.

Interactions between the carer, family member and health care professionals were viewed by the participants as integral to *sustaining the carer*. Care of the family member was often provided without support from other family members or friends. The carer utilised services available from formal resources but primarily managed the care with minimal input from others. At the time of participation in this study not all participants used many supportive resources, but all participants acknowledged the importance of access to professional care and support. Without access to support which may be provided by a formal resource or family and friends it is very difficult for the individual with a terminal illness to remain at home (Ramirez et al., 1998; Beck-Friis 1993).

Access to professional care and support

The importance of access to professional care and support in *sustaining the carer* was highlighted both when it was available and when it was not available (p.87).

When available and accessed by the carer professional support was beneficial in alleviating concerns. This support was provided by general practitioners, community palliative care services and the palliative care staff of inpatient facilities. Supportive actions associated with professional services was revealed as provision of respite, assistance with maintaining the physical care of the family member and assisting the carer to develop the skills necessary to continue to provide care. Uncertainty and distress was increased when professional support was either not available or not utilised through reluctance of the carer or family member.

When discussing the role of the nurse Nash (1988) describes various components which interact and when used effectively permit effective communication. Nash (1988, p.186) points out that the nursing role incorporates that of “expert, advisor, decision maker, teacher and enabler”.

It was not an aim of this study to identify the roles used by Registered Nurses when providing care however the Registered Nurses providing care to the participants and families in this study incorporate many of the roles described by Nash (1988). The roles of advisor and teacher were used when discussing management of dyspnoea and other physical symptoms (p.79) which assisted carers to develop skills but this access to professional care and support also permitted the carer to continue providing care. The decision making role was evident in the interaction between one nurse and the carer in a family which was experiencing difficulty with continuing care due to the extended terminal phase. The nurse in conjunction with the family “...organised shifts that involved all the family” (Nurse: Sue, p. 94) which ensured the family members care needs were met without causing further burden to the family.

Participants identified the use of different management strategies when discussing the difficulties associated with care provision. For one participant this involved informing the health care professional that she was no longer able to cope with the situation. The health care professional was then able to discuss the carer's concerns and adapt the treatment plan to assist the carer to continue managing care at home. By utilising this approach to care planning the health care professional was viewing the carer as a co-client or pseudo client which has been highlighted in previous studies by Kristjanson and colleagues (1996), Payne (2002) and Twigg (1989).

Uncertainty regarding appropriate management of the needs of the family member occurred in relation to not knowing the extent of the disease progression. This was revealed to occur because of the family members differing views on disclosure (p.72) and the status of unrelated carer (p.81). One participant identified that her role had changed from friend to carer. This participant perceived her status as an unrelated carer to be a barrier to obtaining information from some health care professionals. This did not assist with *sustaining the carer*. This concern expressed by the participant has been highlighted previously by Wilson and colleagues (2002) who observed that unrelated carers can experience difficulty in obtaining information relating to prognosis and test results. This also reflects upon the communication patterns between family member, carer and health care professional as previously discussed.

Uncertainty related to differing views on disclosure was revealed by one participant as negatively impacting on the caring experience. This did not deter the carer from continuing to manage the care of the family member at home but strengthened the

resolve of the carer to provide care no matter what happened. Differing views on disclosure, while not impacting on the participants' access to professional care and support did impact on the ability of the health care professional to provide information which would assist in *sustaining the carer*.

Dyspnoea was identified by the carers in this study as a symptom that required intervention by health care professionals. However, when carers did not understand the function of the community palliative care service they chose to manage respiratory symptoms even when fearful of the consequences or if they thought nothing might be offered. This was misunderstanding of the role of the community palliative care service was expressed by Joan "...I did not like disturbing them [nurses]...I thought I was going to lose him" (p. 87).

Access to support from a professional resource is therefore an important aspect in effectively managing the symptom of dyspnoea. Providing support to the carer will also assist with promoting and developing the ability of the carer to manage this symptom within the home.

Access to a 24 hour home visiting service is viewed as an important support resource for both the carer and family member (Beck-Friis, 1993; Grande, Todd, Barclay & Farquhar, 2000; Hull, 1992; Thomas, 2000). Access to professional care and support was discussed in relation to the family member receiving prompt attention from a health care professional. This was supported in this study with participants describing the access to a 24 hour community palliative care service as a supportive resource which assisted with alleviating their concerns (p.87).

Participants who utilised the out of hours' access to the home visiting service described how prompt attention decreased the concerns they had regarding the family members wellbeing. Grande and colleagues (2000) point out that prompt attention to symptom control can prevent further problems from occurring.

This study revealed that while acknowledging the availability of a twenty four hour home visiting service several participants were reluctant to use the service (p.86). Analysis highlighted that the participants did not fully understand the availability and function of the service. Hull (1992) observed that carers may be reluctant to use supports that are offered as they prefer to maintain an image of competence.

All participants in this study discussed the positive aspects of access to support which assisted the carer to continue care provision within the home. These included respite and assistance with physical care (p.89). Some participants highlighted areas of concern. These areas included lack of continuity of care from the formal resources (p.88), and concerns regarding availability of support from general practitioners (p.87). Concerns regarding availability of support from general practitioners were discussed in relation to the carer recognising the need to maintain their own wellbeing.

The data from this study revealed discrepancies in the participant's understanding of the concept of continuity of care. Participants identified this as receiving care from one Registered Nurse whereas the structure of the community palliative care service may necessitate the involvement of several nurses with one family. Analysis of the data revealed that when receiving care from one nurse, not all participants had been

able to develop a therapeutic relationship that permitted discussion of the carers' needs or concerns regarding the family member.

Ingle (2000) and Thomas (2000) discuss the importance of continuity of care in relation to providing an effective support service for carers and their family members. Ingle (2000) expands on this to explain that although lung cancer is viewed as a disease that is manageable in the home setting, the complexity of treatments offered involves the client and carer visiting many different practitioners. Ingle proposes that continuity of care in this population of clients is important as it assists the client and carer to maintain a sense of control through communication and assistance with the transition between services.

When discussing access to professional care and support participants in this study generally found general practitioners to be supportive with some exceptions where difficulties accessing general practitioner services were reported. Farquhar, Grande, Todd and Barclay (2002, p.247) point out that the general practitioner plays a "pivotal role" in the provision of palliative care within the community. Concerns from informal carers regarding general practitioners are associated with inadequate support and inability to manage symptom control (Spiller & Alexander, 1993; Mitchell, 1993). These issues highlight possible discrepancies in information held within the in-patient hospital and that given to the general practitioner in the community. In support of this Farquhar and colleagues (2002) point out that when communication between hospitals and general practitioners is not effective this will influence the quality of information provided to the care and the family member.

Spiritual support was identified by three participants as an essential component of their formal supportive networks (p.95). With each of these participants, spirituality was discussed in the context of formalised religion. Analysis of the data revealed that each participant who discussed spiritual support the importance of their religious beliefs was expressed in relation to understanding and accepting the process of dying. The literature considers the importance of spiritual beliefs with Teno and colleagues (2001, p. 744) explaining that while spiritual support is an essential element of care for the carer it is necessary to introduce this in a “sensitive manner”. Whereas Duhamel and Dupuis. (2003) suggest that spiritual beliefs are one of the most invaluable family resources and health care professionals should assist the family to utilise these resources.

Decreasing the burden of care

This study revealed the importance of formal and informal resources in *sustaining the carer* through decreasing the burden of care. Dyspnoea was identified by participants as the concern of healthcare professionals. However, no participant identified the need for assistance from formal resources in decreasing the burden of care during episodes of dyspnoea experienced by the family member. Informal resources such as family and friends were most often described by the participants of this study as decreasing the burden of care (p.90).

This study highlights the importance of informal support from family and friends. Participants described the comfort they received when able to visit family or friends who would listen to their concerns without providing advice or judgment (p.92).

All participants acknowledged the importance of support provided by informal sources in decreasing the burden of care but the support was utilised in varying ways. The main form of support identified by the carers in this study provided by informal resources was related to respite (p.90). Although not used by all participants of this study, Hull (1992) suggests that periods of respite permit carers to re-energise. Most participants of this study, who used respite, preferred family members or friends to provide this support although respite was offered by formal support agencies. Payne et al., (1999) validates this observation by pointing out that when assessing supportive networks, support is mainly provided by family and friends. In contrast to this Pasacreata and colleagues (2000) observed that it was often difficult for carers to obtain assistance from friends or other family members.

Barriers associated with decreasing the burden of care included the reluctance by the carers to use services available from formal sources. While acknowledging that these services could assist with decreasing the burden of care using the services was not always seen as a viable option. Participants who declined respite care from either formal or informal services indicated that they were concerned about the psychological effect this may have on the family member (p. 93) or revealed that the family member was reluctant to accept care from anyone other than the participant (p.94). The carers prioritised the family member's wishes and needs above any need the carer may have had.

Participants disclosed the feeling of frustration with being with the family member 24 hours a day but remained unwilling to accept respite services because of the reasons mentioned previously. This did not assist with *sustaining the carer*. Duhamel

and Dupuis (2003) propose that it is difficult to cease the caring role and informal carers will refuse respite even if this is indicated for their own well being.

Providing and receiving support was identified as pivotal to the experience of providing care. Providing support for other members of the family, who have a close relationship with the family member receiving care, was viewed by the primary carer as an integral component of their role (p.91). This support was revealed to occur in differing ways. Supportive actions by the carer incorporated ensuring that all individuals within the family were aware of the changes that occurred with the family members' physical condition, ensuring that the care provided by others within the family did not disrupt their lifestyle and informing relatives who lived overseas or interstate of any changes in the prognosis of the family member. Discussing prognosis with the family caused difficulties for one Registered Nurse when the information was misinterpreted and relayed to a family member who lived interstate. This highlights the importance of ensuring that information is provided in language which is understood. Davies and colleagues (1994), when discussing family interactions within the palliative care setting point out some families consider the impact of care provision for all individuals within the family unit.

The importance of informal support in decreasing the burden of care was also highlighted when it was not available (p.92). This resulted for one participant in the feeling of loneliness and sadness as she described how she was unable to receive support from her daughter who is the only other family member residing in Australia. This participant considered the lack of support to be a factor that affected her own wellbeing.

Developing relationships

The participants of this study were determined to continue to provide the care of the family member within the home but the experiences associated with providing this care were revealed as being dependent upon the relationships that developed. *Developing relationships* was revealed to underpin and support all other themes and to be a pivotal component of all sub themes (Refer Figure 5.1, p.60). Therapeutic or trusting relationships that developed between the carer and health care professional promoted a learning environment which supported the carer to meet the challenge of providing care, assisted with developing the skills and sustained the carer during the caring experience (p.98).

Relationships developed between many individuals during the caring experience but the relationship that existed between the family member and the carer was the most important component in the determination of the carer in continuing to manage the care of the family member at home. As previously discussed this relationship often continued to develop during the palliative care phase of the illness and the resultant strengthening of the relationship was described as a positive component of the caring experience.

Health care professionals have a pivotal role in promoting the care of the family member within the home (p.97). Effective communication between the carer, health care professional and family member was highlighted in this study as a pivotal component of developing relationships. Relationships often began to develop at times associated with increased carer stress and also when the family member was physically and psychologically weak. Interaction with health care professionals

which began at the time of the family members' diagnosis was revealed to influence the caring experience.

Participants in this study who discussed difficulties when interacting with health care professionals identified the way in which bad news was broken and the carer's perception of the attitude of the person giving this news as barriers to learning how to care (p.98). When assessing communication between carers and health care professionals the literature suggests that the expectation is for the carer to identify and request information pertaining to their needs (Payne, 2002; Wiles et al., 1999). Further to this, Nolan and Grant (1988) point out carers are sensitive to the attitudes of health care professionals and the carer's perception of these attitudes influences advice seeking behaviour. This latter aspect was confirmed by participants in this study.

The way in which treatment decisions were relayed to the carer influenced the ability of the carer to develop a relationship with the health care professional. Open and empathetic communication assisted the carers to feel supported and therefore encouraged the carer to seek advice and assistance with management of the family member when necessary.

As previously discussed communication has a central role in the delivery of health care. Communication was revealed as an integral component of developing relationships. Many authors argue that the family's communication patterns and interactions which are based on long term relationships impacts on their coping strategies when caring for a family member (Davies et al., 1994; Kristjanson et al.,

1997; McCorkle & Pasacreta, 2001; Pasacreta et al, 2000; Shyu, 2000). This study highlighted the importance of gaining an understanding of the family interactions and the concerns that existed for each family member. This challenged the way in which services were offered but the understanding of the needs and the development of the relationship provided support for the family and primary carer while also promoting independence (p. 99).

Some participants of this study had previous experience of providing care to an individual with a terminal illness but this did not necessarily enable the carer to utilise this experience while providing care to the family member. Whether or not the participants had previous experience, all participants disclosed concerns regarding their ability to continue with providing the care. The development of therapeutic relationships promoted a learning environment and assisted the carers to develop the skills which would enable the carer to manage the physical and psychological needs of the family member. The participants revealed that when a relationship was established they felt comfortable in requesting advice and assistance but a concern which impacted on the carer's willingness to seek advice and express their own needs occurred when interaction between the carer and the health care professional did not promote a therapeutic relationship (p.98).

The important components that emerged following developing a trusting relationship with the carer was described by a Registered Nurse as providing support but also permitting independence. The Registered Nurse explained that this permitted the carer to seek assistance when necessary, but to develop confidence in the carers own ability to manage situations which would previously have been viewed as difficult.

Participants of this study identified that positive interaction between the carer and the health care professional assisted the carer to successfully attend to caring tasks which previously the carer would not have attempted to manage. Ramirez and colleagues (1998) point out that carers who receive valid information are able to manage otherwise difficult situations as their fears are allayed.

Double ABCX model of adjustment and adaptation

As discussed in chapter three the double ABCX model of adjustment and adaptation has been used to promote understanding of the ways in which the impact of the stressor, the families coping resources and their perception of these influence the process of adaptation. Incorporated within the double ABCX model are several factors which are involved in both the pre crisis and post crisis time (refer to Figure 3.1, p.39 & Figure 3.2, p.40). For the purpose of this study the double ABCX model was used to determine how the experience of providing care to a family member with the diagnosis of lung cancer and the symptom of dyspnoea influenced the process of adaptation from the informal carer's perspective. The components of the caring experience which determine whether or not the carer will encounter a crisis situation are outlined in Figures 6.1 (p. 138) and 6.2 (p. 143) and discussed in detail within each factor of the model.

Pre crisis

Pre crisis involves factors a, b, c and x (refer to Figure 6.1, p.138). *Factor a: the stressor event* assesses the actual stressor and the changes that this stressor caused for the family to create hardship. *Factor b: existing resources* determines what resources were used by the carer to meet the resultant hardships. *Factor c:*

perception of a describes how the hardships which resulted from the stressor event impacted on the carer. The final factor in pre crisis is *factor x: crisis*. This factor distinguishes whether or not the carer was able to utilise resources to successfully manage situations which occurred from the stressor event to prevent a crisis from occurring.

a: the stressor event

Prior to commencing the interviews it was the researcher's perception that the stressor event would be associated with the onset of symptoms and symptom management, primarily issues involved with managing the symptom of dyspnoea. Analysis of the interviews revealed that for many participants the stressor event (refer to Figure 6.1) that precipitated change was associated with the initial diagnosis of lung cancer. Many of the family members were described as having shortness of breath or breathing difficulties at the time of diagnosis, which impacted on their ability to manage activities of daily living, but this was not highlighted by the carers as a specific concern at the time of diagnosis. The initial stressor events were connected to the diagnosis, the way in which information was provided by health care professionals or associated with lack of supportive actions by family members.

Participants of this study revealed that some health care professionals lacked insight in how to "break bad news". In contrast to the experience of most participants, analysis of the interviews revealed that for one carer the way in which information was provided by the health care professional resulted in the feeling of rejection, which remained strong several months after the actual meeting had occurred (p.98). This was an important component of the caring experience, as the participant

disclosed that no further advice was sought from the health care professional. The difficulties experienced by health care professionals when “breaking bad news” are acknowledged by several authors (Baile, Lenzi, Parker, Buckman & Cohen, 2002; Fallowfield, Jenkins & Beveridge, 2002; Rudnick, 2002). Rudnick (2002) suggests utilising assessment criteria which would enable information to be provided in a sensitive manner, but also points out that no such assessment criteria has been formulated.

The way in which information was provided at the time of diagnosis impacted on the carer’s perception of the relationship that developed between the health care professional, carer and the family member receiving care. In association with *a: the stressor event*, the findings of this study revealed a connection between those carers unable to develop a relationship with health care professionals and reluctance to request help with managing the difficulties which arose during the caring experience. In support of this Payne (2001) points out that although the provision of information to clients and carers is acknowledged as an important component of health care provision, this information is not always provided in a meaningful way.

The importance of support from the family unit was highlighted by one participant who described the emotional distress and feeling of isolation experienced when the family did not or was not able to support her in the caring role (p.92). The carer did not know how to rectify the situation and was therefore unable to express her concerns or fears to others within the family. In contrast to this, participants who received emotional and physical support from individuals within the family unit did not identify events occurring at the time of diagnosis as causing ongoing hardship to

either the carer or the family member. The family as a unit provides an important role in care provision and ensuring quality of life for each member of the family (Duhamel & Dupuis, 2003).

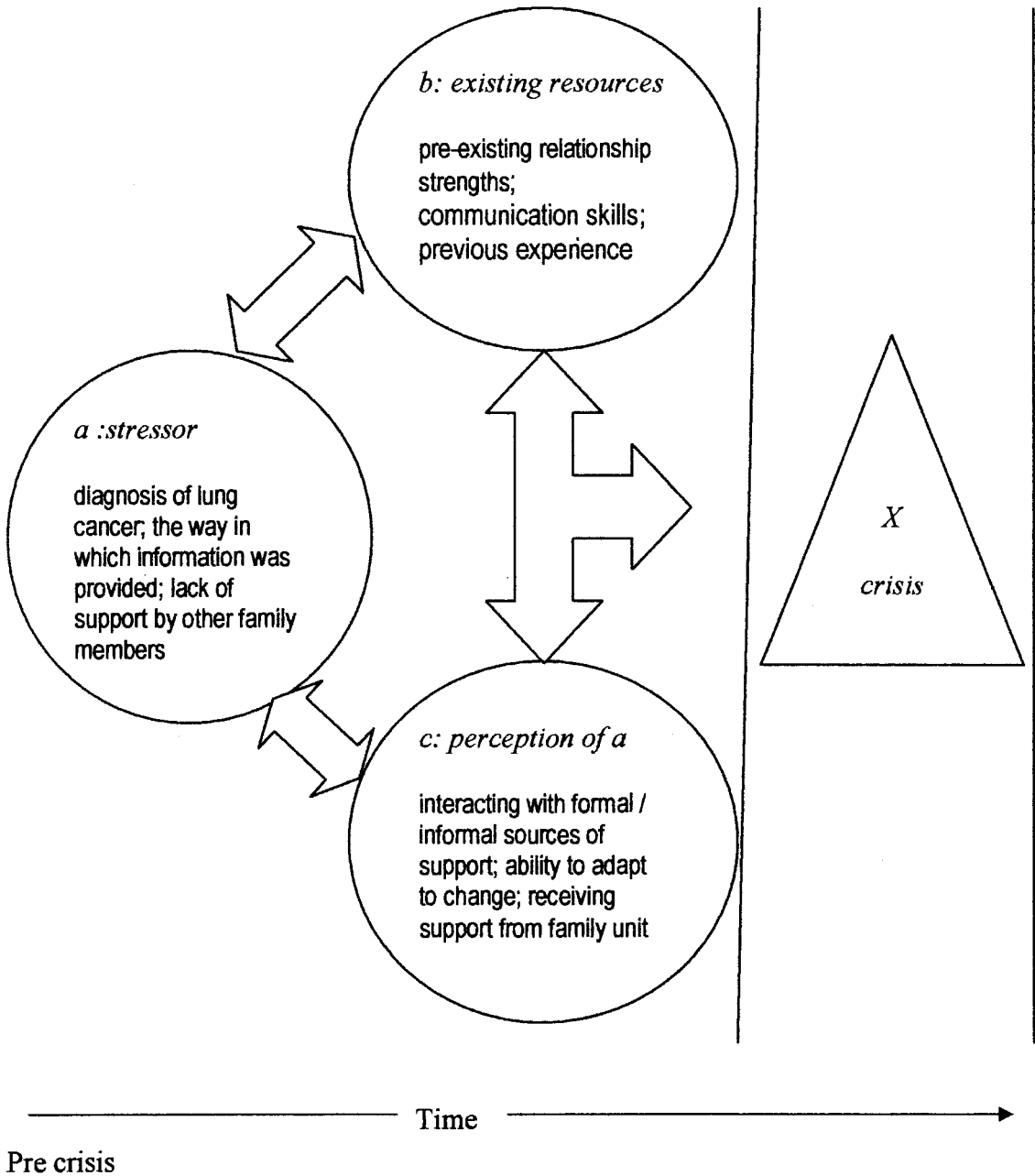
b: existing resources

Not all participants were able to access resources that would enable management of hardship resulting from the stressor event. Participants of this study who utilised factors such as pre-existing relationship strengths (p.64), communication skills (p.79) and previous experience (p.82) were able to set mutual goals and obtain support to meet their emotional, physical and spiritual needs from informal and formal resources.

c: perception of a

The findings of this study reveal that participants who expressed difficulties in communication and/or interaction with either formal or informal sources of support tried to manage difficult events such as episodes of severe dyspnoea without requesting assistance (p.87). When provided with further information and explanation of the role of the community palliative care service, which incorporated a visit by the community palliative care Registered Nurse and explanation of how an earlier visit could have assisted with symptom management and relief of stress for the carer, the participants revealed that for future concerns assistance would be sought. Tomlinson (1986) points out that during a stressful event the perception of the individual will dictate whether or not information that will assist with change is sought. Those individuals who are sure of their ability to adapt to the changing

Figure 6.1: Double ABCX model of adjustment and adaptation. Managing dyspnoea: components of caring influencing adaptive responses of informal carer's - pre crisis.



McCubbin and Patterson 1983, p.12.

situations are more likely to seek information than those who are uncertain of their ability to change.

x: crisis

The diagnosis of lung cancer impacts on the family as a whole. Participants of this study varied in their ways of coping with the diagnosis. Symptoms such as dyspnoea, experienced by the family member at the time of diagnosis were not identified as a cause of concern at that time, but the way in which information was provided (p.63; p.98) and the supportive actions of family members determined the response for some participants (p.89).

Participants of this study who were able to utilise supportive resources did not experience a crisis event. Those participants who were unable to seek help from family members or other resources to assist with meeting the demand for change imposed by the diagnosis of lung cancer experienced a crisis situation that influenced their abilities to adapt to further changes that occurred (p.64), but this did not deter the carer from wanting to continue to manage the care within the home.

Post crisis

The post crisis period aA, bB, cC, coping and xX (refer to Figure 6.2, p.143). Within the double ABCX model of adjustment and adaptation aA: *pile up* may incorporate stressors that have evolved from previous events, family or community as well as those encountered during the current situation (Mays, 1986; McCubbin & Patterson, 1983). *Factor bB: existing and new resources* describes the use of resources to meet the demands caused by the stressors encountered within a:A.

Factor cC: perception of $x+aA+bB$ includes the carer's perceptions of the stressor event, the use of resources to meet the demands of all stressors and the actions taken to achieve balance and functioning (McCubbin & Patterson, 1984). *Coping* bridges bB and cC and incorporates cognitive and behavioural components. The interaction between the elements involved in coping and factors bB and cC determine adaptation or xX (Friedman, 1992; McCubbin & Patterson, 1984). *Factor xX* incorporates adaptation, which is influenced by the individual, family and community (McCubbin & Patterson, 1984). Adaptation is an ongoing variable that is determined by how the three influencing factors interact. This interaction will determine whether the adaptive response is toward bonadaptation or maladaptation.

aA: pile up

The findings of this study revealed that events that contributed to *aA: pile up* of stressors varied between participants. This variation is associated with the carer's ability to adapt to the changes associated with the caring experience and willingness or ability to utilise supportive resources available from formal or informal sources. As the symptoms associated with the diagnosis of lung cancer increased, stressors and resultant hardships increased for the carer, but this did not deter the carer from wanting to continue to provide the care within the home. The symptom of dyspnoea was not highlighted by the carers as a specific management concern, but carers did reveal a lack of understanding regarding appropriate management of this symptom. Management of all symptoms were disclosed as evoking equal concern for many carers, with dyspnoea often being viewed as requiring specialist medical intervention.

Participants identified concerns in relation to providing care (p.78). Several participants of this study expressed that they were unsure of their ability to maintain care when the family member became fully dependent. Holing (1986) and Aranda and Hayman-White (2001) report that when care is provided within the home the onus of care rests with the informal carer. The caring experience is also suggested to adversely impact on the carers' quality of life (Addington-Hall & McCarthy, 1995; Aranda & Hayman-White 2001). Chan and Chang (2000), Nolan and Grant (1989) and Shyu (2000) expand on this to consider the multiple responsibilities the carer is required to manage in addition to the care of the family member and the negative impact these responsibilities have on the emotional and physical wellbeing of the carer. In contrast to this, participants of this study, when discussing other responsibilities, revealed that these responsibilities were not viewed as additional sources of stress.

The *AA: pile up* of stressors that incorporated management of symptoms and the increasing physical care needs of the family member enforced change within the family. Analysis of the interviews revealed the different approaches taken by the carer when managing care (p.67). Participants who described the supportive actions of other family members and / or formal and informal resources were shown to be carers who adapted to the changing situation and provided care to the family member while ensuring their own physical, psychological and spiritual needs were met (p.89).

All carers who participated in this study described how the needs of the family member were paramount. Findings of the study revealed that participants who

continued to manage the care of the family member with minimal assistance from supportive resources did not consider their own wellbeing to be a priority.

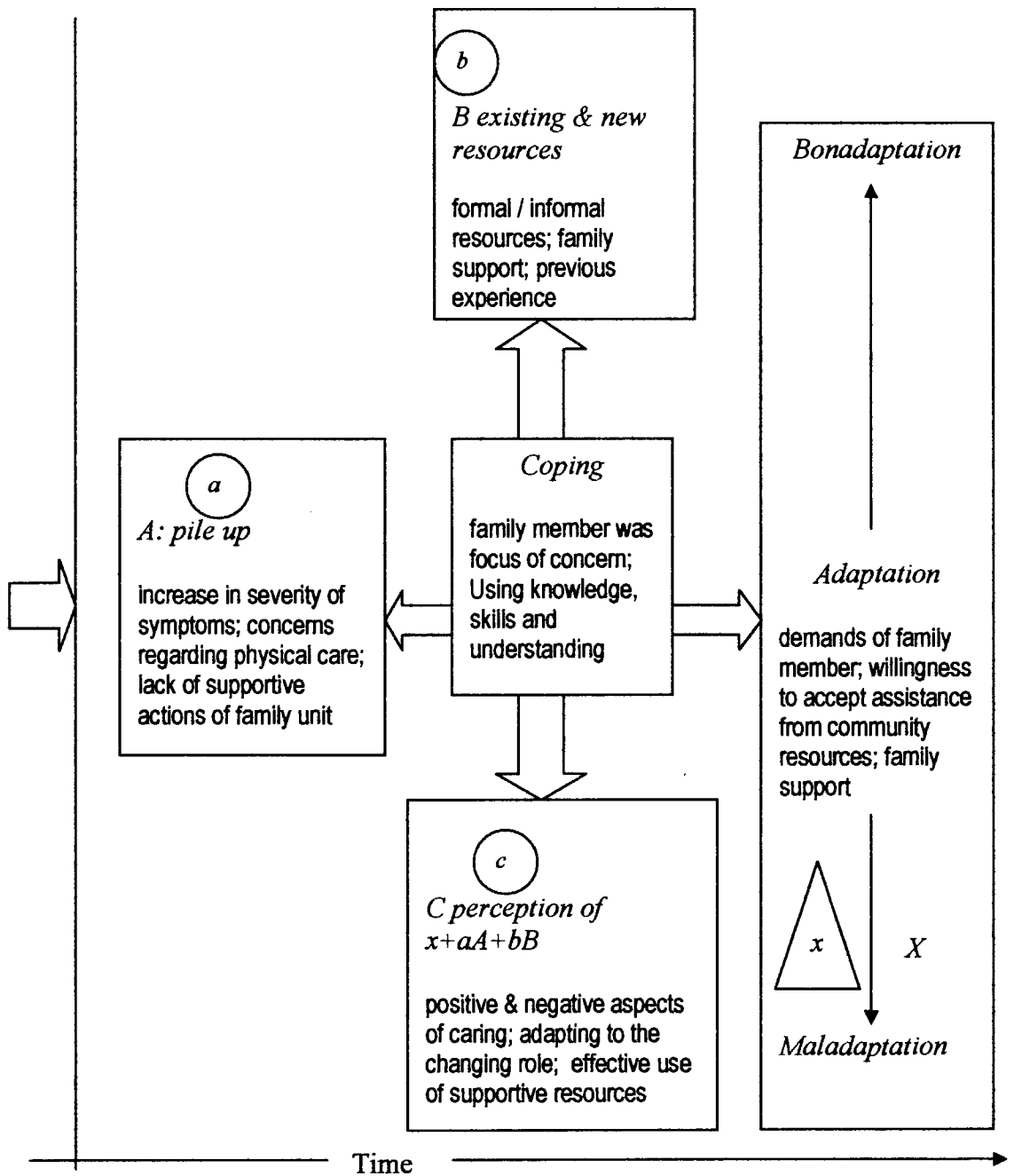
bB: existing and new resources

There is no conclusive evidence from this study to suggest those carers who have had previous experience in the caring role are able to utilise that experience (p.82). Participants of this study who did not or were unable to draw on previous experience had the same needs as those who had no experience. This is supported by Friedman (1992) who points out that that when available resources are not utilised the result is the same as if there were no resources available.

The main focus of formal support described by many participants was associated with the community palliative care service (p.89). Carers primarily accessed this service for assistance with symptom management. Many carers were reluctant to utilise other supportive resources available in the community.

Supportive actions were provided by family and friends. However, family support was accessed by few participants. Participants who discussed the support available from within the family described how this assisted the carer to continue providing care. Supportive actions from family that were utilised by the carers included respite care and assistance to meet the physical needs of the family member (p.90). Carers revealed the importance of listening to their concerns as a pivotal component of support provided by friends (p.92).

Figure 6.2: Double ABCX model of adjustment and adaptation. Managing dyspnoea: components of caring influencing adaptive responses of informal carer's - post crisis.



Post crisis

McCubbin and Patterson 1983. p. 12.

cC: perception of x+aA+bB

Positive and negative interpretations of the stressor that incorporates perceptions, definitions and the use of resources to achieve balance are components of *factor cC: perception of x+aA+bB* (McCubbin & Patterson, 1983). The positive and negative interpretations associated with the caring experience revealed in this study are outlined in Table 6.1.

The findings of this study revealed that all participants experienced both positive and negative interpretations of the caring experience. The ability to incorporate these interpretations and utilise resources to assist with achieving a sense of balance differed between participants.

Table 6.1: Positive and negative interpretations of the caring experience.

Positive	Negative
Strengthening of the relationship between carer and family member	Emotional aspects incorporating guilt and frustration
Increase in carers self esteem	Inability to elicit assistance from other family members
Knowing that carer has the ability to provide care	
Family unity	

Some carers were able to use family support effectively with one participant describing the family's ability to draw on previous experience and adapt the roles within the family to manage the changes associated with caring for the family member (p.90). In support of this, McCubbin and Patterson (1983) point out that the

family's understanding of the event is an essential component in managing the caring situation.

Community (p.93) and spiritual support (p.95) was revealed as an important component in enabling the carer to achieve balance within the caring role. Not all participants of this study were willing to utilise the supportive resources available from the community, preferring to manage the care alone. Many carers related this to their belief that the family member preferred care to be administered by the carer without involvement of others. Few carers discussed the spiritual aspect of meeting their own needs, but no carer disclosed the inability to achieve this need.

Coping

McCubbin and Patterson (1983) point out that *coping* incorporates the ability to manage a situation in its entirety. For the purpose of this study *coping* incorporated the carer's ability to utilise knowledge, skills, understanding of the disease process and its impact on the family member in conjunction with accessing supportive resources which assisted with management of the family member within the home.

The findings from this study revealed that all participants were *coping* with the caring experience. The primary concern of all participants was associated with the family member continuing to receive care within the home even when unsure of their ability to maintain the caring role.

Carers demonstrated understanding of the factors involved in providing care with the majority of participants discussing provision of care within the home until the death

of the family member (p.93). Participants differed when discussing how this care would be achieved.

Utilisation of family resources was discussed in depth by one participant who revealed that without the support of all the family the caring experience would be extremely difficult. Participants also discussed using the community palliative care service to assist with management of care at home. Few participants discussed using respite as a resource to assist with coping, but would utilise the community palliative care service to promote symptom management.

Xx: adaptation

Factor *xX: adaptation* is described by McCubbin and Patterson (1983) as having three units, individual, family and community that interact to achieve balance (refer to chapter three). In the context of this study, the individual is the family member receiving care. The participants of this study revealed that the family member (individual) may place demands on the carer which were difficult to meet therefore preventing the carer from achieving balance between the units. Evidence obtained from this study suggests that demands placed by the family member on the carer could be seen as a reluctance to accept assistance from resources outside of the family (p.71), refusal to disclose issues relating to symptoms experienced (p.72) and an inability to communicate effectively with the family member (p.70) and others involved in the care (p.88). The demands placed on the carer by the family member had no impact on the carer wanting to continue to provide care within the home.

As previously stated the carers were coping with the situation, but not all participants were achieving balance between the three units involved in *factor xX: adaptation*. No conclusive evidence emerged from this study to suggest that using support from family, formal and informal resources impacts on the carers' ability to manage the care of the family member within the home.

Summary

Each participant of this study related differing experiences regarding caring for the family member with lung cancer and the symptom of dyspnoea. While the experience of caring differed, all participants revealed commonalities. The most important component of providing care was a wish / desire to manage the care. Each participant wanted to continue to provide the care within the home with many expressing the desire to perform this care until the family member died. The ability to meet the challenge of providing care, develop the skills and utilise resources that would sustain the carer were common to each participant. Participants differed in the ways in which each of these themes associated with the caring experience were achieved, but analysis of the interviews revealed that the primary concern was meeting the care needs of the family member.

The diagnosis of lung cancer affected all members of the family. The carers and family members differed in their ways of adapting to the diagnosis. The double ABCX model of adjustment and adaptation was a useful framework that demonstrated the different ways in which families adapted to the changing situations that occurred following the diagnosis of lung cancer and the carer's progress towards adaptation. The double ABCX model of adjustment and adaptation revealed that not

all participants of this study were able to utilise resources that would ultimately enable them to achieve balance, but the study highlighted that during the caring phase of the illness the participants' only concerns were related to managing the care of the family member at home.

CHAPTER SEVEN

Reflections on the Study and Recommendations

Introduction

This study has provided an insight into the experience of caring for a family member with lung cancer and the symptom of dyspnoea from the perspective of the informal carer. The experience of the participants from the time the family member was diagnosed with lung cancer through to the development of symptoms and into the palliative care phase of the illness was discussed. Participants revealed the difficulties associated with care provision but also disclosed that no matter what was occurring the focus of care always remained the family member.

Summary of findings

When providing care to a family member with a diagnosis of lung cancer and the symptom of dyspnoea the primary concern of the informal carer is managing the care of the family member within the home. The symptom of dyspnoea did not emerge from analysis of the interviews as a reason for referral of the family member to an inpatient setting.

Communication, adapting to meet the needs of the family member, utilising supportive resources, understanding the disease progression and the ability to manage and / or understand the feelings of the family member and the carer were highlighted in the study as important components of the caring experience. Each of these components was associated with developing relationships. Development of relationships between formal and informal sources of support, the carer and the family member receiving care was found to be the underpinning concept which

influenced the caring experience. Carers develop relationships that impact in varying ways upon the caring experience. Therapeutic relationships, when present, assisted carers to meet the challenges of providing care but the study did not reveal that carers who were unable to establish relationships with either formal or informal resources as unable to continue to provide care within the home.

This study also revealed that communication between carers and community nursing staff did not always result in the intervention suggested by the nurse. Further research is needed into this area of palliative care. Carers may not always fully comprehend the information given therefore it is necessary for nursing staff to develop communication skills that will ensure that the carers understand any suggestions for symptom control or management of the family member.

The double ABCX model of adaptation and adjustment considers factors that precipitate crisis within the family system. For the purpose of this study the double ABCX model was a useful framework in assessing the ability of the carer to adapt to the changing situation associated with providing care to a family member receiving palliative care. Using the model in this study shows that those carers who are able to elicit assistance from family members, formal or informal supportive resources do not experience stressor events that result in hardship to the family. Carers who do not receive support and experience hardships continue to manage the care of the family member within the home without considering the impact this may have on their own wellbeing. Adaptation to the crisis situation varied between the participants dependent upon the level of support received, but this did not impact on the willingness of the carer to continue to maintain care within the home.

Implications for nursing practice

This study has highlighted issues that are an important component of assisting carers to manage care of family members within the community setting. Understanding the stressors that impact on the ability of the carer to provide care within the home and understanding family functioning and its implications on care provision are issues that need to be incorporated into care planning by community palliative care nurses.

By incorporating nursing knowledge relating to the known stressors that impact on the physical and psychological wellbeing of informal caregivers with knowledge regarding family functioning, nurses will be able to achieve higher standards of care for the family member and informal carer. To achieve this, it is necessary for the planning of the care and interventions to be guided by an appropriate conceptual framework that incorporates family functioning such as the double ABCX model of adjustment and adaptation.

Dyspnoea was not revealed in this study as a symptom that caused management concerns to family members, but it was revealed as a symptom that caused distress. This distress was the result of the inability of the carer to manage the symptom and reliance upon specialist medical management. Developments of strategies that will assist the carer to manage difficult symptoms, such as dyspnoea, are revealed as an essential component of enabling the carer to continue to manage care within the home.

Limitations of the study

Lung cancer is the most common diagnosis of clients admitted to SCHCS with approximately 800 clients with this diagnosis admitted each year. This study

incorporated a limited number of these carers. All carers who participated in the study were female. If the study were repeated it would be of interest to interview male carers to determine if there are any differences in experience in comparison to the female carers' experience.

All participants were providing care to a family member who was experiencing dyspnoea classified as unresolved but the symptom of dyspnoea was not measured for this study. It would be suggested that with future research the symptom under investigation is measured using a validated symptom assessment measurement tool.

As previously stated, following transcription and analysis of the interview tapes it became apparent that with some participants, events that occurred at the time of diagnosis influenced the current experience and ability to provide care for the family member. It would be suggested that with future research, the researcher structures the initial opening question to incorporate strategies to understand how the experience obtained during diagnosis has continued to affect current experiences.

Only two Registered Nurses participated in the study to assess the perspective of the Registered Nurse in relation to the needs of the carer and to identify any discordance between the needs identified by the carer and those identified by the nurse. Therefore, the results obtained from this study regarding the discordance between the information provided to informal carers by the Registered Nurses and that understood by the carer should be used with care within and outside of this study. Future studies that assess the experience of the carer in relation to symptom management should incorporate the perspective of the Registered Nurse providing care to the family.

Recommendations for further research

Healthcare will increasingly be provided in the home setting. Therefore, the findings of this study suggest that prospective research is conducted that investigates the experience of providing care to a family member within the home from the time of diagnosis through to the bereavement phase. This will determine how interaction with formal and informal resources influences the caring experience.

Participants of this study described the management of dyspnoea as being the responsibility of health care professionals. Dyspnoea was not identified by any participant as a barrier to providing care but the carers did acknowledge the feeling of helplessness experienced when observing the family member during an episode of dyspnoea. Carers were not fully aware of the management options for dyspnoea, which increased the feeling of helplessness. A recommendation for further research would incorporate development and evaluation of strategies which will enable the carers to provide management of the symptom of dyspnoea within the home setting without relying on and waiting for assistance from health care professionals.

The researcher acknowledges that as only two Registered Nurses were interviewed for this study the results cannot be used to generalise for all nurses but this study did highlight the discordance which occurred between the information provided to carers by Registered Nurses and the care provided by the informal carer to the family member who was experiencing dyspnoea. It would be useful to explore Registered Nurses' understanding of the causes of dyspnoea and treatment options in the palliative care setting and how the Registered Nurse provides this information to the informal carers of palliative care clients.

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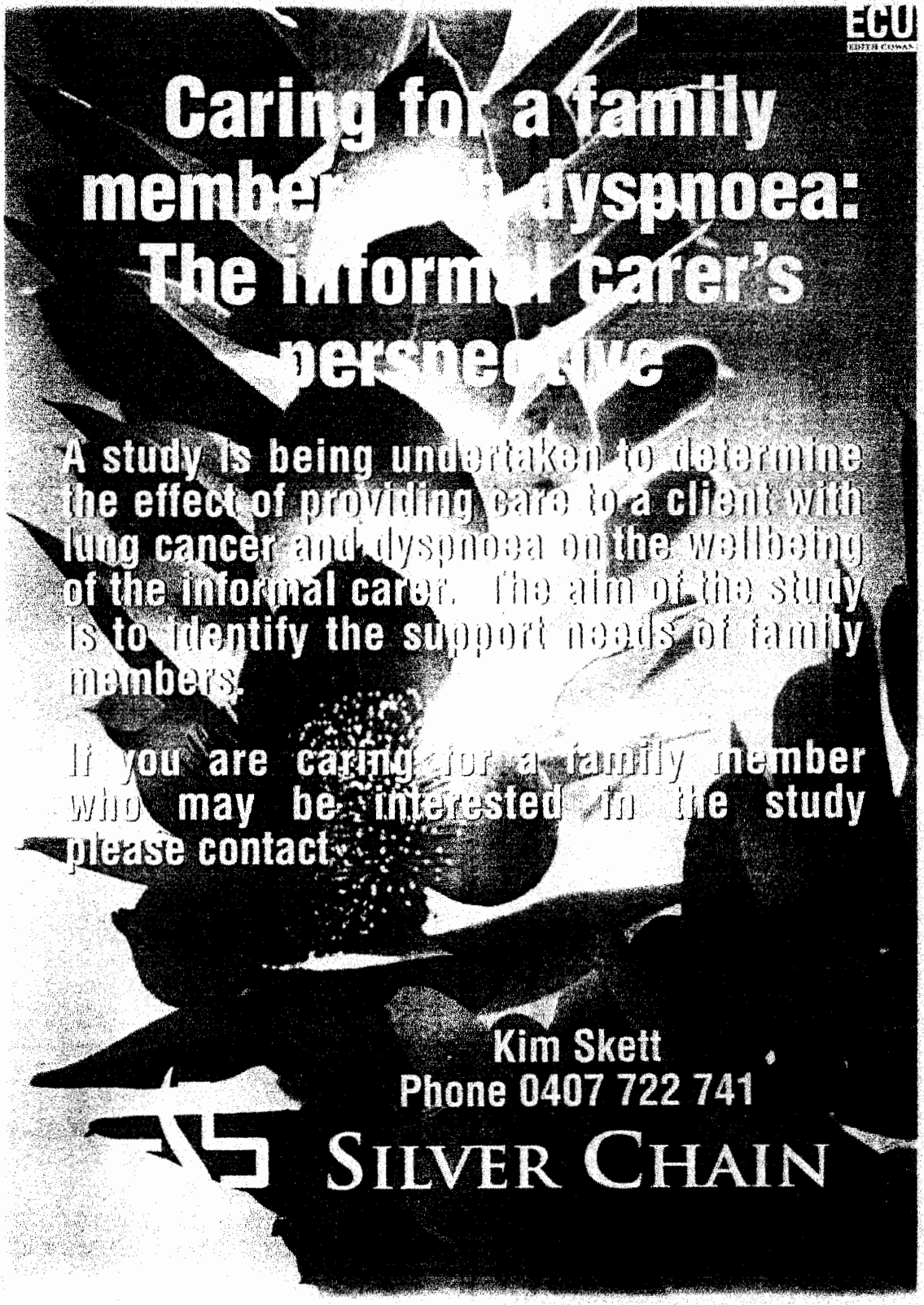
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APPENDIX A:
Cultural background of SCHCS clients July – October 2001

Country of origin	Total number of clients
Australia	479
Austria	4
Bosnia and Herzegovina	1
Burma	5
Cambodia	1
Chile	1
China	1
Croatia	10
Cyprus	1
Czech Republic	2
Egypt	3
England	161
Falkland Islands	1
France	1
Germany	15
Greece	7
Hungary	4
India	12
Indonesia	1
Ireland	10
Italy	41
Kenya	1
Lebanon	2
Liechtenstein	2
Lithuania	1
Macedonia	6
Malaysia	3
Mauritius	4
Netherlands	19
New Zealand	13
Northern Ireland	1
Not Stated/inadequately Described	6
Philippines	2
Poland	9
Portugal	1
Romania	1
Russian Federation	2
Scotland	44
Singapore	4
Slovenia	1
South Africa	6
Sri Lanka	1
Taiwan	1
UK and Ireland NFD	4
Ukraine	1
United States of America	2
Viet Nam	3
Wales	9
Yugoslavia	6
Zambia	3

APPENDIX B

Poster displayed at SCHCS service delivery centres



ECU
ESTHER COOMAN

Caring for a family member with dyspnoea: The informal carer's perspective

A study is being undertaken to determine the effect of providing care to a client with lung cancer and dyspnoea on the wellbeing of the informal carer. The aim of the study is to identify the support needs of family members.

If you are caring for a family member who may be interested in the study please contact:

Kim Skett
Phone 0407 722 741

SILVER CHAIN

APPENDIX C
Registered Nurse interview questions.

How long have you been providing care to.....?

What do you perceive to be the issues for ... ?

What symptoms, if any, are causing concern for... ?

As the primary nurse for this family how do you assess the carers support needs?

What information have you provided to... which assists her to care for... ?

Have you offered to organise respite for the client? If yes, what were the reasons that led to this?

APPENDIX D

Sample questions used to guide informal carer interview

The interview will be unstructured where the participants will be asked to describe their experiences both positive and negative while caring for a client with lung cancer and an uncontrolled symptom of dyspnoea. The interview will commence with a preamble such as:

Thank you for agreeing to participate in this study. As has previously been explained the aim of this study is to gain knowledge of your experience of providing care to ... (clients preferred name), so that improved services can be provided to clients and their families.

Examples of opening questions to be used are:

- To start can you give me a brief background of ... (clients preferred name) medical situation
- Tell me about your experience of caring for ... (clients preferred name) when he/she is short of breath
- What has the experience of providing care to... (clients preferred name) been like for you

Probes may include:

- Could you tell me more about that?
- How did that experience make you feel?

APPENDIX E
Consent form

Study title: Caring for a family member with dyspnoea: The informal carer's perspective.

Investigator: Kim Skett RN, RMHN

Supervisor: Associate Professor Kate White

I have been given clear information (verbal and written) about this study and any questions have been answered to my satisfaction.

I have been told that participation in this study is voluntary and that I have the right to withdraw at any time, either during or at the completion of the interview without affecting the care that my family member or I am receiving.

I have been informed of any possible advantages or risks involved in participating in this study.

I understand that participation in this study entail completion of one interview, which will be audio taped. I understand that my identity will not be revealed at any time, either during or at completion of the study.

Edith Cowan University Ethics Committee has approved this study and its procedures.

I have read this consent form and voluntarily consent to participate in this study

.....
Participants signature

.....
Date

I have explained this study to the above participant and have sought his/her understanding for informed consent.

.....
Research nurse signature

.....
Date

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