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Developing and testing a pain management program for family caregivers of advanced cancer patients

Lynn Oldham
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**DEVELOPING AND TESTING A PAIN MANAGEMENT PROGRAM FOR
FAMILY CAREGIVERS OF ADVANCED CANCER PATIENTS**

By Lynn Oldham, RN, BN (Hons)

**A Thesis Submitted in Fulfilment of the Requirements for the Award of
Doctor of Philosophy (Nursing)
Faculty of Communications, Health and Science.
Edith Cowan University
Churchlands, Western Australia**

Date of Submission: September 2002.

ABSTRACT

Increasingly, advanced cancer patients are receiving care in the community supported by families and hospice home care services. However, little or no preparation is provided to family caregivers who assume this supportive role, often 24 hours per day. Pain management is consistently identified by family caregivers as their primary concern related to care and support of a relative with cancer. This project involved a three-phase program of research to develop and test a pain management program (PMP) that would provide family caregivers of advanced cancer patients with information and skills to manage the patient's pain.

Phase I involved the development of a pain management program for this group of families (N=19) using relevant literature and qualitative methods to elicit information about the components of a pain education program that would be helpful to families. The PMP was developed from this phase and consists of four sequenced, interactive education sessions, a Daily Comfort Diary (DCD) and a video. In Phase II the PMP was pilot tested with 31 family caregivers and the study instruments were assessed for sensitivity to change and for psychometric soundness. Phase III involved a randomised clinical trial to test the intervention with a sample of 117 family caregivers. Participants were randomised into the control group (N=57) to receive the usual home hospice care and the DCD or into the experimental group (N=60) to receive the usual home hospice care, the DCD, the education sessions and the video. In Phases II and III data were collected at three time points - Time I: at consent to participate; Time 2: on completion of the PMP which was approximately three weeks after Time 1 for both groups and Time 3: one week following Time 2 data collection.

In Phase II, data analysis showed statistically significant improvement in the family caregivers' knowledge and experience of and attitudes to cancer pain management over time. In Phase III, the results indicated that in the experimental group, the PMP was most effective in improving family caregivers' knowledge about the ability to relieve cancer pain, addiction and safe use of opioids ($p=0.02$, $p=0.00$, $p=0.02$) respectively, compared with the control group. The PMP was also effective in improving family caregivers' attitudes toward cancer pain management over time however, the interaction effect did not quite reach significance ($p=0.06$), indicating that

the changes in scores for the two groups over time were not large enough to be significant, despite the trend towards improvement for the intervention group. There was no significant improvement in the family caregivers' experience of cancer pain management in the experimental group and both groups showed a similar trend over time. Findings from this study indicated that, at baseline, the family caregivers had good knowledge and attitudes about cancer pain management. This may partly explain the unexpected lack of significant results. Another possible reason for the lack of overall significance may be that all the statistical tests were underpowered (<0.80) due to the small sample size. In this study group it was not possible to recruit and retain the 130 participants during the study period, that would have assured adequate power and thus allowed the detection of significant results. The major conclusion from these results is that the PMP is a simple and effective intervention for addressing the needs of family caregivers to provide pain management in the home to terminally ill cancer patients. The PMP was found to be feasible, well received by participants and adaptable to individual family caregivers' learning needs.

Eight key issues associated with the delivery of education programs for family caregivers were identified. These are the timing of the education program, location for training, the need for individual teaching approach, the use of technology, refinements to outcome measures, rural and regional education issues, educational needs of special populations and education of families to manage other types of symptom distress. These key issues have been discussed and seven recommendations for subsequent research to build on this study's findings have been suggested. Health care professionals must value the work done by family caregivers of advanced cancer patients and include family caregivers as members of the multi-disciplinary palliative care team. Families must be provided with on-going information and education to strengthen and support their inestimable contribution to patient care.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;*
- (ii) contain any material previously published or written by another person except where due reference is made in the text; or*
- (iii) contain any defamatory material.*

Signed:

A solid black rectangular box redacting the signature.

Date

20 February 2003

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CHAPTER I

INTRODUCTION

When caring at home for a family member who has advanced cancer, family caregivers are required to be both knowledgeable about the principles of cancer pain management and able to maintain and sustain their own health and roles within the family. Family caregivers' needs throughout the caring journey are complex and demanding. The need for pain management skills is especially acute.

There is an expectation among many health professionals that, given basic support, any willing family caregiver of a cancer patient will cope in spite of a lack of cancer pain management education. The importance of the role of family caregivers in relieving pain and the impact of unrelieved pain on the patient and family caregiver has been acknowledged, but not formally addressed in the Australian palliative care setting. Family caregivers' knowledge and experience of, as well as attitudes to cancer pain management are the main foci of this study. This chapter outlines the background to the study and explains the purpose and significance of the work.

Background to the Study

In 1996, there were 34,770 cancer deaths in Australia. Approximately 56% of those people who died of cancer received some support from a palliative care service and approximately 26% of people who received palliative care support died at home (Palliative Care Australia, 1998). In 1998, Palliative Care Australia estimated that between 4,000 and 4,200 of individuals with cancer would die at home in 1998, and the number would continue to increase. The most recent projections of cancer incidence rates suggested that Australia would have approximately 76,000 new cancer cases per annum diagnosed by 1999 (Commonwealth Department of Health and Family Services, 1997).

Increasingly, advanced cancer patients are receiving care in the community supported by families and home hospice services. However, little or no preparation is provided to family caregivers who assume this supportive role, often for 24 hours per day.

Pain management is consistently identified by family caregivers as their primary concern related to care and support of their relatives with advanced cancer (Bucher, Trostle & Moore, 1999; Ferrell, 2001; Harrington, Lackey & Gates, 1996; Ferrell, Taylor, Grant, Fowler & Corbisiero, 1993; Ward, Berry & Misiewicz, 1996).

This is a significant issue for family caregivers who provide home care because unrelieved cancer pain is an overwhelming experience for the patient and family. Poorly managed pain destroys the patient's quality of life and increases the patient's and family's fear of disease progression and can lead to anxiety and depression (Riddell & Fitch, 1997). Poorly managed pain is also emotionally and physically exhausting for both the patient and family. The family caregiver who is unable to ease the patient's suffering, is often severely burdened with feelings of guilt and despair and may experience a profound sense of helplessness (Ferrell, Rhiner & Grant, 1991). Although some patients and families may be supported by a home hospice service, the majority of time spent providing care remains a family duty.

Family caregivers who do not feel confident and knowledgeable about pain management are more likely to require hospital admission and more frequent medical interventions for their relatives and need greater respite care for themselves (Ferrell, Taylor, Grant, Fowler & Corbisiero, 1993). Given recent cost containment pressures within the health care system, prevention of factors that might trigger unnecessary health expense is warranted. As well, family caregivers who are unfamiliar with pain management medications may over-medicate or under-medicate patients with opioids, resulting in medical complications and increased suffering.

Several studies have shown that educational programs for family caregivers can improve knowledge and attitudes (Ferrell, Grant, Chan, Ahn & Ferrell, 1995; Wells, Hepworth, Murphy, Wujcik & Johnson, 2002) about cancer pain management and also improve family caregiver skills and reduce caregiver burden (Pasacreta, Barg, Nuamah & McCorkle, 2000). To date these studies have all been conducted in North America.

In summary, increasing numbers of people with advanced cancer are receiving care in the community supported by families and home hospice services. Family caregivers have consistently identified pain management as a primary concern related to care of a family

member. The impact of unrelieved cancer pain on the patient, family and health care system has been reported. There is a need to educate family caregivers in the principles of pain management and care.

The study reported here involved the development and testing of a family pain education program that was based upon Ferrell, Grant, Padilla, Vemuri and Rhiner's (1991) model entitled *Impact of Pain on the Dimensions of Quality of Life*. The relevant components from the model are detailed in the third chapter of the thesis.

Guided by this model, the researcher developed a pain education program based on qualitative methods and relevant literature. The pain education program was pilot tested and refined, and then implemented in a randomised controlled trial with family caregivers of cancer patients.

The researcher selected two existing instruments to measure family caregivers' knowledge and experience of, and attitude to cancer pain management. The psychometric properties of these instruments were tested prior to implementation in the randomised controlled trial.

Purposes of the Study

The overall aim of the study was to develop and test a pain management program (PMP) to provide family caregivers of advanced cancer patients with information and skills to manage the patient's pain. The study was conducted in three phases. Phase I involved the development of an education program for this group of families using relevant literature and qualitative methods to elicit information about the components of a pain education program that would be helpful to families. Phase II pilot tested the education program and determined the extent to which the outcome measures were sensitive and psychometrically sound. Phase III involved a randomised clinical trial to test the education program with a random sample of family caregivers. Conceptual definitions can be found in Appendix A.

Research Questions – Phase I

Articulation of Pain Management Content and Teaching Strategies for Families of Advanced Cancer Patients.

The following research questions were formulated from the literature and were used to elicit information about cancer pain management education from the family caregivers' perspectives.

1. What are the problems associated with advanced cancer pain management at home?
2. What types of information would assist family caregivers to manage cancer pain at home?
3. What educational strategies in cancer pain management do family caregivers perceive to be most helpful?

Research Questions – Phase II

Development and Testing of the Outcome Measures to Assess the Intervention.

In Phase II, the following research questions guided the pilot testing of the PMP and framed the psychometric assessment of the instruments.

1. To what extent do the outcome measures demonstrate clarity, content validity and apparent internal consistency?
2. To what extent do the outcome measures demonstrate internal consistency reliability?
3. To what extent is the pain management intervention feasible?
4. To what extent is the pain management intervention acceptable to family caregivers?

5. To what extent is the pain management intervention effective in improving family caregivers' knowledge of and attitudes to pain management?
6. To what extent is the pain management intervention effective in improving family caregivers' experience of pain management?

Hypothesis – Phase III

The following research hypothesis was tested to determine whether the family caregivers who participated in the PMP demonstrated improved knowledge of and attitudes towards cancer pain management, as well as an improved pain management experience.

Research Hypothesis

Family caregivers of advanced cancer patients receiving care through a home hospice service who participate in a pain management program (PMP), will obtain improved pain knowledge scores, improvements in attitudes toward pain management and improvement in their pain management experience and will provide more appropriate pain management interventions to patients than family caregivers who do not participate in the PMP.

Secondary Research Question

To what extent is the Daily Comfort Diary useful to the family caregivers?

Significance of the Study

As more families are choosing or are expected to care for advanced cancer patients at home, their knowledge about how to provide pain management becomes increasingly important. There are many potential benefits arising from this study. Findings from this study have potential to improve the advanced cancer patient's quality of life, reduce the long-term impact of poorly managed pain, lessen the caregiver burden and improve caregiver well being. Findings from this study also have potential to reduce health care

costs for cancer patients. These cost savings could be realised in three ways. Firstly, family members of patients who are more knowledgeable will make more appropriate use of pain medications. Secondly, family members who are better prepared may be less likely to become sick because of a care-giving burden for which they are inadequately prepared. As well, study findings have the potential to reduce costs for health care in-patient services by reducing the need for hospital admissions caused by inadequate cancer pain management at home. As the numbers of people with cancer and family home caregivers increase, this study has the potential to offer a simple, clinically useful approach that can be incorporated into routine nursing practice. The pain management model developed from this study may also be transferable to other clinical symptoms and settings.

To date, no Australian research has been undertaken to develop and test family pain management interventions. Outside Australia, research on pain management for family caregivers of advanced cancer patients is limited. This study makes a significant contribution to knowledge in an under-researched area and will allow beginning comparisons to be made across countries.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter examines published literature related to cancer pain management for advanced cancer patients and their families. Databases used to locate relevant literature were the Medline and CINAHL data bases from 1975 to 2002 and the PsycINFO data base from 1984 to 2002. Australian Commonwealth and State Health Department Cancer Reports were also reviewed. Four major themes emerged from this literature:

1. Pain associated with advanced cancer
2. The impact on and the coping strategies of family caregivers caring for advanced cancer patients at home.
3. The families' needs in providing cancer pain management at home.
4. Preliminary evidence that educational programs directed towards patients and families may improve cancer pain management at home.

This literature review provides theoretical and empirical rationales for the conceptual framework underpinning the study.

1) Pain associated with advanced cancer

This section of the literature review includes a discussion of the incidence and severity of cancer pain, the knowledge deficits among health care providers and patients with advanced cancer and their families about cancer pain management and the barriers to effective cancer pain management.

Although use of effective management of cancer pain has improved during the past 20 years because of advances in technology and improved knowledge of analgesics, as

many as 75% of advanced cancer patients will experience pain that is moderate to severe in intensity at some time during the illness (Bucher, Trostle & Moore, 1999; Cleeland et al., 1994; Johnston & Abraham, 1995; Portnoy, 1989; Thomason et al., 1998). A number of studies report a high incidence of severe pain for patients cared for in hospital and at home in the terminal phase (Bonica, 1985; Coyle, Adelhardt, Foley & Portenoy, 1990; Ferrell, Borneman & Juarez, 1998; Steinhauser et al., 2000; Stjernsward, Colleau & Ventafridda, 1996; Zhuvosky, Gorowski, Hausdorff, Napolitano & Lesser, 1995). For example, Bucher, Trostle and Moore (1999) interviewed a random sample of 170 family caregivers of cancer patients to explore the presence and degree of cancer pain experienced by patients according to their family member in the last month of life. Data were collected using a 71 item structured telephone questionnaire. The presence and degree of cancer pain was elicited by the question, “ In the month before (his/her death), how much pain because of cancer did (he/she) experience? Would you say a great deal, quite a bit, some, a little, or no pain?” Of the 147 caregivers who reported pain experienced by their family member during this time, 70% of these caregivers reported “a great deal” to “quite a bit” of pain.

Similar findings were reported by Cleeland and associates (1994) in a study that described the prevalence and severity of cancer pain in a group of 1,308 outpatients with metastatic cancer during a 12- month period from 1990 to 1991. The Brief Pain Inventory [BPI] (Daut, Cleland & Flanery, 1983) was used by the patients, to assess the severity and the impact of pain. Patients also rated the mildest pain that they had experienced, their average degree of pain and the pain that they were having at the time of the study. In this group 59% had pain related to metastatic cancer, and 62% of the patients with pain rated their pain as substantial (a score of 5 or higher).

A study conducted in an in-patient oncology and haematology clinic by Zhuvosky, Gorowski, Hausdorff, Napolitano and Lesser (1995) documented the prevalence and intensity of cancer pain and the unmet analgesic needs of a group of 101 in-patients. Findings were similar to previous studies. Forty-four percent reported inadequate analgesia and described their pain as moderate or greater than moderate in intensity. The authors discussed the need for improvement in the health professionals’ knowledge of pain syndromes and greater patient control over the analgesic regimen.

McCaffrey and Ferrell (1997) conducted a pre-test survey of pain management knowledge among nurses who were attending pain conferences in 1995 and compared the results to a similar survey conducted in 1991. The aim of the research was to identify the educational needs and evidence of improvement in pain management education of the general population of practicing nurses. There were 450 nurses in the former group and 456 in the latter. The results of four earlier addiction surveys (1988-99[N=2296], 1989-90[N=2063], 1992[N=150], 1992-93 [N=656]) among nurses were also compared with results from data collected in 1995.

The authors reported some improvement in pain knowledge deficits among nurses over time. These deficits were in the areas of pain assessment, opioid doses and the possibility of addiction. Of major concern for the researchers was the fact that fewer than half the nurses in the 1995 study believed in the patient's self report of pain and consequently indicated that they would not initiate a safe increase in opioid dosage based on the patient's own pain assessment. Although nurses' knowledge about addiction improved over time, findings of the 1995 study showed that nurses believed that addiction was more likely when opioid medication was used for a three- month period or longer. Limitations of the pain management survey results included the use of different pain rating scales and medication administration routes and the absence of a pain rating goal between the original survey and the 1995 survey. The authors also discussed the issue of sample bias and considered the possibility that participating nurses were more highly motivated to learn than those nurses who did not attend pain conferences and thus the findings did not accurately reflect the pain management knowledge of the general nursing population.

Whether improvements in pain management knowledge had occurred or not, it is evident that there are still grave knowledge deficits in important areas of pain management that need to be addressed if cancer patients are to receive effective pain management at home. If nurses' knowledge is inadequate, they are in no position to provide or teach pain management education to patients and families at home.

In the home care setting, Ferrell, Borneman and Juarez (1998) found basic pain knowledge deficits among 77 home care nurses in 10 of 39 survey items. Deficits occurred in the area of opioid and non-opioid pharmacology, non-drug interventions, understanding the prevalence of addiction and pain assessment related to patient behaviour. Effective

control of cancer pain involves family caregivers, patients and health professionals. Although family caregivers, nurses and doctors may be committed to providing a high standard of pain management in the home, it is evident that the challenges of providing complex cancer pain management for patients choosing to live at home are considerable.

The most frequently reported reasons for inadequate management of cancer pain at home include: a lack of understanding about pain, a lack of knowledge of medication dosages, a fear of addiction, misconceptions about the use of opioid and adjuvant medications using various routes and a lack of knowledge of non-pharmacological pain interventions (Ferrell, Ferrell, Rhiner & Grant, 1991; Lothian & Muir, 1998; Ward, Carlson-Dakes, Hughes, Kwekkeboom & Donovan, 1998).

For example, Ferrell, Ferrell, Rhiner and Grant (1991) reported the findings of a research study that involved a group of 85 family caregivers recruited from both in-patient and home hospice care. The researchers sought to describe the experiences, knowledge and roles of the family caregivers in relation to pain management. The impact of cancer pain from the family perspective was also explored. Data were collected using the profile of mood states [POMS] (McNair, Lorr & Droppelman, 1971), the caregiver burden scale [CBS] (Robinson, 1983), the family knowledge and attitudes about pain [FKA] which was developed by the authors for this study, and a demographic data tool. Results of this study indicated that the family caregivers consistently rated their relative's pain distress as severe, and they reported fears of addiction, a general lack of knowledge of medication administration and were unaware of non-pharmacological interventions.

Lothian and Muir (1998) discussed the barriers to cancer pain management in the home care setting and proposed strategies for improvement in this area. Strategies for successful pain management were illustrated with case studies. The authors stated that a lack of understanding about the effects of opioids was a major obstacle to achieving relief from cancer pain. The importance of pain assessment and the need for health professionals to believe the reality of the patient's self-report of pain was emphasised in this paper. The authors also stated that it was often the health care provider's fear of the patient's addiction that frequently prevented effective pain control.

In 1998, Ward and colleagues reported the findings of a study that examined relationships between quality of life and patient -related barriers to pain management. One

hundred and eighty two cancer outpatients completed four instruments. A short form of the Barriers Questionnaire (BQ) (Ward et al, 1993) was used to measure beliefs. Pain severity was measured using three items from the Brief Pain Inventory (BPI) (Cleeland, 1989) and impairments in Quality of Life data were also collected with this tool. The participant's coping in relation to analgesic use was measured by the Pain Management Index (PMI) (Zelman, Cleeland & Howland, 1987). Depressed mood was assessed by the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977). Patients completed the questionnaires while in the clinic waiting rooms. Results demonstrated that higher pain belief barrier scores were associated with less effective coping strategies and the less able the patients were to cope the higher the reported pain severity scores. Results also showed that patients with high pain barriers were more likely to take inadequate opioid doses to manage their pain.

The review of the literature related to cancer pain management clearly demonstrates the barriers to achieving effective cancer pain management that exist in the health care community and among its consumers. If advanced cancer patients are to receive state-of-the-art pain management, these obstacles to quality care warrant specific attention.

2) The impact on and coping strategies of family caregivers caring for advanced cancer patients at home

This section of the literature review examines the impact on family caregivers of caring for a relative with cancer and the coping strategies that they use in response.

Impact

In a review of the research literature of family adjustment to cancer from 1977 to 1991, Sales, Scherlz and Biegel (1992) reported on five objective stressors that impacted on the family. These were the patient's prognosis and degree of distress, the stage and length of the patient's illness and the consequent demands on the family caregiver. As well, demographic characteristics of family caregivers and family relational qualities were examined for their impact on family distress. The authors examined age, gender, socio-economic status and health status of the family caregivers. The family relational variables that were explored were the quality of marriage, marital communication, stage of the family and the family's social support.

The authors concluded that younger family caregivers experienced more emotional distress than aging family caregivers. Younger caregivers could manage the role of caregiving without feeling overtaken by the task, while aging family caregivers had the greatest difficulties with coping with the physical needs of their relative's illness. Women were more likely to express feelings of emotional distress than men and family caregivers who lived on a low income and had limited education experienced more fear about managing their relative's illness than those on a higher income with higher educational achievements. Family caregivers with poor health or other life stressors were most likely to find the task of caring for a patient with advanced cancer a stressful and negative experience. The authors also reported that strong, close marriages helped family caregivers cope in the early stages of cancer, but may have contributed to more distress for the family caregiver as the patient's disease advanced. Social support for family caregivers was reported to be important although under researched.

The findings from Sales, Scherlz and Biegel's (1992) review of the literature suggest that patients with advanced metastatic disease who have been living with cancer for some time and who were debilitated by the disease had the greatest negative impact on family distress.

It is evident that the experience of caring for a family member with advanced cancer can often be challenging, burdensome and all encompassing for family caregivers (Yates, 1999). Northouse and Peters (1993) describe the experience of cancer as being "an assault on the entire family unit". Families experience changes in their daily routine, well-being, roles and relationships and financial situations. Families also describe an underlying fear of and uncertainty about the future (Jassak, 1992). For example, Aranda and Hayman-Whyte (2001) reported the findings of a descriptive study of 42 Australian family caregivers providing home care to persons with advanced cancer. In this study, family caregivers assumed responsibility for all household tasks, were more anxious than the general population, had little time for themselves and reported high levels of fatigue.

Depression and anxiety have also been frequently reported in studies that have examined family caregivers of advanced cancer patients (Given & Given & Kozachil, 2001; Given et al., 1993; Grbich, Parker & Maddocks, 2001; Hinds, 1992; Miaskowski, Kragness, Dibble & Wallhagen, 1997). Hinds (1992) described the sources of suffering of a

random sample of 83 family caregivers of cancer patients. A semi-structured interview guide that included demographic information was used to collect the data. Findings were reported by using four family caregiver profiles with accompanying categories and comments. In this study, family caregivers described their suffering in terms of their fears of loneliness, uncertainty about the future for both the patient and themselves, lifestyle disruptions, communication breakdown, perceived lack of support and helplessness.

Grbich, Parker and Maddocks (2001) conducted longitudinal case studies with a stratified random sample 20 family caregivers of patients with advanced cancer over a period of 15 months. The same interviewer conducted monthly interviews with each caregiver. Seventeen patients died during the data collection period and 14 family caregivers were interviewed after their bereavement. The data were analysed thematically. The findings reported that all 20 family caregivers described feelings of shock, distress, anger, fear and depression at the initial diagnosis. During the actual caring journey, family caregivers described both positive and negative emotions frequently dependent on the severity of the patient's symptoms. Seventeen family caregivers described being 'physically and mentally exhausted', and having frequently disturbed sleep. Family caregivers also expressed feelings of loneliness and reported health problems that required counselling or medication. In the post bereavement phase, the family caregivers predominantly conveyed expressions of 'physical and emotional exhaustion.'

Stetz and Hanson (1992) surveyed 65 bereaved family caregivers during the time they were providing care and six months after the death of their family member (n=31). Findings of this study revealed families' personal regrets about their caring roles. Participants reflected the desire to have asked for more information and resources to help them with their care giving activities. The most difficult aspect of care giving for these family caregivers was their sense of powerlessness over their family member's illness.

Miaskowski and colleagues (1997) further document the centrality of pain management to the caregiving experience in research. These researchers, using a descriptive approach and a convenience sample, found that family caregivers of oncology outpatients with cancer related pain reported significantly more tension, depression and total mood disturbances than family caregivers of oncology outpatients without cancer related pain. There were 86 caregivers in the former group and 42 in the latter. Kristjanson

and Avery (1994) have termed these stressful responses of the family to pain in a loved one as "vicarious suffering". As well, there is evidence to suggest that family members who experience a difficult death or unrelieved patient distress (eg, poorly managed pain) may be at risk for more complicated grief reactions.

For example, Kristjanson (1983) used a descriptive approach with a convenience sample of ten bereaved families, comprising 60 people, to explore family decision making in terminal cancer. Open ended, semi structured interviews and field notes were used to collect data. Content analysis was employed to analyse the data. The six main themes identified from the analysis were decision control, information, the meaning of the situation, patterns and characteristics of family interaction related to terminal care decisions, planning for death and the effects of the terminal care process on survivors. Families of patients who had experienced suffering and loss of dignity in the end stage or sudden death described feelings of guilt and regret. These feelings lingered in the families long after the death of their relative.

Ferrell et al (1991b, 1991c, 1993, 1995) and Ferrell and Dean (1995) have clearly documented the negative impact that the patient's pain has on the family. Family members report feelings of helplessness, anxiety, and may even wish for the patient's death when they feel unable to relieve the suffering of their loved one (Ferrell, 1991a).

These study findings illustrate the profound challenges that many caregivers experience. Interventions directed toward information provision and practical pain management education would appear to be beneficial to both patients and family caregivers. Therefore, an intervention that provides family caregivers with knowledge and skills to manage cancer pain has the potential to mediate the negative emotional burden and decrease the sense of powerlessness experienced by family caregivers.

Families' coping strategies

This section of the literature review examines the ways in which family caregivers cope with the role of being the family caregiver of a relative with advanced cancer.

Hull, (1992), employing qualitative techniques, examined coping strategies of 14 family caregivers enrolled in a hospice home care. In this population, the coping strategies were reported as taking one day at a time, accepting and rationalising changes in the patient's condition and avoidance. Another qualitative study conducted by Rose, Webb and

Waters (1997) described the coping strategies of 21 family caregivers who were caring for a terminally ill relative. These strategies were depicted as denial, normalising and togetherness and were fluid, as family caregivers' were observed to move within and between strategies. In this study, the authors reported that the strategy of planning care and working together increased family caregiver satisfaction and patient well-being.

Similar findings were reported by Grbich, Parker and Maddocks (2001). Coping strategies were described in terms of ways of separating themselves from the situation by taking short breaks, maintaining social networks and previous interests or if unable to physically leave the home by listening to music, talking with others or "functioning on automatic". The authors reported that this group of family caregivers expressed a sense of pride that they had managed to cope despite minimal information and service provision and no previous experience.

Families have a wide variety of coping strategies that they employ throughout the experience of care giving. The themes of tiredness, loneliness, isolation and lack of knowledge about care provision are frequently balanced by the desire and the pleasure of "doing a good job". There is a clear need to provide family caregivers with information and skills about cancer pain management to strengthen their coping strategies and assist them to fulfil the caregiver role with a minimum of regret.

3) The families' needs in providing cancer pain management at home

Considerable work has been undertaken to document the needs of family members of advanced cancer patients in a variety of settings (Blank, Clark, Longman & Atwood, 1989; Grobe, Ahman & Ilstrup, 1982; Kristjanson, 1986, 1989; Laizner, Yost, Barg & Mccorkle, 1993; Leonard, Enzle, McTavish, Cumming & Cumming, 1995; Lewis, 1990; Rose, 1999; Stetz 1987; Wilkes, White & O'Riordan, 2000; Wingate & Lackey, 1989). The priority patient care need that family members consistently identify is a need to comfort the patient (Ferrell et al., 1991b, 1991c; Ferrell & Dean, 1995; Ferrell & Schneider, 1988; Juarez & Ferrell, 1997; Kristjanson, 1986, 1989; Lewandowski & Jones, 1988; Magrum, Bentzen & Landmark, 1996; Skorupka & Bohnet, 1982; Taylor, Ferrell, Grant & Cheyney, 1993; Wright & Dyck, 1984).

Most specifically, family caregivers in home settings have also identified needs for increased information about how to provide comfort and manage pain medications (Ferrell, 1999; Kristjanson, 1989; Taylor, Ferrell, Grant, & Cheyney, 1993). Family members report fears of drug addiction, respiratory depression and drug tolerance and may under-medicate patients even when patients are experiencing unrelieved pain (Ward, Berry & Misiewicz, 1996; Ferrell, 1991b). The challenges of administering opioids, managing infusion pumps, and delivering multiple medications have been reported to be anxiety producing for family members (Ferrell, 1999; Ferrell et al, 1991a, 1991b; Hays, 1986; 1988).

There is an obvious need to provide pain management information and skills to family caregivers to assist them to provide comfort care to their family members and to alleviate their fears and anxieties about pain medications. Also, it is logical to assume that pain management education will enable family caregivers to work more effectively with the health care professionals caring for their family member and remove some of the barriers to effective cancer pain control. For example, teaching family caregivers to assess and record pain and to understand how medications work for different types of pain, will improve communication between families and health care professionals and help to ensure that the appropriate medication is given.

To provide effective cancer pain management in the home, it is essential that family caregivers have the ability to assess and manage pain using basic pain management principles (Ferrell, Grant, Chan, Ahn & Ferrell, 1995; Pasacreta, Barg, Nuamah & McCorkle, 2000). In the past twenty years, the importance of the role of the knowledgeable and skilful family caregiver has been recognised as integral to achieving successful pain management in the home (Aranda & Hayman-Whyte, 2001; Elliot, Elliot, Murray, Braun & Johnson, 1996; Ferrell, Grant, Chan, Ahn & Ferrell, 1995; Grobe, Ilstrup & Ahman, 1981). However, this researcher believes that family caregivers who have no specific knowledge or pain management skills are in a poor position to provide this support.

In the past decade, researchers have acknowledged that many family caregivers have become more involved in pain management (Aranda & Hayman-Whyte, 2001; Ward, Berry & Misiewicz, 1996) although there has been a limited amount of research that describes ways to assist the family caregivers in this role (Ferrell et al, 1995; Skipwith,

1994; Wells et al., 2002). These and other studies will be considered in more detail in the following pages.

4) Preliminary evidence that educational programs directed towards patients and families may improve cancer pain management at home

The first part of this section of the literature review will discuss research related to educational pain management programs developed for cancer patients to increase their attitudes and knowledge in this area. Education programs to overcome barriers to effective cancer pain management and to reduce the severity of pain for cancer patients will also be reviewed. The second part of this section will explore the status of cancer pain management at home and the development and outcomes of educational cancer pain management programs specifically designed for family caregivers of advanced cancer patients.

Pain management education for patients

A number of studies have demonstrated that educational programs for cancer patients can improve knowledge and attitudes about cancer pain management (De Wit et al., 1997; Ferrell, Ferrell, Ahn & Tran, 1994; Ward, Donavon, Owen, Grosen & Serlin, 2000; Wells, Hepworth, Murphy, Wujcik & Johnson, 2002) and overcome barriers to pain management (Ward, Donavon, Owen, Grosen & Serlin, 2000). In some instances, the patients' pain intensity may be decreased (Clotfelter, 1999; De Wit et al., 1997; Du Pen et al., 1999; Ferrell, Ferrell, Ahn & Tran, 1994; Oliver, Kravitz, Kaplan & Myers, 2001).

For example, Ferrell and colleagues (1994) described the impact of a cancer pain management program for 66 elderly cancer patients at home. The Quality of Life tool (Ferrell, Wisdom & Wenzl, 1989), the Self-Care Log and the Patient Pain Questionnaire (PPQ) were used to collect data. A demographic and treatment data tool was used to describe the participants and their treatments. In this study, the patients reported improvement in pain intensity, distress and pain relief across the three evaluation points. Significant improvement in the patients' knowledge and attitudes for eight of the 14 items was also reported. The authors discussed the importance of improving patients' knowledge and attitudes about cancer pain to break down the previously cited barriers to effective pain management.

In 1997, De Wit et al. reported the findings of a stratified randomised controlled trial to test a pain education program (PEP) for 313 chronic cancer pain patients at home. The participants were randomised into four groups (control group with or without district nursing and experimental group with or without district nursing). Socio-demographic data about the participants was also collected. Pain experience was measured by the Dutch language version of the McGill Pain Questionnaire [MPQ-DLV] (Melzack, 1975). Patients' Present Pain Intensity and Average Pain Intensity during the last week was measured by an 11 point numeric rating scale ranging from 0 to 10. Quality of life was assessed by the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire [EORTC QLQ-C30] (Aaronson et al., 1993). Patients' pain knowledge was assessed Ferrell's Patient Pain Questionnaire, the Dutch language version (PKQ-DLV). The authors reported acceptable levels of validity and reliability for the four instruments.

In this study, the authors reported a statistically significant difference in overall pain knowledge, post intervention, between the control and experimental groups and commented that the overall pain knowledge of this group of cancer patients with chronic pain was poor both at baseline and post intervention. The lowest levels of knowledge included the areas of medication dose, appropriate medication and addiction. A significant improvement in pain intensity was reported for the experimental group post intervention. The findings also reported no significant change in the quality of life for the participants in this study. The advanced stage of cancer and the deteriorating health status of the participants may explain the lack of improvement in the quality of life scores.

It is evident that pain management interventions are effective in improving the patients' knowledge and attitudes about pain management and in improving pain outcomes. It is also clear that pain education programs are feasible and acceptable to patients. It is reasonable to assume, considering the previously cited literature on the impact of caring on the family caregivers of patients with cancer, that pain management interventions designed for the family caregivers will also improve their knowledge and attitudes about cancer pain management and contribute to improved pain outcomes for the patients.

Pain management education for family caregivers

In the last decade, several descriptive studies report some improvement in the management of cancer pain in the home from the family caregivers' perspective (Beck-Friis

& Strang, 1993; Silveira & Winstead-Fry, 1997; Steele & Fitch, 1996). For example, Beck-Friis and Strang (1993) explored the experience of caring among 87 bereaved caregivers whose relatives had been cared for by a home hospice service. The authors developed a “satisfaction with care provided by staff questionnaire” based on a literature review, interviews with staff and the researchers’ own experiences of bereavement visiting. Internal consistency reliability of the instrument was reported to be high. The questionnaire contained 13 items, one of which asked for satisfaction with “good pain relief” using a nine point scale. Participants received the questionnaire 6 to 28 months after their family member had died. The findings from this study reported that satisfaction with good pain relief was reported by 89% of the family caregivers.

These results appear to be encouraging and the high response to satisfaction with good pain relief in this group may be due to the home hospice care that was available to them, 24 hours per day. However, systematic selection of the participants may be a limitation of the study, as both patient and relative had to approve the patient joining this particular home care service and may have meant that the family caregivers were more motivated than those coming from outside the home care service, thus leading to more positive responses. Finally, the authors suggest that the findings may be influenced by the relationship between the “questioners and respondents” despite assurances of anonymity and confidentiality, because the questionnaire asked about satisfaction with the same staff who had been their health care providers.

In 1996, Steele and Fitch identified the needs of a convenience sample of 20 family caregivers of patients with cancer who were enrolled in a home hospice service. The Home Care Needs Survey (HCNS) (Hileman, 1989) was used to identify the importance of needs of the home caregivers as well as the extent to which these needs were being met. The HCNS is a 90-item, six-dimension, self-report survey that incorporates two seven-point modified Likert-type scales that rate both the importance of and satisfaction with each need at the time of completion of the questionnaire. Hileman, Lackey and Hassanein (1992) reported Cronbach’s alpha co-efficients of the dimensions ranging from 0.87 to 0.96 for this instrument.

The findings from this study reported the most frequently identified need for the 10 family caregivers was to have “time for myself away from the house.” Pain and symptom

information was identified in four separate questions. These questions were: information about the underlying reason for symptoms (n=5), methods of pain control (n=4), information about what symptoms to expect (n=4) and information about the physical needs of my patient (n=4). These findings suggest that this small convenience sample of family caregivers has some pain management knowledge and is moderately satisfied with the current pain regimen for their family member.

However, the authors reported that the participants were selected into the study because they were perceived to not be under any significant stress and therefore may have fewer needs and be unrepresentative of the general population of family caregivers of cancer patients. A further consideration is the fact that family caregiver needs were investigated at one time point only, which failed to encompass the changing nature of care giving over time.

A number of descriptive studies have been undertaken that document the information needs and concerns of family members with respect to management of pain of the patients (Ferrell, Taylor, Grant, Fowler & Corbisiero, 1993; Hileman, Lackey & Hassanein, 1992; Juarez & Ferrell, 1996; Laizner, Yost, Barg & McCorkle, 1993; Longman, Atwood, Sherman, Benedict & Shang, 1992; Steele & Fitch, 1996; Silveira & Winstead-Fry, 1997). However, few intervention studies have been undertaken to assist family caregivers to comfort their ill relatives.

Skipwith (1994) reported use of a telephone counselling intervention to assist family caregivers cope with the demands of care giving, to increase confidence in care management, help family identify supports and resources and guide them in problem solving. Unfortunately, the results of this intervention were not systematically evaluated and are reported in the form of four case studies. No direct pain management support strategies were offered.

Another study (Pasacreta, Barg, Nuamah & McCorkle, 2000) assessed the impact of a six-hour psycho-education program on 187 family caregivers of cancer patients. The education program was taught in an institutional setting over three two-hour group sessions and contained information about symptom management, improving technical competence and medication administration. The outcomes were measured by the Caregiver Reactions Inventory (Given et al, 1993) and the Caregiver Demands Scale (Stetz, 1989). Data were

collected at baseline and four-month post intervention. Results of this study indicated that, post intervention, caregiver skills were improved and that there was a reduction in caregiver burden over time.

There have been several studies that have explored the use of problem solving therapy for patients and family caregivers to help them resolve their cancer related issues (Bucher et al., 2001; Meyer & Melvin, 1995; Nezu et al., 1999; Toseland, Blanchard & McCallion, 1995). A convenience sampling method was used by Bucher et al., (2001) to explore the feasibility and the effect of a problem solving cancer care education program for 49 patients with advanced cancer and their family caregivers in a clinical setting. Fifty-four family members participated in this study. The intervention consisted of one 90-minute educational session on creativity, optimism, planning and locating expert information (COPE problem-solving principles) related to cancer care. Written information was also provided. All the participants completed baseline and two-month post education questionnaires and family caregivers also completed the Social Problem-Solving Inventory-Revised (SPSI-R) survey (D'Zurilla & Maydeu-Olivares, 1994). Improvement in information about community resources and family caregiver problem-solving scores was reported. The findings, while limited by the lack of a control group, support earlier work that involved the education of family caregivers about pain management (Ferrell, Grant, Chan, Ahn & Ferrell, 1995).

In a landmark study that involved a pain management intervention for both patients and family caregivers, Ferrell, Grant, Chan, Ahn and Ferrell (1995) reported the findings of a pain education program that was successful in improving knowledge and attitudes to cancer pain management for family caregivers of elderly patients. Ferrell and colleagues (1995) implemented and tested a pain education program in the home, for 50 family caregivers of cancer patients using a stratified, random sampling method and experimental design. The education program consisted of three one-hour sessions about general pain information including assessment, pharmacological pain principles and non-drug pain management principles. Audiocassette tapes of the educational content of the program and written instructions for 19 non-pharmacological interventions were also provided for the participants. The Quality of Life Tool and the Family Pain Questionnaire (Ferrell, Rhiner & Rivera, 1993) and the Caregiver Burden Tool (Robinson, 1983) were used to measure the

family caregivers' quality of life, knowledge and attitudes about pain management and the burden of pain management.

Family members benefited from the intervention as indicated by improved scores on pain knowledge and attitude scales, medication compliance, a decrease in patients' pain intensity and severity ratings, decreased patient anxiety, and increased use of non-medication techniques (eg, massage). The addition of a control group to the research design would have allowed for stronger inferences to be drawn from the results. These results are promising and indicate that further work to develop and test pain education programs for families of advanced cancer patients is needed.

Wells, Hepworth, Murphy, Wujcik and Johnson (2002) described their findings following a brief pain education program for 64 cancer patients and their primary caregivers. Patients were randomised into one of three information groups that received either pain education, pain education with access to a pain hot line or pain education followed by routine provider-initiated weekly telephone follow up calls. Both patient and family caregiver were included in the education process that lasted 20 to 30 minutes and was located in a clinical setting. The education program consisted of a 15-minute videotape that contained information about pain, methods to control pain and the importance of communication. It also included information about addiction, opioids and other pain medications. An individualised tailored component accompanied the video that included consultation, written information about analgesic medication and discussion about the patient's current pain regimen.

The researchers used the Barrier's Questionnaire-revised (Wells, Johnson & Wujcik, 1998) to measure the short-term effect of education on patients' beliefs that influence communication about pain and their use of opioids. The researchers reported that the sub scale Knowledge of the Family Pain Questionnaire (Ferrell, Rhiner & Rivera, 1993) was revised to improve internal consistency. This revised version consisted of four items that was used to assess family caregivers' beliefs about the use of analgesics. The internal consistency of the revised version of the FPQ was not reported. Long term outcomes of cancer pain control were evaluated monthly for six months following the pain education by the Wisconsin Brief Pain Inventory (Daut, Cleeland & Flannery, 1983).

Results indicated that the pain education program had a positive impact on patients' beliefs about the importance of communicating information about their cancer-related pain to their health care providers. The program also improved the family caregivers' beliefs about pain medication. This study reported no improvement in the patients' pain control after the baseline education for the three groups.

Limitations of this study are worthy of note. The authors reported the lack of a control group, multiple missing data points and a small sample size that was inadequate to detect small effect sizes.

All of the previously cited studies about pain management interventions for family caregivers have indicated that pain education programs are feasible and acceptable. The pain education programs have the potential to benefit both the caregivers and the patients, despite the reported high attrition rates at follow-up (35% and 26% respectively) noted by Bucher et al., (2001) and Wells, Hepworth, Murphy, Wujcik and Johnson (2002). In both these studies, the reasons for attrition were attributed to patient death or difficulty getting to the education locations. Ferrell, Grant, Chan, Ahn and Ferrell (1995) reported that of the 80 patients originally enrolled in the study, 66 (83%) completed and that all of the family caregivers enrolled completed all the evaluation points. It is reasonable to assume from these studies that an education program delivered in the family home may be more acceptable to family caregivers and may also help to lower the attrition rate of the participants. Offering the education program soon after the patient and family has been admitted to a home hospice service may also reduce attrition. It is also evident that a randomised clinical trial, with a larger sample would provide more rigour and allow for stronger inferences to be drawn from the results of a pain management education program for family caregivers.

All of the family education studies have been conducted with North American family caregivers. The extent to which these findings are applicable in an Australian home hospice context is uncertain. The program of research proposed here developed and evaluated a PMP from an Australian perspective.

Summary

In Australia in 2002, the pain management needs of advanced cancer patients being cared for at home by family caregivers, are not being adequately met (Armitage, 2001; Aranda & Hayman-White, 2001; Wakefield & Ashby, 1993). The literature clearly documents the complexity of cancer pain management, the impact and coping strategies and the information needs of family caregivers of advanced cancer patients as well as the negative effect of poorly managed cancer pain on the patient and family. The few intervention studies that have been reported were found to be beneficial to advanced cancer patients and family caregivers in the home, but were limited by the lack of control groups, small sample sizes and attrition among the participants. The development of an effective PMP for family caregivers of advanced cancer patients that addresses the methodological issues previously discussed will assist the caregivers in the specific area of cancer pain management by improving their knowledge, attitudes and skills.

CHAPTER 3

CONCEPTUAL FRAMEWORK

The study reported here involved the development and testing of a family pain education program that was based upon Ferrell, Grant, Padilla, Vemuri and Rhiner's (1991) model entitled Impact of Pain on the Dimensions of Quality of Life (see Figure 1). The relevant components from the model are described in this chapter.

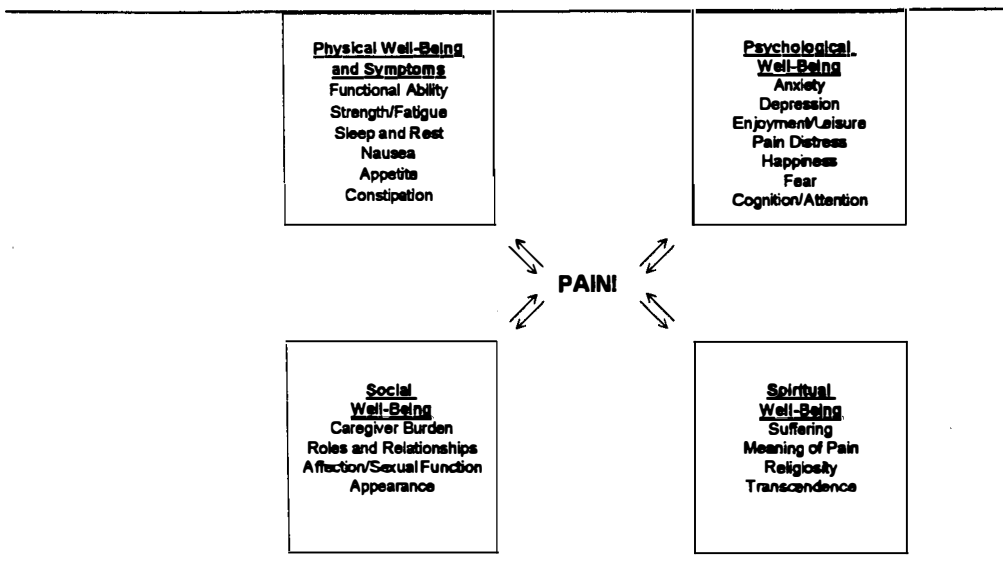


Figure 1. The Impact of Pain on the Dimensions of Quality of Life (After Ferrell et al. 1991)

Ferrell and colleague's model describes the influence of pain on the four domains of the patient's quality of life: physical well-being and symptoms, psychological, social and spiritual well-being. All the components and the individual aspects of the Quality of Life domains have been validated (Ferrell, Cohen, Rhiner & Rozek, 1991; Ferrell, Grant, Padilla, Verumi & Rhiner, 1991; Ferrell, Wisdom & Wenzel, 1989; Grant, Padilla, Ferrell & Rhiner, 1990).

The social well-being domain was developed and refined by the authors based on the importance of the family caregiver role in relieving pain and the impact of pain on family caregivers. In the study presented here, components of the social well-being domain of Ferrell and colleagues' (1991) model, specifically caregiver burden and caregiver roles and responsibilities were used to select the family caregiver outcomes of interest.

The social well-being domain of the family caregiver is clearly reflected in the four major themes of the literature review in this study. The first theme discussed the issues surrounding cancer pain. The second theme described the impact and coping strategies of family caregivers caring for advanced cancer patients at home. The third theme considered families' needs in providing cancer pain management at home and the fourth theme explored the evidence that educational programs directed towards patients and families may improve cancer pain management at home.

The conceptual model developed for this study (Figure 2) demonstrates the relationships between the impact of the patient's pain on the family caregiver (Sales, Scherlz & Biegel, 1992; Miaskowski, Kragness, Dibble & Wallhagen, 1997) and the social well-being of family caregivers in terms of their knowledge, attitudes and experience about cancer pain management. The model also demonstrates the proposed beneficial relationship between a cancer pain management intervention for family caregivers at a specific time in the illness transition and their subsequent social well-being which is measured by the concepts of their knowledge, attitudes and experience related to cancer pain management.

This conceptual model depicts the illness transition from diagnosis to admission to a home hospice service to death. The circles represent the patient's pain and the family caregiver well being and show the enfolding process or impact of the patient's pain on the social well-being of the family caregiver (Sales, Scherlz & Biegel, 1992) that occurs along the illness journey. The larger overlap between the patient's pain and the family caregiver well-being post intervention represents an improvement in the family caregivers' knowledge, attitudes and experience about cancer pain management and therefore an improvement in their social well-being. Tests 1, 2 and 3 refer to the time of the administration of the instruments at baseline, immediately post intervention and one week later, respectively. The model proposes that:

1. There is a relationship between the patient's pain and the family caregiver's knowledge, attitudes and experience.
2. A cancer pain education program implemented soon after the patient and family are admitted to a home hospice service will result in an improvement in the knowledge, attitudes and experience of the family caregiver which will in turn lead to an improvement in the social well-being of the family caregiver. The instruments chosen to measure the research outcomes are consistent with this domain.

Conceptual and Operational Definitions

Knowledge

Conceptual Definition: Family caregivers' knowledge of basic pain principles such as causes of pain, pain relief using medication and comfort therapies, regular use of medication and addiction.

Operational Definition: Family Pain Questionnaire, Knowledge sub-scale.

Attitudes

Conceptual Definition: Family caregivers' concerns about analgesic medications, their expectations of pain relief, their beliefs in the effectiveness of comfort therapies and the impact of psychosocial and spiritual issues on pain.

Operational Definition: Cancer Pain Attitude Questionnaire.

Experience

Conceptual Definition: Family caregivers' perceptions of the patient's pain, their own distress about the patient's pain and their anticipation of the patient's future pain.

Operational Definition: Family Pain Questionnaire, Experience sub-scale.

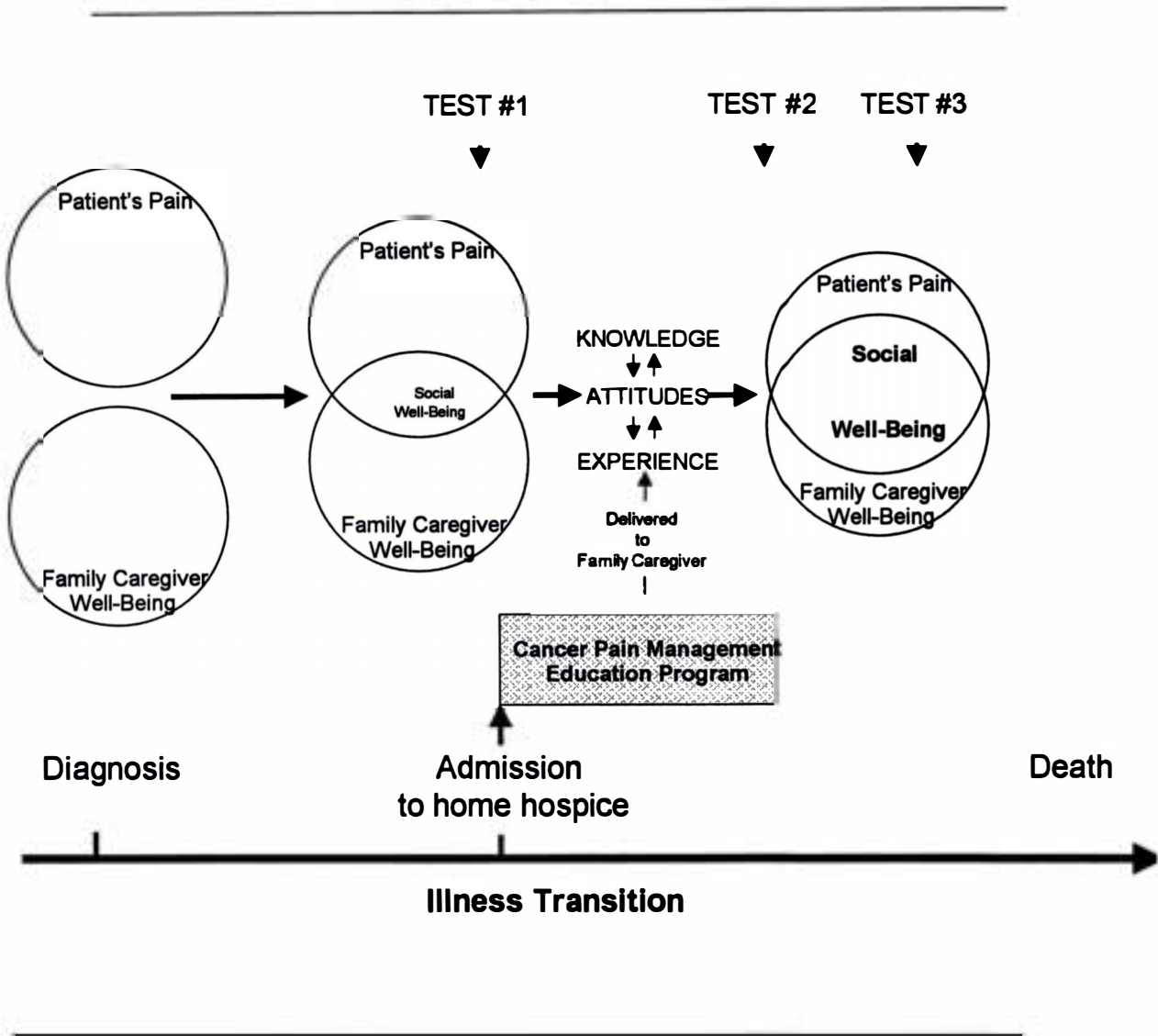


Figure 2. Conceptual Model of the Impact of a Cancer Pain Management Education Program on the Social Well-Being of Family Caregivers of Patients with Advanced Cancer

CHAPTER 4

METHODOLOGY

Introduction

In this chapter the methods and procedures used to conduct Phases I, II and III will be discussed. For clarity, the first component of this chapter will describe the method and procedures related to Phase I. Similarly, the second component will describe the methods and procedures related to Phase II and the third component will describe the methods and procedures related to Phase III.

Research Plan

The project involved a three-phase program of research to develop and test pain management interventions that would provide family caregivers of advanced cancer patients with information and skills to manage the patient's pain. Phase I involved the development of an education program for this group of families using relevant literature and qualitative methods to elicit information about the components of a pain education program that would be helpful to families. Prior work by Ferrell and colleagues (1995) provided a foundation for structuring the education program. Phase II involved a pilot test of the education program and determined the extent to which outcome measures were sensitive and psychometrically sound. Instruments used by Ferrell and colleagues (1995) and Elliot, Elliot, Murray, Braun and Johnston (1996) were adapted and tested for use in this Australian population. Phase III involved a randomised clinical trial to test the intervention with a sample of family caregivers. The methods for each phase are described below.

Phase I – Articulation of Pain Management Content and Teaching Strategies for Families of Advanced Cancer Patients

Design

A descriptive design was used for this phase employing relevant literature and qualitative methods to collect and analyse data. To ensure that the program developed and instruments used were appropriate within an Australian home hospice service context and culture, qualitative interviews were undertaken with family caregivers of advanced cancer patients who were receiving care in a home hospice service.

The purpose of the interviews was to elicit family caregivers' perceptions about the components, content, amount and timing of an educational program that might be useful in educating them about pain management. Interviews were taped, transcribed and content analysed to identify key elements of the PMP for families. This information, combined with the earlier work by Ferrell and colleagues (1995) was structured into a formal PMP.

Population and Sample

A sample of 19 family caregivers of advanced cancer patients, who reported pain as a current symptom, were included. Family caregivers were defined by the home care service as the person primarily involved in the patient's care. These individuals were not necessarily legal or blood relatives of the patient, but had been identified by the patient as the primary caregiver. Participants were at least 18 years of age and able to speak, read and write English.

Study Setting

Silver Chain Hospice Care Service (SCHCS) provides care to approximately 500 advanced cancer patients and their families at any one time. The home hospice service is divided into three geographic locations that encompass 1.5 million people living in the metropolitan area of Perth, Western Australia. Based on their residential addresses, patients receive care from one home hospice area only. Patient details are maintained on a computer database from which a random sample can be generated given the required criteria.

Negotiating Access

Ethical approval from the Edith Cowan University Ethics Committee was obtained (Appendix B). Permission was then sought from the Professional Services Advisory Committee of the Silver Chain Hospice Care Service (SCHCS) to conduct the study through this service (Appendix C). Once permission was given (Appendix D), recruitment for Phase I commenced. The researcher requested the Research Officer of SCHCS to mail a letter (Appendix E) to 100 family caregivers randomly selected from the SCHCS database informing them about the study. The rationale for nominating 100 family caregivers was based on previous work using this population (Kristjanson, Nikoletti, Porock, Lobchuk and Pedler, 1998), where a response rate of 20-25% was achieved. Family caregivers were asked to contact the researcher if they were interested in the study. The researcher arranged interview times with participants who had contacted her by telephone (Appendix F). Prior to the interview commencing, informed consent was obtained from the family caregiver (Appendix G) and permission to access the patient's medical records (Appendix H) that are retained in the home was sought.

Prior to the commencement of the study the researcher organised an information meeting with the team coordinators of the home hospice program. At this meeting the researcher introduced the study, advised them of the content and plan of the study and encouraged them to disseminate this information to all palliative care nurses working in their teams (Appendix I).

Data Collection and Protocol

Interview Guide

A semi-structured interview, based on relevant literature was used to elicit information about the family caregiver's knowledge and experience in managing cancer pain in the home (Appendix J). This type of interview was chosen because it is focused and participant time is carefully used (Patton, 1990). The opening questions for each participant was "I am interested in understanding what might be helpful to you in providing comfort for your relative. What is important to you in managing your relative's pain in the home?" As this was a semi-structured interview guide, these opening questions were intended to act as a 'grand tour', with general questions and prompts for specific items

characterising the 'mini tour' (Spradley, 1980). The general questions were designed to elicit the family caregiver's individual responses, in their own words and to allow free response. For example, the general question about the impact of the relative's pain was "What is the impact on you and your family when your relative is in pain?" The prompts are "Do you feel inadequate/ out of control/ helpless/ sad/ frustrated/ overwhelmed/ angry/ exhausted/ guilty/ despairing/ in conflict with ill relative/ other family members?" "Is there anything else in relation to the impact of your relative's pain that we haven't discussed?"

The ordering of the questions was designed to start with the less sensitive questions. These were questions about caregiver's knowledge and attitudes to learning about pain management. The researcher's intention was to explore the less sensitive topics first, hoping this would enhance the early development of rapport and trust, and subsequently encourage the family caregiver to communicate openly and comfortably.

The interview guide was pre-tested with three family caregivers to establish clarity of language, acceptability and relevance of the questions, and the overall response to the approach used by the researcher. The interview guide was assessed for readability/comprehension for this population by using the, Flesch-Kincaid Grade Level on Microsoft Word Readability Statistics. The comprehension level of the interview guide was assessed to be Year 8.

Demographic data tools were used to describe the family caregiver and the patient (Appendices K and L).

The data for this phase of the study were collected during a four - week period in August 1999.

Data Analysis Plan

The data analysis plan for this phase of the study findings included provision for the following descriptive analysis of the characteristics of the participants and qualitative content analysis of each of the transcribed interviews. The qualitative content analyses were conducted according to the guidelines documented by Patton (1990).

The researcher and her supervisor became immersed in the data in order to understand the frame of reference of each participant. Transcripts were read and re-read and notes were made about the overall impression given by the interview. Unusable

material, that which was unrelated to the interview topic, was bracketed. An inductive approach was used to develop the codes, categories and patterns. Definitions were written for each code that emerged. The initial codes were discussed with five expert practitioners of palliative care nursing and grouped into clusters. The researcher then organised the clusters into categories. The pain management teaching plan was developed from these categories and then returned to the five expert palliative care nurses for review and validation.

The Intervention – The Pain Management Program

The researcher developed a PMP comprising four sequenced education sessions, a Daily Comfort Diary and a video.

Education Sessions

The four sessions deal with understanding and assessing pain, managing pain and understanding medications, some comfort therapies, knowing when to ask for help with pain management, and support strategies for the family caregiver.

Each session takes approximately an hour. The entire program is delivered using Powerpoint with a laptop computer and data projector. All the sessions are conducted interactively with text, graphics and photos (Appendix M).

Sessions can be tailored to meet individual needs while maintaining the basic pain management principles. The PMP is portable and could be used by both community nurses and palliative care nurses.

Daily Comfort Diary (DCD)

The DCD was based on the Patient Self-Care Log developed by Ferrell and colleagues (1995). This diary was designed to measure compliance with drug and non-drug interventions and the perceived effectiveness of interventions. The diary was adapted for the use of the family caregiver. In this study, the DCD was designed to reinforce the education content by teaching participants to rate pain consistently and evaluate the effectiveness of their interventions (Appendix N).

Video

The video is designed to help family caregivers when moving their relative/friend in or out bed, walking with someone who is unsteady and what to do if someone falls. The program can be taught in the family home or in a location that is most suitable for the family caregiver (Appendix O).

Ethical Considerations

The ethical issues considered in this research were the same for the three sections of the methodology; qualitative interviews, pilot testing and the randomised controlled trial. These included general issues concerning the involvement of human participants and issues arising when selecting a sample from a vulnerable population.

The use of human participants

Burns and Grove (1987) outline four central issues when conducting research involving human participants; balance the potential risks and benefits of the proposed research, submit research proposals for institutional review, obtain informed consent from participants, and protect the rights of these participants.

For this study, risks to the wider community were non-existent, and risks to the participants were restricted to the possibility of the interviewees becoming distressed when discussing their relative's illness. A plan was developed prior to the interviews to minimise distress in participants. This plan was that the interviewer (researcher) was to offer to terminate the interview if a respondent became upset, and to inform the interviewee of available counselling services. The researcher is an expert clinical nurse practitioner in the area of palliative care who has had long experience with the psychosocial and spiritual needs of families with advanced cancer. If at any time a participant required assistance to access available counselling services, the researcher would have ensured that referral was undertaken effectively and compassionately. Also, all participants were provided with brochures of the availability of counselling services specifically developed to assist those living with cancer. Several participants did become upset during the interview, but asked to carry on. These participants stated that it helped them to speak about their experiences.

The researcher obtained written informed consent to participate from all participants. All participants in the study were made aware that they had the right to

confidentiality, to refuse or cease participation at any time and to have their questions answered. They were also given contact numbers where inquiries about their participation would be answered. Only the researcher, her principal supervisor and her research nurse had access to the records. The raw data were kept in a locked filing cabinet and the computer files used for data entry were protected by a password known only to the research nurse and the researcher. Consent forms and the lists of participants were kept in separate files in a locked filing cabinet. No names were used when entering data onto the computer and all data had a code number. Named information was not used in any reports. A data entry clerk transcribed the taped interviews, which were then erased. All raw data and signed consent forms were kept in a locked filing cabinet. At the completion of the study, the original materials were stored in locked filing cabinets in the locked office of the Cancer and Palliative Care Collaborative Research Team, led by Professor Kristjanson. After five years, the original materials will be shredded.

Phase II – Testing of the Outcome Measures to Assess the Intervention

Design

A methodological design was used for this phase of the study. The design involved a pilot test of the education program to determine the extent to which the outcome measures were sensitive to change and psychometrically sound.

Population, Sample and Setting

The study instruments were administered to a sample of 31 family caregivers of advanced cancer patients who were receiving care in a home hospice service. Family caregivers were defined by the same characteristics as the participants in Phase I and were drawn from the same setting.

Negotiating Access

The same process for negotiating access for Phase I of the study was implemented in Phase II. The researcher requested the Research Officer of SCHCS to mail a letter (Appendix P) to 250 family caregivers randomly selected from the SCHCS data-base informing them about the study. The rationale for nominating 250 family caregivers was

based on previous work using this population (Kristjanson, Nikoletti, Porock, Lobchuk & Pedler, 1998), where a response rate of 20 to 25% was achieved. Family caregivers were asked to contact the researcher if they were interested in the study. When they contacted the researcher by telephone (Appendix Q) they were invited to participate in a pain education program designed to assist the family caregiver in managing the patient's care in the home. Prior to the education program commencing, informed consent was obtained from the family caregiver (Appendix R) and permission to access the patient's medical records (Appendix S) that were retained in the home, was sought. Once consent had been obtained, the time and place for the education sessions was discussed. All the family caregivers chose to do the education program in the family home.

As outlined in Phase I, prior to the commencement of the study, the researcher organised an information meeting with the team coordinators and clinical nurses of the home hospice program. At this meeting she introduced the research nurse and advised them of the outcomes of Phase I, described Phase II, and encouraged them to share this information with all palliative care nurses working in their teams (Appendix T). The researcher also sought feedback about Phase I from the base coordinators.

Data Collection Tools

1). Demographic forms for the family caregiver and the patient were used to describe the sample population (Appendices K and L).

2). The Family Pain Questionnaire (FPQ) (Ferrell, 2000) was used at three time points to collect data about family caregivers' knowledge and experience of pain management in an advanced cancer home care context (Appendix U). The FPQ has 16 items measured on an ordinal scale from 0 to 10 and consists of two sub-scales, knowledge and experience. The nine-item knowledge sub-scale measures family caregiver knowledge about managing chronic cancer pain. The experience sub-scale has 7 items that measure family caregiver experience in managing chronic cancer pain. The total FPQ score is obtained by summing the values for individual items. High scores for the FPQ mean low knowledge and poor experience. The instrument can be administered by mail or in person. Satisfactory construct and concurrent validity and reliability have been reported for this instrument.

3). Cancer Pain Attitude Questionnaire (CPAQ) developed by Elliot, Elliot, Murray, Braun and Johnson (1996) was used in conjunction with the FPQ to measure family caregivers' attitudes towards cancer pain management (Appendix V). The CPAQ has 9 items measured on an ordinal scale from 0 to 10. The items represent the major myths that interfere with the report of cancer pain and the effective management of cancer pain. The total CPAQ score is obtained by summing the values for the individual items. High scores for the CPAQ mean low/poor attitude toward cancer pain management. The instrument can be administered by mail or in person. The authors reported a Cronbach alpha coefficient of 0.83 for this scale.

4). The Daily Comfort Diary (DCD) was used to reinforce the education content of the PMP by teaching participants to rate pain consistently and evaluate the appropriateness and effectiveness of their interventions (Appendix N).

Data Collection and Protocol

The data collection and implementation of the PMP for this phase of the study was performed during a four month period from August 2000 to November 2000.

After obtaining informed consent and permission to access the patient's medical records in the home, family caregivers were asked to complete the socio-demographic forms. Family caregivers were also asked to complete the FPQ and the CPAQ prior to the implementation of the education program (Time 1), upon completion of the four sessions (Time 2) and one week after completion (Time 3). The rationale for having only one week between the second and third data collection points was based on the premise that advanced cancer patients have limited time and the researcher wished to avoid attrition among the participants.

The Daily Comfort Diary was explained to the participants at Time 1. Family caregivers were asked to record and rate all episodes of their relative's pain in the DCD, beginning when informed consent had been obtained and ending one week after completion of the training program.

The data collection and the implementation of the PMP were shared between the researcher and her research nurse. For example, for each participant, if the researcher was the educator, the research nurse was the data collector in order to avoid any response bias.

The questionnaires were produced in the form of small booklets in three different colours, one for each time point. The booklets were left in the home during the implementation of the PMP and the data collector telephoned each participant to ask them to complete the questionnaires (at Time 2 and Time 3) and arranged a suitable time to call back to ask for the scores for each question. The data collector then asked the participant to dispose of the completed questionnaire.

The DCD was collected at Time 3. Seven participants asked to keep the DCD and in those cases, the information recorded in them was photocopied and the DCD returned.

Testing the Instruments

Instruments were assessed for internal consistency reliability using Cronbach's alpha coefficient, with a correlation of 0.70 or higher being accepted as a reasonable criterion. Instruments were also be tested for stability over time using a test-retest procedure as described by Woods and Catanzaro (1988) over a 24 to 48 hour time interval. Data were analysed using intra-class correlations (McGraw & Wong, 1996). The criterion for this assessment was be 0.80 or higher (Nunnally, 1978). The tools were also assessed for clarity and content validity using a panel of six experts. Percent agreement was used to determine content validity with 83% or higher established as the pre-set criterion for retention of instrument items (Lynn, 1986).

Data Analysis Plan

The data analysis plan for this phase of the study included descriptive analysis of the characteristics of the participants, exploration of all other data, management of missing data, and confirmation that data met statistical assumptions for analysis using univariate and multivariate statistical techniques with the Statistical Package for the Social Sciences (SPSS) for Windows (Version 10).

Significance levels were set at ≤ 0.05 for all tests. Continuous data were normally distributed, therefore the changes between scores for knowledge, attitude and experience in the group over time were measured using repeated measures ANOVA. The acceptability and use of the DCD to the family caregiver was assessed.

Ethical Considerations

Approval for all phases of this project was reported in Phase I. No participants became distressed during this phase of the study and many participants expressed appreciation for the opportunity to be involved.

Phase III – Hypothesis Testing

Phase III involved a randomised clinical trial to test the intervention with a sample of family caregivers. The allocation sequence was generated using block randomisation and computer generated numbers to ensure the numbers of family caregivers allocated to each group were close at all times. These numbers were concealed in sequentially numbered, opaque, sealed envelopes until the participant was randomised. As this was a multi site study, the researcher centrally coordinated the randomisation.

The following hypothesis was tested:

Hypothesis

Family caregivers of advanced cancer patients receiving care through a home hospice service who participate in a pain management program (PMP), will obtain improved pain knowledge scores, improvements in attitudes toward pain management and improvement in their pain management experience and will provide more appropriate pain management interventions to patients than family caregivers who do not participate in the PMP.

Secondary Research Question

To what extent is the Daily Comfort Diary useful to the family caregivers?

Population, Sample and Setting

The sample comprised family caregivers from each of the three geographic areas served by the Silver Chain Hospice Care Service (SCHCS), the Cancer Support Association (CSA), the Palliative Home Care Service at Hollywood Private Hospital (HPH), the Palliative Care Outpatients and the Radiation Oncology Clinics at Sir Charles Gairdner Hospital (SCGH) and A. H. Crawford Lodge. The A. H. Crawford Lodge provides accommodation for country patients receiving cancer treatments and their caregivers. All eligible family caregivers were contacted by mail and/or newsletter and invited to participate. Recruitment took place over eight months, between February and September 2001.

Sample size was determined using the data from Phase II and performing power calculations for repeated measures ANOVA. The power calculations indicated that a sample of 130 (65 in each group) would allow detection of a difference of 25% with a power of 81%, with 95% confidence (Cohen, 1988).

Family caregivers were defined by the same characteristics as the participants in Phase II. Pain as a current symptom was omitted from the selection criteria in Phase III as patients in Phase II had demonstrated that all patients had experienced pain at some time during their illness. The researcher believed that while some patients had been admitted to the SCHCS without pain as a symptom, it was likely to develop over time.

A total of 126 family caregivers responded to the information booklet (Appendix W) and letters of invitation from SCHCS to participate in the study. At SCHCS, a total of 349 letters of invitation (Appendix X) were sent to family caregivers of which 80 responded and 71 (20%) consented to participate in the study. Four hundred and fifty information booklets about the study were also made available to be inserted in the home notes of each new admission into this service over the recruiting time period. At A.H. Crawford Lodge, 34 information booklets were distributed and 26 (76%) family caregivers consented to participate. Fourteen (28%) family caregivers consented from Palliative Care Outpatients and the Radiation Oncology Clinics at SCGH after the distribution of 50 information booklets at these clinics. The Palliative Home Care Unit (PHCU) at Hollywood Private Hospital was provided with 50 information booklets about the study to be placed in

the home care notes and three (6%) family caregivers responded. Two family caregivers responded to an article about the study in the local newspaper and one family caregiver responded to an article in the CSA web site (Appendix Y).

Of the 126 family caregivers who responded to the information booklets and letters, nine family caregivers (from SCHCS) failed to enrol in the study due to their relative's death. Eighty-one family caregivers (69%) completed the full study. Twenty-four patients (22%) died and 12 family caregivers (10%) withdrew during the study. Of the 12 family caregivers that withdrew, ten patients were either at the end stage of their illness and needed admission to an in-patient unit and two family caregivers failed to contact the researcher after the initial consent.

In summary, a response rate of 20% was achieved from SCHCS, 76% from AH Crawford Lodge, 28% from the two clinics at SCGH and 6% from the PHCU at Hollywood Private Hospital. A minimal response was seen from the newspaper article and CSA newsletter. Of the 117 participants, 60 were randomly assigned to the experimental group and 57 to the control group. Eight family caregivers who had completed the control arm of the study asked to do the intervention. This was achieved and their data were analysed separately. The overall attrition rate during the study period was 31%.

Negotiating Access

The process for obtaining permission to undertake Phase III of this study was identical to Phases I and II. Originally, permission was sought from SCHCS and CSA. Once permission was given, recruitment for Phase III commenced. Three months after recruitment commenced permission was also sought and received from the PCHC at Hollywood Private Hospital, the Palliative Care Outpatients and the Radiation Oncology Clinics at SCGH and A. H. Crawford Lodge to increase the rate of recruitment.

At SCHCS, the researcher provided the three bases with the Information Booklets (Appendix W) and these were given to all home care families. As recruitment was slow, in the first three months, the Research Director of SCHCS also mailed personal letters of invitation to participate to the family caregivers.

The CSA placed an Invitation to Participate (Appendix Y) on its Web site and published the Information Booklet in their newsletter. Family caregivers were asked to contact the researcher if they were interested in the study.

At PCHC, the Information Booklets were provided for distribution to all families in the service. The low response rate suggests that they were not widely distributed.

At A. H. Crawford Lodge, Information Booklets and a personal letter from the Coordinator of the Lodge were given to all families who were currently living there.

At the Palliative Care Outpatients and the Radiation Oncology Clinics at SCGH, a research nurse offered the Information Booklet to the accompanying family members of patients who were receiving care at the clinics. These family members were only approached following prior consultation with the clinic staff.

In both the Information Booklets and the letters, family caregivers were asked to contact the researcher if they were interested in the study. When the participants contacted the researcher by telephone (Appendix Z) they were invited to participate in the evaluation study designed to assist the family caregiver in managing the patient's care in the home. It was clearly explained to the participants that they would be assigned to one of two groups. Prior to this phase of the study commencing, informed consent was obtained from the family caregiver and permission to access the patient's medical records that were retained in the home, was sought (Appendices AA and BB).

As for Phases I and II, prior to the commencement of Phase III of the study, the researcher organised information meetings with the health care teams at all sites. Outcomes from Phases I and II were shared along with information about Phase III (Appendix BB). The researcher and her research nurses maintained weekly contact with clinical nurses from each site throughout the recruitment process.

Data Collection and Protocol

The Phase II data collection instruments were used in Phase III. Once participants had consented to take part in the study, the family caregivers were randomly assigned to either the control or experimental group. Randomisation was achieved by using an opaque,

sealed envelope technique containing group allocation in blocks of 10, five for each group. All participants were instructed on the use of Daily Comfort Diary to document their relative's pain experience and the interventions that they used to manage the pain.

The experimental group participated in an education program comprising four sequenced sessions designed to educate the group about pain management in a cancer home care context. Pain management notes and a video were also provided. All participants completed pain knowledge, experience and attitude questionnaires prior to the training program, upon completion of the four sessions, and one- week after completion. After consent had been given, demographic data were also obtained from the patient's home care notes. All family caregivers were asked to record and rate all episodes of their relative's pain in the DCD. Family members in the control group were offered the opportunity to participate in the education program at the conclusion of the study. Eight family caregivers from the control group asked to do the education program at completion of the study and this was achieved.

Data Analysis Plan

The data analysis plan for this phase of the study findings included descriptive analysis of the characteristics of the participants, exploration of all other data, management of missing data, and confirming that data met statistical assumptions for analysis using univariate and multivariate statistical techniques with the Statistical Package for Social Sciences (SPSS) for Windows (Version 10).

Significance levels were set at 0.05 or less for all tests. The Type I error probability was adjusted for repeated significance testing using the Bonferroni method (Tabachnick & Fidell, 1996). Continuous data were normally distributed, therefore the differences between scores for knowledge, experience and attitudes among the two groups were assessed using a t -test. Mixed between-within subjects analysis of variance (SPANOVA) techniques were used to assess changes in outcome variables over time. The use of the DCD between the two groups was compared.

Ethical Considerations

Approval for this phase of the study was also sought and gained from the Cancer Support Association (CSA), the Palliative Home Care Service at Hollywood Private Hospital (HPH), the Palliative Care Outpatients and the Radiation Oncology Clinics at Sir Charles Gairdner Hospital (SCGH) and A. H. Crawford Lodge (Cancer Foundation of WA). The CSA accepted the approval for the study from the Ethics Committee at Edith Cowan University. The Hollywood Private Hospital Research Ethics Committee gave approval for the study in February 2001 (Appendix DD) and the Sir Charles Gairdner Nursing Research Scientific Sub-Committee approved the study in May 2001 (Appendix EE). The Director of Patient Services for the Cancer Foundation of Western Australia wrote a letter of approval for the study in June 2001 (Appendix FF).

CHAPTER 5

RESULTS

Introduction

This chapter documents the participants' characteristics, the qualitative analysis of the data in Phase 1 and the statistical analysis of the data in Phases II and III of the study. Details of the preparation of the data for univariate and multivariate analysis will be reported. Each phase of the study will be described separately.

Phase I Findings

Participant Characteristics

Letters of information about the study were mailed to 152 family caregivers by the SCHCS. Of these, 22 responded and 19 were included in the analysis. Two of the family caregivers telephoned to cancel, in one case because the patient had died the evening before the interview took place, and in the other case the patient had been transferred to an in-patient hospice prior to the interview. The third respondent was the father of a young boy with congenital heart disease, and although the interview was conducted, the data were not included in the analysis as pain was not a problem. Of the nineteen participants interviewed, one man who was recently widowed asked to be included in the interviews despite his recent bereavement, as he had cared for his wife at home for many months. All interviews took place at the family caregivers' home, each interview lasting from one to two hours. Interviews were completed within four weeks. Demographic characteristics of the caregivers and patients are described below.

Family caregivers

Family caregivers' ages ranged from 41 to 85 years, with a mean age of 60 years. There were 13 female and 6 male participants. Fifty eight percent of the family caregivers were spouses, thirty seven percent were daughters and one woman was a friend who lived in the same apartment complex as the patient.

One participant indicated that she had received only primary level education. Eight family caregivers had completed secondary level education and seven had trade qualifications. Three family caregivers had completed university degrees.

Eight of the caregivers were employed either full time (n=4) or part time (n=4). The remaining family caregivers were either retired or unemployed (n=11).

The majority of family caregivers were Australian born (n=15) and living on a low income, 11 participants earned < \$20,000 per annum, four participants earned between \$20,00 to \$50,000, two earned > \$50,000 and two participants declined to state their income.

Only two family caregivers, both registered nurses, reported previous pain management education. One caregiver had been to a pain management study day and stated she was interested and practised pain management in the workplace. The other caregiver described "ongoing education in the workplace". Both caregivers worked part time in a residential aged care facility.

Patients

Patient's ages ranged from 47 to 87 years, with a mean age of 73 years. There were almost equal numbers of males (n=9) and females (n=10). The patients' countries of birth were identical to those of their caregivers.

Twelve patients had had been diagnosed with cancer for more than one year. Most (n=14) of the patients reported that they had been living with pain related to cancer for between one and six months. Seventeen patients reported both visceral and bone pain. One patient reported emotional pain. Patients' cancer profiles are described in Table 1.

Table 1.

Frequency and Percent Distribution of Patients According to Diagnosis and Secondary Disease

Primary cancer diagnosis	n	%	Secondary involvement	n	%
Prostate	3	(15.8)	Bone	5	(26.3)
Lung	3	(15.8)	Bone + brain	1	(5.3)
Breast	3	(15.8)	Bone + brain +liver + lung	2	(10.5)
Bowel	2	(10.5)	Liver	2	(10.5)
Gynaecological	2	(10.5)	Liver + lung	1	(5.3)
Bladder	1	(5.3)	Lung	1	(5.3)
Unknown	1	(5.3)	Other	6	(31.6)
Other	4	(21.1)	Nil	1	(5.3)

The other diagnoses included chronic obstructive airway disease (COAD), renal cell carcinoma, parotid cell carcinoma and metastatic melanoma. The other secondary involvement included the para-aortic nodes, chest wall, spleen, bowel and vagina, lymph nodes, bone marrow and kidney.

Only one patient indicated he had no pain. Ten patients reported living with one type of pain, seven patients reported coping with two types of pain and one patient reported three different pain types.

Most patients (84%) were taking oral opioid medication for pain control. Medication and other pain management modalities are reported in Table 2.

Table 2.

Patients' Treatment Profile (n = 19)

Treatment	N	%
Medication		
Opioid	16	84.2
Steroid	8	42.1
NSAID	4	21.1
Adjuvant	3	15.8
Other	12	63.2
Other modalities		
Physiotherapy	0	0
Radiotherapy	2	10.5
Chemotherapy	1	5.3
Surgery	0	0
Acupuncture	0	0
Comfort therapies		
Massage	4	21.1
Other	2	26.3

Note. NSAID refers to Non-steroidal anti-inflammatory drugs

Note. Percentages add up to more than 100% because patients reported the use of more than one treatment

Adjuvant medication included simple analgesics (eg. paracetamol), anticonvulsants, antidepressants and muscle relaxants. Many other medications were also prescribed including drugs acting on; the alimentary system (ranitidine, hyoscine butylbromide, omeprazole and docusate sodium and senna); the cardiovascular system (both anti-hypertensive agents and diuretics) and the central nervous system (sedatives and anti anxiety agents).

Other comfort measures described by the patients included relaxation tapes and Reiki. None of these patients reported having any surgical procedures or using aromatherapy for pain relief.

Content Analysis of the Interviews

Interviews were conducted to explore concerns about cancer pain management at home and educational strategies that would be helpful to address these concerns. Content analysis of the transcribed interviews revealed that the families lacked knowledge regarding pain, medications, comfort therapies and general comfort measures. Family caregivers described their own feelings of suffering and being unprepared for caring for a relative at home.

None of the family caregivers had participated in any formal cancer pain education. For many caregivers, some information had been provided at the time of diagnosis and any other information was gathered in an *ad hoc* manner by asking nurses and doctors, usually when cancer pain management at home was in crisis.

What are the problems associated with advanced cancer pain management at home?

Family caregivers' interviews revealed numerous problems associated with advanced cancer pain management at home. These included lack of knowledge of pain types and pain assessment, lack of or partial knowledge of medication used to treat cancer pain, lack of knowledge of comfort therapies, difficulty remembering pain management information and strategies, caregiver suffering in response to ineffective pain management (blinded by emotions, sad, angry, despairing, helpless, powerless, frustrating, impatience descriptors), tiredness and fear and an overall lack of preparation for the task. Table 3 summarizes the problems related to knowledge deficits at home, interview exemplars and the related PMP content.

Table 3.

Type of Knowledge Deficit, Exemplars and Related PMP Content

Type of knowledge deficit	Interview Exemplars	Related PMP Content
Pain types & assessment	<p>“Practically everything because unless you’re aware of how to manage it (pain) you don’t know what there is to manage...you need the whole thing, you need to start from the beginning” (19)</p> <p>“ I don’t know anything. I’m just learning as we go along, you know” (13)</p> <p>“to be briefed and to be able to be briefed by someone who can brief them and then warn them, that’s more important to be warned, know what you’re going to have to watch for, and learn some basic techniques.”(2)</p> <p>“I’ve never had any experience with cancer pain” (17)</p> <p>“Well, I don’t really know what type of pain it is you see” (11)</p> <p>“ Understanding it, understanding exactly what will come next, you know, the first time he went into pain I thought he was gone, I thought, gee I didn’t have the foggiest” (1)</p>	<p>Understanding pain</p> <p>Pain types (mechanistic classification)</p> <p>Acute and chronic pain</p> <p>Pain assessment and rating</p> <p>Daily Comfort Diary</p>
Lack or partial knowledge of medication	<p>“ I was frightened of him perhaps overdosing. What I did was, everything I gave him I wrote everything down and if I gave him anything and if I altered it I wrote in why.” (9)</p>	<p>Daily Comfort Diary</p> <p>Commonly used cancer pain medications (opioids, non-</p>

Type of knowledge deficit	Interview Exemplars	Related PMP Content
	<p>“All I know is that I give him the drugs the doctor has told me to give him and the nurse told me about Panadol” “ Even though I don’t understand I would assume it just attacks the nervous system in some way, I don’t know, to numb the pain. I don’t know where it comes from or how it eventually gets there or anything else, I just know that it works”(1)</p>	<p>opioids, co-analgesics and how they work</p> <p>Ways of taking pain medications</p> <p>More information about morphine</p>
	<p>“I don’t know anything. I’m just learning as we go along” (13)</p>	<p>Obstacles to achieving pain control</p> <p>Side effects of opioids</p> <p>Pain management plan for discussion with home care nurse</p>

What types of information would assist family caregivers to manage cancer pain at home?

The types of information that would assist family caregivers to manage cancer pain at home included knowledge of pain types, assessment and management, current knowledge of all pain medications used in the treatment of cancer pain, knowledge of disease progression (what to expect), and knowledge of, and ways to access, local resources. The cancer pain management information and related PMP content is illustrated in Table 4.

Table 4

Information Needs, Exemplars and Related PMP Content

Information Needs	Interview Exemplars	Related PMP Content
Pain types, assessment and management	“ Just how to make the person you are caring for comfortable and they’re in the right position, making sure they’ve got no pressure points that are going to cause more problems”(16)	Video Comfort therapies
Cancer pain medications	<p>I’d like to know more about the tablets myself. Whether I could remember them, you see. I’d have to have them written down and described on a piece of paper, because the mind doesn’t absorb it all. I can take it in, but I forget about it (11)</p> <p>... I would like to learn... Yes. And where the different drugs fit in with the different types of pain.” (1)</p> <p>“Obviously I want to know, the parameters on medication, I want to know about medication. How to deal with her and any psychological tricks and techniques that one can acquire to ease her through it. Do I divert her mind from the pain, or that kind of thing?” (2)</p> <p>“ Maybe a graduated scale (medications), this is what you use when its minor, this is what you use when its major, so somewhere in between there’s other ones before you get up to the major one” (15)</p>	<p>Commonly used cancer pain medications (opioids, non-opioids, co-analgesics) and how they work</p> <p>Ways of taking pain medications</p> <p>More information about morphine</p> <p>Obstacles to achieving pain control</p> <p>Side effects of opioids</p> <p>Clarify the pain management plan for discussion with home care nurse</p>
		Knowing when to ask for

Information	Interview Exemplars	Related PMP Content
Needs		help with pain management
Disease progression as it related to ongoing pain management	<p>“ I would like to learn the steps. There must be I’m not quite sure of the words, but the stages of the cancer (1)</p> <p>“ I just, I think at that point of time you need someone who’s not talking over your head, who can sit down with you or with one or two of you, whatever the case may be and say, now look, this is what can happen..” (2)</p> <p>“Yes, because I have to go through it, I have to know what to expect and I want to know what to expect.” (10)</p> <p>“”He said there had been discussion and they decided they weren’t going to give him any more chemo because it is not worth it. I asked if there was anything else he could have and he said No. It’s best to go home and come what may in a couple of months.” (9)</p>	<p>Questions to ask the health care team</p> <p>Daily Comfort Diary as an aid to clear communication</p> <p>Accessing local information centres (eg Cancer Foundation Helpline) and local resources</p>

What educational strategies in cancer pain management do the family caregivers perceive to be most helpful?

The education strategies deemed helpful by family caregivers included short ongoing sessions conducted in small groups close to the home, an educational video, brochures or books, Internet information, a telephone help line, a community college course and support groups. Most family caregivers stated that they would like to learn about cancer pain management at diagnosis and then have their knowledge reinforced and expanded with ongoing sessions either at or close to the family home. The educational strategies, interview exemplars and related PMP content are depicted in Table 5.

Table 5

Educational Strategies, Exemplars and Related PMP Content

Educational Strategies	Interview Exemplars	Related PMP Content
Short ongoing sessions	“Education sessions (about four sessions, not far from where you are)... Yeah, that would be fine” (18)	Four sessions: Session I – Pain types and assessment and using the Daily Comfort Diary Session 2 - Managing pain and understanding medications Session 3 – Managing pain using comfort therapies Session 4 – Sustenance and support for the family caregiver
Video	“I would’ve used it (video), yes, yes. Because visual learning is, you know, I think that would be quite good..I think we would remember more” (17)	Video which demonstrates sitting up in bed, moving from bed to chair, relieving pressure, walking with an unsteady patient and what to do if the patient falls.
Brochures and books		Handouts of each session
Internet information and /or helpline		Brochures about local palliative care services
Support group		Phone numbers of local support groups

The Best Time to Learn

There was a varied response from the family caregivers when asked about the best time to learn about cancer pain management. For some people, the time of diagnosis was

thought to be most helpful. One family member commented, *“When they are first diagnosed I think. Then you’ve got it to work with and toward, haven’t you? (4)”*

For others, during hospitalisation for treatment was deemed the most appropriate time. One woman stated *“I think probably when, you have got more confidence when you are in hospital because you’ve got all the care providers around you. You can ask the questions all the time, whereas I think possibly in the home, when you get home, quite useful (5)”*.

Ongoing educational sessions at home were also considered to be helpful because the difficulties in either leaving or arranging care for an ill family member were not appealing. As one family member stated, *“Its very difficult to find the time to go somewhere... so for us it would have to be at home because we can’t go and leave Grandma on her own (15)”*.

Caregiver Suffering

When caregivers were asked what the benefits and/or burdens of cancer pain management were, many described feelings of suffering and helplessness, both verbally and with their body language. One daughter described how she had cried all the way home from hospital where she had been visiting her mother, and cried again as she recounted the story. She described her feelings about visiting her mother who was in respite care. She stated, *“When I leave the hospital I cry all the way home, you can’t do anything for her, its just like watching anyone in pain, what can you do (20)?”*

Many caregivers spoke about feeling useless and frustrated because they didn’t have any skills in pain management. As one family member stated, *“I felt quite useless. There was nothing much you could do. He was also very weepy so it was quite traumatic (17)”* and *“It’s frustrating when you don’t know what to do. I think, what do I do to help him (10)?”*

An elderly woman related her own frail health status and required help to move from her chair during the interview. She said, *“No, my own pain, arthritic pain, while he’s been sick, I’ve had a bout of shingles. It’s terrible. I really don’t know how much pain he is in. I can only sit and hold his hand. (6).”*

These comments from the family caregivers clearly describe their feelings of inadequacy and suffering. It is evident that providing this population with the appropriate knowledge and skills could ameliorate the burdens often associated with cancer pain management at home.

Overall Lack of Preparation

The overall lack of preparation was reflected in all the family caregiver interviews. The sense of helplessness and fear of both present circumstances and future pain management problems was apparent. Despite these anxieties, all participants were firm in their resolve to care for their loved one at home and voiced a willingness to learn “how to do it better”. The overall lack of preparation is illustrated in Table 6.

Table 6

Preparation Deficit, Exemplars and Related PMP Content

Preparation Deficit Response	Interview Exemplars	Related PMP Content
Helplessness	<p>“and all of a sudden she’s home and the pain starts and neither of us is capable of being alert, particularly the carer, I think, being alert to the fact that boy you’ve got problems coming on there, you’ve got to do it, and I think I floundered a bit.”(2)</p> <p>“Well, I don’t really know what type of pain it is you see. Whether I can help or not. I know that she is lying there in pain and I can’t do anything to help her. I’ve just got to stand by.” (11)</p>	<p>Pain types and assessment and using the Daily Comfort Diary</p> <p>Managing pain and understanding medications</p> <p>Managing pain using comfort therapies</p> <p>Sustenance and support for the family caregiver including self care and accessing local resources</p>
Fear, anger and fatigue	<p>it’s frightening, frightening enough for me and I’m used to horrible things” (2)</p> <p>“I’m inclined to get angry over the whole business (pain) .I think why, why is this happening? I don’t know, I suppose you tend to be blinded by your emotions” (5)</p>	<p>Sustenance and support for the family caregiver including self care and accessing local resources</p>

The Benefits

Despite the suffering and lack of preparation for many of these family caregivers, the benefits of caring for a loved one at home and the sense of loving were evident. Family

caregivers clearly expressed the value and importance of being together at home throughout this time in their lives. One woman reflected back over the time she had cared for her father and said, “ *Yes, I just wish there were more people that could have the support to have somebody at home. It was worth having my father there It’s just so impersonal in hospital (14).*”

The importance of being in familiar surroundings was also seen as a benefit. One daughter stated, “*She’s happy, she’s more settled, she’s on familiar ground with her things around her (2).*” Others commented on the importance of being able to stay close to one another. One spouse reflected, “*The benefits are having him with me. That is the biggest thing. To be able to talk together, just everything (3).*” The sense of being at home together and staying close is beautifully articulated in the words of a young wife as she spoke about managing her husband’s cancer pain. “*It was something I could do for him...you know, in sickness and in health, basically...he responded well to me and he loved his home. I would sing to him and even right towards the end when he was not quite with us, we could hear him trying to sing to me (9).*”

The content analysis of these 19 family caregiver interviews combined with relevant current literature (Ferrell, Ferrell, Rhiner & Grant, 1991; Ferrell, Taylor, Grant, Fowler & Corbisiero, 1993; Ferrell, Grant, Chan, Ahn & Ferrell, 1995; Johnston & Abraham, 1995; de Wit, van Dam, Zanderbelt, Buuren, van Heijden, Leenhouts & Loustra, 1997; Harrington, Lackey & Gates, 1996; Riddell & Fitch, 1997; Ferrell, Borneman & Juarez, 1998; Butcher, Trostle & Moore, 1999) informed the teaching content, the diary and the video of the PMP for family caregivers of advanced cancer patients.

The Pain Management Program (PMP)

The PMP consists of four sequenced sessions, a Daily Comfort Diary and a video. The sessions focus on helping the family caregiver to understand and assess pain, manage pain and understand medication use, learn comfort therapies, know when to ask for help with pain management, and identify/expand support strategies for themselves. The teaching plan for the PMP (Appendix M) describes the educational content and strategies. The 12-minute video (Appendix O) demonstrates ways to move patients in bed, out of bed

and into a chair and how to support an unsteady patient when walking. The video also shows what to do if a patient falls at home.

Each session lasts approximately an hour. The entire program is delivered using a laptop computer and a data projector. All sessions are supported by an interactive Power point presentation, making use of graphics and photographs. Handouts of each session were provided at the end of each session and feedback was encouraged. Sessions could be tailored to meet individual needs while maintaining the basic pain management principles.

The PMP is designed to be implemented in the family home or wherever is most suitable for the family caregiver.

Phase II Findings

Participant Characteristics

Letters of information about the study were mailed to 160 randomly selected family caregivers by the SCHCS. Of these, 34 (21%) responded and 31 family caregivers and 31 patients were recruited at Time I. The three family caregivers who were not recruited all had wives who were terminally ill in in-patient units. Twenty- four family caregivers completed Time 2, resulting in an attrition rate of 22.5%. Reasons for attrition included: one family member leaving the city, three patients dying, patients becoming terminally ill, and one was too busy to continue. Nineteen family caregivers completed Time 3 resulting in an attrition rate of 20.8%. The sole reason for withdrawal from the study between Time 2 and Time 3 was the death of five patients. The overall attrition from Time 1 to Time 3 was 38.7%.

Family caregivers

Family caregivers' ages ranged from 37 to 88 years, with a mean age of 57 years. There were 22 (71%) female and 9 (29%) male participants. Twenty-five (81%) of the family caregivers were spouses. There were three (10%) daughters, two (6%) sisters and one (3%) woman was caring for her son.

Four (13%) family caregivers had pre-school children and six (19%) family caregivers had school age children to care for. Six (19%) family caregivers reported other

commitments that included caring for sick parents, babysitting grandchildren and an older child living at home. This question was added to the demographic questionnaire as a result of Phase I, where the researcher observed the role of the caregivers at home.

Sixteen (51%) family caregivers had completed secondary level education and twelve (39%) had trade qualifications. Three (10%) family caregivers had completed university degrees.

Ten (10%) caregivers were employed either full time (16%) or part time (16%). Twenty one (68%) of the family caregivers were either retired or not employed.

Twenty-four (77%) family caregivers were born in either Australia (51%) or the British Isles (26%). Seven (23%) were born in Europe. Many of these families lived on a low income, 18 (59%) participants earned < \$20,000, seven (22%) earned between \$20,000 to \$50,000, five (16%) earned > \$50,000 and one (3%) family caregiver declined to state income.

Only two family caregivers reported previous informal pain management education. One family caregiver described informal education given by the home care team who visited and the other family caregiver described the experience of caring for his mother who had died from cancer.

Patients

Patients' ages ranged from 31-87 years, with a mean age of 59 years. There were 18 (58%) males and 13 (42%) females. The patients' countries of birth were similar to those of their family caregivers.

Thirteen (42%) patients had been diagnosed with cancer for more than one year. Eighteen (58%) patients reported that they had been living with pain related to cancer for between one and six-months, and 13 (42%) patients had been living with pain related to cancer for nine to eighteen months.

Twenty (65%) patients reported visceral pain, two (6.5%) patients reported visceral plus bone pain and three (10%) patients reported visceral plus neuropathic pain. Three (10%) reported bone pain and one patient reported bone plus neuropathic pain. One patient reported no pain. Data were missing for two patients. No patients reported emotional pain. The patients' primary and secondary cancers are described in Table 7.

Table 7

Frequency and Percent Distribution of Patients According to Diagnosis and Secondary Disease

Primary Cancer Diagnosis	n %	Secondary Disease	n %
Lung	6 (19.4)	Bone	6 (19.4)
Bowel	6 (19.4)	Liver	6 (19.4)
Pancreas	4 (12.9)	Lung	4 (12.9)
Prostate	3 (9.7)	Brain	3 (9.7)
Breast	2 (6.4)	Liver + lung	3 (9.7)
Other	10 (32.3)	Bone + liver + brain + lung	1 (3.2)
		Other	4 (12.9)
		Nil	4 (12.9)

The other diagnoses included osteosarcoma, mesothelioma, glioblastoma, melanoma, hystocytoma, Non Hodgkin's lymphoma and gastric and gallbladder cancers. Bone and liver were the sites of the most frequent secondary disease, followed by lung and brain. Other secondary involvement included the abdominal wall, spleen, lymph nodes and the orbital cavity.

Medications and other pain management modalities are described in Table 8.

Twenty-eight (90%) patients were taking an opioid medication for pain control. The oral route was used for 93.5% (n=29) of this group, three (10%) people were receiving some medication subcutaneously and one (3%) person was receiving percutaneous medication via a skin patch.

Table 8

Patients' Treatment Profile (n=31)

Treatment	<u>n</u>	%
Medication		
Opioid	28	90.3
Steroid	12	38.7
NSAID	5	16.1
Adjuvant	6	19.4
Other	19	61.3
Other modalities		
Physiotherapy	1	3.2
Radiotherapy	6	19.4
Chemotherapy	3	9.7
Acupuncture	1	3.2
Comfort therapies		
Massage	4	12.9
Psychotherapy	1	3.2
Other	3	9.7

Note. NSAID refers to Non-steroidal anti-inflammatory drugs

Note. Percentages add up to more than 100% because patients reported the use of more than one treatment

Adjuvant medication included simple analgesics (eg. paracetamol), anticonvulsants, antidepressants and muscle relaxants. Many other medications were also prescribed including drugs acting on; the alimentary system (ranitidine, hyoscine butylbromide, omeprazole and docusate sodium; senna); the cardiovascular system (both anti-hypertensive agents and diuretics) and the central nervous system (sedatives and anti anxiety agents).

None of these patients reported having had any surgical procedures or using aromatherapy for pain relief. Other comfort measures described by the patients included craniosacral manipulation and Reiki.

Data Preparation and Exploration

Before analysis of Phase II data, the researcher re-coded negatively worded scale items, assessed the psychometric properties of the instruments as used in this study, replaced missing responses, explored data, and screened data to ensure the necessary assumptions for the analysis were met, taking action when this was required. The specific processes used are detailed in the following paragraphs.

Re-coding of Scales

The researcher reverse coded items 2 to 4, 7 to 9 and 12 in the FPQ and items 6 to 9 in the CPAQ. All items on both questionnaires were formatted such that 0 equalled the most positive outcome and 10 equalled the most negative outcome.

Assessment of the Psychometric Properties of the Instruments

The researcher first evaluated the psychometric properties of the two instruments used in this study, the Family Pain Questionnaire (FPQ) and the Cancer Pain Attitude Questionnaire (CPAQ).

As the first step towards assessing properties of the instruments, the researcher checked proportions of “missing” responses for each item. No item had a greater than 5%

incidence of missing responses. The missing responses were not replaced for these first reliability estimates.

Clarity, content validity and apparent internal consistency of the outcome measures

Clarity

Item clarity is designed to convey a single message or part of the inductively generated concept (Imle & Atwood, 1988). Six expert nurse practitioners received instructions, instruments, and a response format that asked whether each item was clear or unclear. Space for comments was provided beside each item. Before the data collection, an *a priori* criterion of 66% agreement was set for clarity for each scale item and 80% agreement as the criterion for the overall scales (Imle & Atwood, 1988). All the items on the CPAQ and the FPQ achieved the preset criteria (Imle & Atwood, 1988).

Content validity

This stage involved providing the panel members with definitions and concept labels for the instruments and asking them to make judgements about the content validity of the items individually and as a set. Content validity assessments involve a test or evaluation of the extent to which items on a scale fit the domain of interest (Nunnally, 1978). Not only is it important to assess the adequacy of items to tap the meaning of the conceptual domain, as defined in the study, but it is necessary to also evaluate redundancy among scale items (Imle & Atwood, 1988).

Panel members were asked to read the items on the sub-scale label (eg. Knowledge sub-scale, Item 2 states “Pain medicines should only be given when pain is severe”) and rate whether or not the item matched the label. The question of redundancy was addressed by asking raters to indicate if each item was unique. Space was provided for comments. A final question asked raters to add any items they considered to be missing from each scale.

The *a priori* criterion for acceptance was 80% agreement for each item (Imle & Atwood, 1988). However, with six raters the practical criterion of 83% agreement for both procedures was used, five out of six raters agreeing (Lynn, 1986). All the items on the CPA and the FPQ-knowledge met the criterion of 83% agreement.

Apparent internal consistency

Internal consistency is a preliminary requirement for both reliability and construct validity according to the domain sampling model (Nunnally, 1978). Domain sampling is based on the idea that there exists a hypothetical group of items that are correlated to some extent. This average correlation of items in a particular domain represents internal homogeneity, which serves as a basis for later estimates of internal consistency and content validity (Imle & Atwood, 1988). Imle & Atwood (1988) used the phrase “apparent internal consistency” to describe the non-quantitative assessment of the homogeneity of content, done before pilot quantitative data are gathered. Therefore, the intent of this third assessment was to estimate the apparent internal consistency of the scales so that the scales could be revised if there was evidence of inadequate domain sampling.

Panel members were asked two questions: “Do these items generally belong together?” and “Does each item belong in the sub-scale?” Space was also provided for panel members to comment on items. The *a priori* criterion for an item to be retained was 83% agreement among raters per item (five of six raters agreed). All items in both instruments met or exceeded the preset criterion of 83% agreement.

Internal consistency reliability of the outcome measures

The FPQ consists of two sub-scales that measure knowledge and experience. The reliability estimate for the 9 item Pain Knowledge sub-scale according to the standardised Cronbach’s alpha coefficient was 0.49 at Time 1, improving to 0.61 when Item 9 was deleted. This item stated “If the pain is worse, the cancer must be getting worse”. At Time 2, the standardised Cronbach’s alpha coefficient was 0.79, and 0.83 with the deletion of Item 5. This item stated “It is better to give pain medications around the clock (on schedule) rather than only when needed”. At Time 3, the standardised Cronbach’s alpha coefficient was 0.63 and improved to 0.66 with Item 9 deleted. Based on these findings Item 9 was deleted from the scale. At all three time points, more than 50 % of the FPQ-knowledge scores achieved item-to-total correlations within the recommended range of 0.40 to 0.70 (Nunnally & Bernstein, 1994). Inter-item correlations for this sub-scale were examined with the aim of identifying how many fell within the recommended range of 0.30 to 0.70. At Time 1 only 28.5% met this criteria. At Time 2, 53.5% and at Time 3, 42.8%

met this criteria. These findings suggest that an internal consistency reliability model may not be the best approach for testing the tool's reliability. It may be that knowledge in some areas is separate and does not overlap with knowledge in other areas. Nevertheless, it appears that internal consistency increased over time, suggesting that improved knowledge may be transferred.

Reliability estimates for the 7 item Pain Experience sub-scale were 0.63 at Time 1, improving to 0.73 with Item 12 deleted. Item 12 asked "How much pain relief is your relative/friend currently receiving?" At Time 2, the standardised Cronbach's alpha coefficient was 0.32, improving to 0.50 with the deletion of Item 12. At Time 3, the standardised Cronbach's alpha coefficient was 0.58, improving to 0.80 with Item 12 deleted. Based on these findings Item 12 was deleted from the scale. All inter-item and item-to-total correlations for the FPQ-experience sub-scale fell within the pre-set ranges of 0.30 to 0.70 and 0.40 to 0.70 respectively.

Findings of reliability estimates indicated that the standardised Cronbach's alpha coefficient for the nine item CPAQ was 0.66 at Time 1 (n=31). This figure was improved by the deletion of Item 8, giving a standardised Cronbach's alpha coefficient of 0.77. At Time 2 (n=24), the standardised Cronbach's alpha coefficient was 0.74 and was improved by deleting Item 9, giving a standardised Cronbach's alpha coefficient of 0.81. At Time 3 (n=20), the standardised Cronbach's alpha coefficient was 0.84 with no items deleted. Additionally, it was noted that at Time 1 more than 50% of the CPAQ items achieved item-to-total correlations in the range 0.40 to 0.70, and 47% of inter-item correlations fell between 0.30 and 0.70. At Time 3, 58% of the CPAQ item-to-total correlations were between 0.40 to 0.70. More than 50% of inter-item correlations fell between 0.30 and 0.70. This confirmed that the items were internally consistent and not redundant. Therefore, all items in the CPAQ were retained for the third phase of the study. Table 9 provides a summary of the psychometric properties of the instruments used in this study.

Table 9

Psychometric Properties of Items from Scales used in Phase II

Statistic	CPAQ – Attitudes			FPQ- Knowledge			FPQ – Experience		
	T1	T2	T3	T1	T2	T3	T1	T2	T3
Inter-item correlations:									
Mean	0.18	0.24	0.36	0.09	0.29	0.16	0.19	0.06	0.16
Range	1.12	1.21	1.17	0.98	1.06	1.05	1.34	1.24	1.57
SD	0.01	0.01	0.01	0.00	0.00	0.00	0.02	0.02	0.04
Item-to-total correlations:									
Mean	0.37	0.44	0.57	0.24	0.48	0.31	0.36	0.14	0.36
Range	0.96	0.81	0.84	0.77	0.84	0.71	1.04	0.83	1.30
Cronbach’s alpha	0.69	0.76	0.87	0.48	0.78	0.59	0.25	0.60	0.58
Standardised item alpha	0.66	0.72	0.85	0.42	0.78	0.63	0.32	0.50	0.80
Number of items	9	9	9	9	9	9	7	7	7
After items 9, 12 deleted									
Cronbach’s alpha	No deletion for this sub-scale			0.60	0.76	0.66	0.74	0.50	0.80
Standardised item alpha				0.57	0.76	0.68	0.74	0.51	0.78
Number of items				8	8	8	6	6	6

Note. T1, T2 and T3 represent the time points 1, 2 and 3.

Stability over Time

The instruments were tested for stability over time using a test-retest procedure as described by Woods and Catanzaro (1988). The criterion for this assessment was to be 0.80 or higher (Nunnally, 1978). Twelve family caregivers participated in the test-re-test with 24 to 48 hours between Time 1 and Time 2. This short time interval was chosen to avoid the possible influence of changes in the phenomena being measured. Data were analysed using intraclass correlation coefficients (ICC) (McGraw & Wong, 1996). Both instruments demonstrated acceptable estimates of stability over time (CPAQ, $r = 0.87$; FPQ, $r = 0.80$).

Findings of Initial Data Exploration

The researcher next examined descriptive statistics obtained using the CPAQ and the FPQ. The CPAQ asks for ratings for concerns and reluctance to give pain medications, beliefs about the effectiveness of non-medical treatments and the importance of psychosocial and spiritual issues in the area of cancer pain management. At Time 1, the mean score of the CPAQ was 33.19 and the standard deviation was 13.42. This baseline mean score of 33.19 is below the mid-point of 45.00 on the CPAQ scale indicating that attitudes of this sample tended to be somewhat positive.

The FPQ Knowledge sub-scale asks for ratings for knowledge and beliefs about cancer pain relief, pain medications, addiction and non-medication treatments. At Time 1, the FPQ-knowledge mean score was 32.45 with a standard deviation 12.43. This baseline mean score is also below the mid-point of 40.00 on the FPQ-knowledge scale with Item 9 deleted, also indicating that the level of knowledge was reasonably good in this sample.

The FPQ Experience sub-scale asks for ratings of recent cancer pain experience, relative's current of pain relief, pain distress, sense of ability to control relative's pain and future expectation of relative's pain. At Time 1, the FPQ-experience mean score was 38.54 with a standard deviation of 10.02. The FPQ-experience scale has a mid-point of 30 with Item 12 deleted thus the baseline mean score for the FPQ-experience in this sample was above the mid point for the scale, indicating that the experience of cancer pain management was somewhat negative. Findings are summarised in Table 10 and are based on total scores for each instrument.

Table 10

Descriptive Statistics from the Scales used in Phase II

Scale	Minimum	Maximum	Min-Max	<u>M</u>	<u>SD</u>	<u>n*</u>
CPAQ						
Time 1	10.00	55.00	0 - 90	33.19	13.42	31
Time 2	2.00	55.00	0 - 90	24.13	12.79	24
Time 3	3.00	54.00	0 - 90	24.05	14.84	20
FPQ:						
Knowledge ^a						
Time 1	2.00	58.00	0 - 80	32.45	12.43	31
Time 2	0.00	56.00	0 - 80	24.42	14.69	24
Time 3	3.00	50.00	0 - 80	24.50	12.50	20
Experience ^b						
Time 1	21.00	57.00	0 - 60	38.55	10.02	31
Time 2	11.00	46.00	0 - 60	34.00	7.71	24
Time 3	10.00	56.00	0 - 60	35.10	12.90	20

Note. N* varies according to the amount of missing data for each scale.

Note. ^a Eight items (Item 9 deleted). ^b Six items (Item 12 deleted).

Ferrell, Grant, Chan, Ahn and Ferrell (1995) report a higher baseline score for knowledge and a similar score for experience among a sample of 50 family caregivers prior to three 'pain instructional sessions'. In Ferrell and colleagues' population the knowledge mean score was 53.2 with a standard deviation of 19.8 and the experience mean score was 38.8 with a standard deviation of 15.7. While no items were deleted from either sub-scales

in Ferrell and colleague's study, these results would suggest that the population in the 1995 study had less knowledge of, and worse experiences in, cancer pain management than the population in this study.

Missing Responses

No item had a greater than 5% incidence of missing responses for both instruments. After consultation with a bio-statistician, the researcher replaced missing data with estimated means using the SPSS EM (expectation-maximisation) method to maximise the data. This conservative method was chosen because it does not alter the mean for the distribution as a whole (Tabachnik & Fidell, 1996).

Data Screening

Data screening to check that variables met necessary assumptions for one-way repeated measures ANOVA resulted in a variety of actions being taken, as recommended by Pallant (2001). The two statistical assumptions for one-way repeated measures ANOVA, using multivariate tests are that the values of outcome variables are normally distributed and the population variance is homogeneous. These assumptions were met.

To what extent is the pain management intervention effective in improving the family caregivers' knowledge and experience of, and attitudes to cancer pain management?

Knowledge

A one-way repeated measures ANOVA was conducted to compare scores on the Knowledge sub-scale at Time 1 (prior to the intervention), at Time 2 (following the intervention) and at Time 3 (one-week follow-up). The means and standard deviations are presented in Table 11. There was a significant effect for time, Wilks' Lambda = 0.528, F , $p = 0.001$, multivariate eta squared = 0.530.

Table 11

Descriptive Statistics for FPQ Knowledge with Statistic Test Scores for T1, T2, T3

Time period	<u>n</u>	<u>M</u>	<u>SD</u>
Time 1 (pre-intervention)	20	33.40	13.32
Time 2 (post-intervention)	20	24.05	15.61
Time 3 (1 week follow-up)	20	24.50	12.50

Experience

A one-way repeated measures ANOVA was conducted to compare scores on the Experience sub-scale at Time 1 (prior to the intervention), at Time 2 (following the intervention) and at Time 3 (one-week follow-up). The means and standard deviations are presented in Table 12. There was a significant effect for time, Wilks' Lambda =0.470, $F(2,38) = 10.17$, $p = 0.001$, multivariate eta squared = 0.530.

Table 12

Descriptive Statistics for FPQ Experience with Statistic Test Scores for T1, T2, T3

Time period	<u>n</u>	<u>M</u>	<u>SD</u>
Time 1 (pre-intervention)	20	40.40	9.45
Time 2 (post-intervention)	20	33.70	8.05
Time 3 (1 week follow-up)	20	35.10	12.90

Attitudes

A one-way repeated measures ANOVA was conducted to compare scores on the Cancer Pain Attitude Questionnaire at Time 1 (prior to the intervention), at Time 2 (following the intervention) and at Time 3 (one-week follow-up). The means and standard deviations are presented in Table 13. There was a significant effect for time, Wilks' Lambda = 0.577, $F(2, 18) = 8.06$, $p = 0.003$, multivariate eta squared = 0.472.

Table 13

Descriptive Statistics for Cancer Pain Attitudes with Statistic Test Scores for T1, T2, T3

Time period	<u>n</u>	<u>M</u>	<u>SD</u>
Time 1 (pre-intervention)	20	34.20	12.33
Time 2 (post-intervention)	20	22.70	13.50
Time 3 (1 week follow-up)	20	24.05	14.85

These findings report statistically significant increases in knowledge and improvements in attitudes and experiences among the participants from baseline testing to post intervention and one week on.

To what extent is the pain management intervention feasible and acceptable to family caregivers?

All of the family caregivers completed the pain management intervention apart from those whose relatives had deteriorated and required in-patient care, or died. The interactive educational model used to implement the intervention was effective and easy to use in all of the families' homes.

The family caregivers welcomed the opportunity to improve their knowledge and skills. Many of the participants also spoke altruistically about wanting to help other people in the same situation as themselves. The notes on each session were shared among family members and friends and kept with the DCD. Many participants had follow up questions at subsequent education sessions.

All of the original participants agreed to use the DCD at the commencement of the program. Sixteen of the 19 family caregivers that completed the intervention found the DCD helpful. At the completion of the study seven caregivers asked to keep their diary and as they wanted to continue to use it for their relative.

Phase III Findings

Participant Characteristics

Study letters of invitation were mailed to 349 randomly selected family caregivers by the SCHCS. Of these, 80 (22.9%) responded and 71 (20.3%) consented to participate. Four hundred and fifty information booklets about the study were also made available to be inserted in the home care notes of each new admission into this service over the recruiting time period. At A. H. Crawford Lodge, 34 information booklets were distributed and 26 (76.4%) family caregivers responded. Fourteen (28%) family caregivers responded from the Palliative Care Outpatients and the Radiation Oncology Clinics at SCGH after the distribution of 50 study information booklets. The PHCU at Hollywood Private Hospital was provided with 50 study information booklets to be placed in the home care notes and three (6%) family caregivers responded. Two family caregivers responded to an article about the study in the local newspaper and one family caregiver responded to an article about the study in the CSA newsletter. A total of 117 family caregivers and 111 patients consented to participate in the study. Three patients were not well enough to sign the consent form at the time the family caregivers were recruited and deteriorated further with no data being obtained. Consequently demographic and baseline data only was obtained from the three family caregivers, before they withdrew. No patients refused to participate when their relatives had agreed to participate.

At Time 1, 60 family caregivers were randomly assigned to the experimental and 57 family caregivers were randomly assigned to the control group. At Time 2, 84 family caregivers remained in the study, 41 in the experimental group and 43 in the control group. At Time 3, 81 family caregivers remained to complete the study with 38 in the experimental group and 43 in the control group. The overall attrition rate was 30.7%, with the majority of the family caregivers withdrawing between Time I and Time 2. Twenty-four patients died and 12 family caregivers withdrew from the study. Of the 12 family caregivers that withdrew, ten patients were either at the end stage of their illness and/or needed admission to an in-patient unit and two family caregivers failed to contact the researcher after the initial consent. Table 14 describes the recruitment progress.

Table 14

Recruitment and Attrition of Family Caregivers

Family caregivers	Time 1	Time 2	Time 3	Reason for withdrawal
Experimental	60	41	38	14 deaths, 8 not completed
Control	57	43	43	10 deaths, 4 not completed
Total	117	84	81	24 deaths, 12 not completed

Most of the deaths and withdrawals from the study occurred between Times 1 and Time 2, therefore the researchers, following consultation with the participating family caregivers, delivered the PMP over a one to two week period rather than the four week period used in Phase II. This reduced the loss of participants from 38.7% in Phase II to 30.7% in Phase III.

Characteristics of the Family Caregivers – Whole Group

Family caregivers' ages ranged from 13 to 87 years with a mean age of 59 years. The thirteen-year-old caregiver was the daughter of a patient from the country who was staying with her mother, in the city for treatment. The mother gave permission for her daughter to participate.

There were 78 (67%) female and 39 (33%) male participants. Ninety-four (80%) family caregivers were spouses, 11(9%) were daughters, 2 (2%) were sons, 3(3%) were mothers and seven (6%) were close friends of the patient. Ninety one percent of the family caregivers described themselves as the primary caregiver.

Five (4%) of the family caregivers had pre-school or school age children to care for. Five (4%) family caregivers reported other commitments that included community service, having an adult child living at home and babysitting grandchildren.

Ten (8%) family caregivers had primary level education, 57 (49%) family caregivers had completed secondary level education, forty (34%) had trade qualifications. Nine (8%) family caregivers had completed university degrees and one family caregiver had post graduate education.

Almost half of these families lived on a low income, 55 (47%) family caregivers earned < \$20,000, 27 (23%) participants earned < \$50,000, 20 (17%) earned between \$20,000 to \$50,000 and 15 (13%) participants declined to state income. Twenty-seven (23%) percent of the caregivers were employed either full time (13%) or part time (10%). Ninety (76%) of the family caregivers were either retired or not employed.

One hundred and five (90%) family caregivers were born in either Australia (71%), New Zealand (3%) or the British Isles (16 %). The other cultural backgrounds were Canadian (n=1, 1%), European (n=6, 4%), Asian (n=5, 3%). All but two family caregivers spoke English as their first language, Italian was the other language spoken.

Nine (8%) family caregivers reported some previous pain management education. This included the background of nursing (two retired and one practicing), and medicine. Other family caregivers described informal education given by a hospice home care team

who visited for other family members illnesses, verbal information given by a hospital on discharge, visits to a Pain Clinic for neuralgia and the experience of caring for an adult child with spinal damage. None of the family caregivers had any previous formal education in cancer pain management.

Characteristics of the Family Caregivers – Experimental Group

There were 60 family caregivers randomly assigned to the experimental group.

Family caregivers' ages ranged from 19 to 87, with a mean age of 60 years. There were 39 (65%) female and 21 (35%) male participants. Forty-eight (80%) family caregivers were partners or spouses, seven (12%) were daughters, one (2%) was a son, two (3%) were mothers and two (3%) caregivers were close friends. Fifty-seven (95%) participants described themselves as the primary caregiver.

None of this group of family caregivers had pre school or school age children. Two participants had other commitments which were described as community service responsibilities and having an adult child living at home.

Twenty-seven (45%) family caregivers had completed secondary level education and twenty-one (35%) had trade qualifications. There were five (12%) university graduates. Seven (8%) family caregivers had completed primary level education.

Twelve (20%) caregivers were employed either full time (n=8, 13%) or part time (n=4, 7%). Forty-eight (80%) were either retired (n=34, 57%) or unemployed (n=14, 23%). Many of the families in this group lived on a low income. Thirty (50%) families earned < \$20,000, thirteen (22%) families earned between \$20,000 and \$50,000 and six (10%) families earned > \$50,000. Eleven (18%) participants declined to state their income.

Most of this group was born in Australia (n=44, 72%) or the British Isles (n=11, 18%). Other participants included four (7%) Europeans and one (2%) Asian family caregiver. The culture of the family caregivers reflected their birth countries and was predominantly Australian (n=46, 77%). All but one family caregiver spoke English as their first language, Italian was the other language spoken in this group.

Six (10%) family caregivers reported some previous pain management education. This included the background of nursing (two retired and one practicing), and medicine.

Other family caregivers described informal education given by a hospice home care team who visited for other family members' illnesses, verbal information given by a hospital on discharge and visits to a Pain Clinic for neuralgia. None of the family caregivers had any previous formal education in cancer pain management.

Characteristics of the Family Caregivers – Control Group

There were 57 family caregivers randomly assigned to the control group.

Family caregivers' ages ranged from 13 to 82 years, with a mean age of 57 years. There were 39 (68%) female and 18 (32%) male participants. Forty-six (81%) family caregivers were partners or spouses, four (7%) were daughters, one (2%) was a son and one (2%) caregiver was a mother. The remaining five (9%) caregivers in this group described themselves as close friends. Fifty (88%) participants were primary caregivers.

In this group five (9%) family caregivers had pre school children or school age children. Three (5%) participants had other commitments which were described as babysitting grandchildren or having an adult child living at home.

As for the experimental group, 32 (56%) family caregivers had completed secondary level education and 18 (32%) had trade qualifications. There were three (5%) university graduates, including one participant with postgraduate degrees (2%). Three (5%) family caregivers had completed primary level education only.

Fifteen (26%) caregivers were employed either full time (n=7, 12%) or part time (n=8, 14%). Forty-two (74%) participants were either retired (n=28, 49%) or unemployed (n=14, 25%). Almost half of these families lived on a low income. Twenty-five (44%) participants earned < \$20,000, 14 (24%) family caregivers earned between \$20,000 and \$50,000 and 14 (24%) earned > \$50,000. Four (8%) family caregivers declined to state their income.

Most of this group was born in Australia (n=40, 70%) or the British Isles (n=7, 12%). The culture of the family caregivers reflected their birth countries and was predominantly Australian (n=42, 68%). Other participants included four (7%) Asian, two(4%) European and one (2%) Canadian family caregiver. All but one family caregiver spoke English as their first language, Italian was the other language spoken in this group.

Three (5%) family caregivers reported some previous pain management education. This was generally described as the experience of caring for other family members with cancer and visiting them in a hospice setting. None of the family caregivers had any previous formal education in cancer pain management.

Characteristics of the Patients – Whole Group

Patients' ages ranged from 33 to 88 years, with a mean age of 63 years. There were 59 (53%) males and 52 (47%) females. One hundred and two (93%) patients lived with a partner. Three (3%) patients had never married, two (2%) participants were divorced and three (3%) patients were widowed.

Most of the patients were born in either Australia (n=76, 69%) or the British Isles (n=19, 17%). As with the family caregivers, the culture of the participants reflected their birth countries. The cultural backgrounds of the patients was Australian (n= 76, 69%), British Isles (n=19, 17%), European (n=7, 6%), Asian (n=4, 4%), and other (Russian, North American and North African (n=3, 3%). Data for two patients were missing.

Fifty-nine (53%) patients had been diagnosed with cancer for more than one year. Thirty-seven (33%) patients had been diagnosed within one to six months and fifteen (13%) had been diagnosed between six months to one year.

Breast and prostate cancer were the most commonly diagnosed cancers in this population, followed by lung and bowel cancers. Table 15 describes the frequency and percent distribution of patients according to cancer diagnosis and secondary disease for the whole group.

Table 15

Frequency and Percent Distribution of Patients According to Cancer Diagnosis and Secondary Disease – Whole Group (n =111)

Primary Cancer Diagnosis	n %	Secondary Disease	n %
Breast	20(18.0)	Nil	47(41.4)
Prostate	18(16.2)	Bone	28(24.3)
Lung	13(11.7)	Liver	12(10.8)
Bowel	12(10.8)	Lung	6(5.4)
Oesophagus/stomach	10(9.0)	Brain	1(1.8)
Pancreas	5(4.5)	Bone + liver +brain + lung	7(13.2)
Gynaecological	5(4.5)	Other	6(11.3)
Mesothelioma	3(2.7)	Missing	1(1.8)
Bladder	2(1.8)		
Multiple sites	3(2.7)		
Non cancers	2(1.8)		
Other	18(16.2)		

The other primary diagnoses included multiple myeloma, renal cell cancer, adenocarcinoma of unknown origin, glioma, Non-Hodgkin's lymphoma, sarcoma, pituitary tumour, melanoma, testicular cancer, craniopharyngioma, hepatocellular cancer and leukaemia. The two non-cancer diagnoses were motor neurone disease and idiopathic fibrosing alveolitis.

Forty-six (41%) patients had no reported secondary cancer. Twenty-seven (24%) patients described bone secondaries and nine (8%) people had multiple secondary sites. Other secondary spread sites included the neck and shoulders, cervix, abdominal wall, trachea, lymph nodes and the thyroid gland.

In this group, 22 (20%) patients reported no pain at the time of recruitment although pain had been present at times, since diagnosis. Fifty-six (51%) patients had been living with pain between one and six months, and 32 (29%) patients had been living with pain related to cancer for nine months or longer. Data were missing for one participant.

Visceral pain was the most frequent pain type reported. Five (5%) patients reported emotional pain. Table 16 describes the pattern of pain types experienced by this whole group of patients.

Table 16

Patients' Pain Types – Whole Group (n = 111)

Pain type	n	%
Visceral	43	36.7
Bone	17	15.3
Neuropathic	12	10.8
Visceral + bone	3	2.7
Visceral + neuropathic	3	2.7
Bone + neuropathic	9	8.1
Visceral + bone + neuropathic	2	1.8
Emotional + physiological	5	4.5
No pain	22	19.8

Seventy-six (68%) patients were taking an opioid medication for pain control. One hundred (90%) patients took their medication orally. Four (4%) people were receiving some medication subcutaneously and one (1%) person was receiving intrathecal medication. Medications and other pain management modalities are described in Table 17.

Table 17

Patients' Treatment Profile – Whole Group (n = 111)

Treatment	n	%
Medication		
Opioid	76	68.5
Steroid	32	28.8
NSAID	29	26.1
Adjuvant	62	55.9
Other	56	50.5
Other modalities		
Physiotherapy	5	4.5
Radiotherapy	52	46.8
Chemotherapy	23	20.7
Surgery	7	6.3
Other	2	1.8

Treatment	n	%
Comfort therapies		
Aromatherapy	9	8.1
Massage	20	18.0
Psychotherapy	2	1.8
Other	13	11.7

Note. NSAID refers to Non-steroidal anti-inflammatory drugs.

Note. Percentages add up to more than 100% because patients reported the use of more than one treatment

Adjuvant medication included simple analgesics (eg. paracetamol), anticonvulsants, antidepressants and muscle relaxants. Many other medications were also prescribed including drugs acting on; the alimentary system (ranitidine, hyoscine butylbromide, omeprazole and docusate sodium with senna); the cardiovascular system (both anti-hypertensive agents and diuretics) and the central nervous system (sedatives and anti anxiety agents).

Other medical modalities for pain management were described as seeing a psychiatrist and having Sirsphere (Strontium) treatment. Other comfort measures that were used by the patients included prayer, heat packs, Reiki, reflexology, acupressure and relaxation tapes.

Characteristics of the Patients – Experimental Group

There were 58 patients in the experimental group.

The patients' ages ranged from 35 to 88 years, with a mean age of 66 years. There were 28 (48%) males and 30 (52%) females. Almost all the patients lived with a partner

(n= 55, 95%). One (2%) patient had never married and two (4%) participants were divorced.

Most of the patients in the experimental group were born in either Australia (n=46, 80%) or the British Isles (n=8, 14%). As with the family caregivers, the culture of the patients reflected their birth countries. Other cultural backgrounds of these patients included three (6%) participants from Europe and one (2%) patient from Russia.

Twenty-nine (50%) patients had been diagnosed with cancer for more than one year. Eighteen (31%) patients had been diagnosed within one to six months and eleven (19%) had been diagnosed between six months to one year.

Breast and prostate cancer were the most commonly diagnosed cancers in this population, followed by lung and bowel cancers. Table 18 describes the frequency and percent distribution of patients according to diagnosis and secondary disease for the experimental group.

Table 18

Frequency and Percent Distribution of Patients According to Diagnosis and Secondary Disease – Experimental Group (n=58)

Primary Cancer Diagnosis	n (%)	Secondary Disease	n (%)
Breast	15(25.9)	Nil	24(41.4)
Prostate	10(17.2)	Bone	19(32.8)
Lung	7(12.1)	Liver	8(13.8)
Bowel	7(12.1)	Brain	1(1.7)
Oesophagus/stomach	5(8.6)	Bone + liver + brain + lung	3(5.2)
Pancreas	2(3.4)	Other	3(5.2)
Mesothelioma	2(3.4)		
Gynaecological	1(1.7)		
Multiple sites	1(1.7)		
Other	8(13.8)		

The other primary diagnoses included gliomas, Non-Hodgkin's lymphoma, hepatocellular cancer and leukaemia. There were no non-cancer diagnoses in this group.

Twenty-four (41%) patients reported no secondary cancer. Nineteen (33%) patients described bone secondaries and three (5%) people had multiple secondary sites. Other secondary spread sites included the neck and shoulders, cervix and the abdominal wall.

In this group, nine (15%) patients reported no pain at the time of recruitment although pain had been present at times, since diagnosis. Twenty-nine (50%) patients had been living with pain between one and six months, and 18 (31%) patients had been living with pain related to cancer for nine months or longer. Data were missing for one participant.

Visceral pain was the most frequent pain type reported. Two (3%) patients reported emotional pain. Table 19 describes the pattern of pain types experienced by this experimental group of patients.

Table 19

Patients' Pain Types - Experimental Group (n = 58)

Pain type	<u>n</u>	%
Visceral	20	34.5
Bone	13	22.4
Neuropathic	8	13.8
Visceral + neuropathic	1	1.7
Bone + neuropathic	4	6.9
Visceral + bone + neuropathic	1	1.7
Emotional	2	3.4
No pain	9	15.5

Forty (69%) patients were taking an opioid medication for pain control. Fifty-three (91%) patients took their pain medication orally. Two (3%) people were receiving some medication subcutaneously. Medications and other pain management modalities are described in Table 20.

Table 20

Patients' Treatment Profile – Experimental Group (n=58)

Treatment	<u>n</u>	%
Medication		
Opioid	40	69.0
Steroid	16	27.6
NSAID	16	27.6
Adjuvant	34	58.6
Other	33	56.9
Other modalities		
Physiotherapy	4	6.9
Radiotherapy	27	46.6
Chemotherapy	7	12.1
Surgery	5	8.6
Other	2	3.4
Comfort therapies		
Aromatherapy	7	12.1
Massage	11	19.0
Other	8	13.8

Note. NSAID refers to non-steroidal anti-inflammatory drugs.

Note. Percentages add up to more than 100% because patients reported the use of more than one treatment.

Adjuvant medication included simple analgesics (eg. paracetamol), anticonvulsants, antidepressants and muscle relaxants. Many other medications were also prescribed including drugs acting on; the alimentary system (ranitidine, hyoscine butylbromide, omeprazole and docusate sodium with senna); the cardiovascular system (both anti-

hypertensive agents and diuretics) and the central nervous system (sedatives and anti anxiety agents).

The experimental group did not use psychotherapy and acupuncture. Other medical modalities for pain management were described as seeing a psychiatrist and having Sirsphere (Strontium) treatment. Other comfort measures that were used by the patients included prayer, heat packs, Reiki, reflexology, and relaxation tapes.

Characteristics of the Patients – Control Group

There were 53 patients in the control group.

The patients' ages ranged from 33 to 79 years, with a mean age of 62 years. There were 32 (60%) males and 21 (40%) females. Forty-eight (90%) patients lived with a partner. Two (4%) patients had never married and three (6%) participants were widowed.

Forty-four (83%) patients were born in either Australia (n=34, 65%) or the British Isles (n=10, 18%). As with the family caregivers, the culture of the patients reflected their birth countries. Other cultural backgrounds included Europe (n=4, 7%), Asia (n= 2, 4%), North America (n=1, 2%) and North Africa, (n=2, 4%).

Thirty (57%) patients had been diagnosed with cancer for more than one year. Nineteen (36%) patients had been diagnosed within one to six months and four (8%) had been diagnosed between six months to one year.

Prostate cancer was the most common diagnosis in the control group, followed by bowel, lung and breast cancers. Table 21 describes the frequency and percent distribution of patients according to diagnosis and secondary disease.

Table 21

Frequency and Percent Distribution of Patients According to Diagnosis and Secondary Disease –Control Group (n=53)

Primary Cancer Diagnosis	n(%)	Secondary Disease	n (%)
Prostate	8(15)	Nil	20(37.7)
Lung	6(11.3)	Bone	8(15.0)
Bowel	5(9.4)	Lung	6(11.3)
Breast	5(9.4)	Liver	4(7.5)
Oesophagus/stomach	5(9.4)	Brain	1(1.8)
Gynaecological	4(7.5)	Bone + liver + brain + lung	7(13.2)
Pancreas	3(5.6)	Other	6(11.3)
Bladder	2(3.7)	Missing	1(1.8)
Mesothelioma	1(1.8)		
Multiple sites	2(3.7)		
Other	9(17.0)		
Non cancer	2(3.7)		
Missing	1(1.8)		

The other primary diagnoses included multiple myeloma, renal cell cancer, adenocarcinoma of unknown origin, sarcoma, pituitary tumour, melanoma, testicular cancer and a craniopharyngioma. The two non-cancer diagnoses were motor neurone disease and

idiopathic fibrosing alveolitis. Twenty-two (42%) patients reported no secondary cancer. Eight (15%) patients described bone secondaries and six (11%) people had multiple secondary sites. Six (11%) patients had other secondary spread sites that included the trachea, bronchi, thyroid and lymph nodes.

In this group, eight (15%) patients reported no pain at the time of recruitment although pain had been present at times, since diagnosis. Twenty-seven (50%) patients had been living with pain between one and six months, and 18 (34%) patients had been living with pain related to cancer for nine months or longer. Visceral pain was the most frequent pain type reported. Three (6%) patients reported emotional pain. Table 22 describes the pattern of pain types experienced by these patients.

Table 22

Patients' Pain Types – Control Group (n = 53)

Pain type	<u>n</u>	%
Visceral	23	43.4
Bone	4	7.5
Neuropathic	4	7.5
Visceral + bone	3	5.6
Visceral + neuropathic	2	3.7
Bone + neuropathic	4	7.5
Visceral + bone + neuropathic	2	3.7
Emotional	3	5.6
No pain	8	15.1

Thirty-six (68%) patients were taking an opioid medication for pain control, with 47 (89%) using the oral route. Two (4%) people were receiving some medication

subcutaneously and one (2%) person was receiving intrathecal medication. Medications and other pain management modalities are described in Table 23.

Table 23

Patients' Treatment Profile – Control Group (n=53)

Treatment	n	%
Medication		
Opioid	36	67.9
Steroid	16	30.2
NSAID	13	24.5
Adjuvant	28	52.8
Other	23	43.4
Other modalities		
Physiotherapy	1	1.9
Radiotherapy	25	47.2
Chemotherapy	16	30.2
Surgery	2	3.8
Comfort therapies		
Aromatherapy	2	3.8
Massage	9	17.0
Psychotherapy	2	3.8
Other	5	9.4

Note. NSAID refers to non-steroidal anti-inflammatory drugs

Note. Percentages add up to more than 100% because patients reported the use of more than one treatment.

Adjuvant medication included simple analgesics (eg. paracetamol), anticonvulsants, antidepressants and muscle relaxants. Many other medications were also prescribed including drugs acting on; the alimentary system (ranitidine, hyoscine butylbromide, omeprazole and docusate sodium with senna); the cardiovascular system (both anti-hypertensive agents and diuretics) and the central nervous system (sedatives and anti anxiety agents).

The control group did not use acupuncture. No other medical pain management treatment was reported. Other comfort measures used were heat packs, Reiki and reflexology.

Chi square analysis for proportions and t-tests for means (Appendices FF and GG) were conducted to compare the control and experimental groups for all demographic data. There were no significant differences between the two groups apart from the area of chemotherapy treatment. The control group showed a higher use of chemotherapy compared with the experimental group.

Eight family caregivers that had completed the control arm asked to do the intervention. This was provided upon completion of the study.

Data Preparation and Exploration

Before analysis of Phase III data, the researcher reverse coded negatively worded scale items, re-assessed the internal consistency reliability of the instruments as used in this study, explored data, and screened data to ensure the necessary assumptions for the analysis were met, taking action when this was required. The specific processes used are detailed in the following paragraphs.

Re-coding of Scales

All items on both questionnaires were formatted such that 0 equalled the most positive outcome and 10 equalled the most negative outcome. The researcher reverse coded items 2 to 4 and 7 in the FPQ and items 6 to 9 in the CPAQ. Item 12 in the FPQ was deleted based on findings from Phase II. Following consultation with a bio-statistician, the

researcher decided to include Item 9 in the FPQ Knowledge sub-scale and to re-examine the internal consistency reliability of the scale at the completion of data collection in Phase III.

Re-assessment of the Psychometric Properties of the Instruments

The researcher first evaluated the psychometric properties of the two instruments used in this study, the Family Pain Questionnaire (FPQ) and the Cancer Pain Attitude Questionnaire (CPAQ). As the first step towards assessing properties of the instruments, the researcher checked proportions of “missing” responses for each item. No item had a greater than 5% incidence of missing responses. The missing responses were not replaced for these first reliability estimates.

Internal consistency reliability of the outcome measures

The FPQ

The reliability estimate for the 9 item Knowledge sub-scale for the whole group according to the standardised Cronbach’s alpha coefficient was poor (0.42) despite the removal of Item 9 at Time 1. There was little improvement in reliability estimates for each group at Time 2 and Time 3. Following discussions with the original author of the FPQ, the decision was made to leave Item 9 in the scale and to compare scores for each item on this knowledge sub-scale at each time point.

The reliability estimate for the 6 item Experience sub-scale for the whole group was 0.78 at Time 1. All inter-item and item-to-total correlations for the FPQ-experience sub-scale fell within the pre-set ranges of 0.30 to 0.70 and 0.40 to 0.70 respectively.

The CPAQ

The standardised Cronbach’s alpha coefficient for the nine item CPAQ for the whole group was 0.71 at Time 1. Additionally, it was noted that at Time 1 more than 50% of the CPAQ items achieved item-to-total correlations in the range 0.40 to 0.70, and 47% of inter-item correlations fell between 0.30 and 0.70.

Findings of Initial Data Exploration

Descriptive statistics were used to summarise responses for the CPAQ and the FPQ. The CPAQ asks participants to rate their concerns about cancer pain medication, their reluctance to give strong pain medication, their beliefs in the effectiveness of non-medical pain management treatments and the importance of psychosocial and spiritual issues in the management of cancer pain. At Time 1, the mean CPAQ score for both groups was 31.94 and the standard deviation was 14.00.

At Time 1, the FPQ-knowledge mean score for both groups was 38.76 with a standard deviation 11.99. Similarly, at Time 1, the FPQ-experience mean score was 33.30 with a standard deviation of 14.28. Findings for each group are summarised in Table 24 and are based on total scores for each instrument.

Table 24

Descriptive Statistics for the Scales used in Phase III

Scale	n	Minimum	Maximum	Possible	M	SD
				Min - Max		
CPAQ						
Time 1						
Experimental	57	0.00	59.00	0 - 90	31.23	15.66
Control	52	11.00	57.00	0 - 90	32.65	12.33
Time 2						
Experimental	41	1.00	61.00	0 - 90	25.27	15.01
Control	42	8.00	49.00	0 - 90	31.26	10.06
Time 3						
Experimental	37	2.00	60.00	0 - 90	25.70	16.65
Control	43	8.00	55.00	0 - 90	33.09	11.22
FPQ:						
Knowledge						
Time 1						
Experimental	52	6.00	63.00	0 - 90	39.12	11.10
Control	50	5.00	61.00	0 - 90	38.40	12.87
Time 2						
Experimental	34	0.00	53.00	0 - 90	27.62	12.90
Control	40	10.00	57.00	0 - 90	37.92	11.92
Time 3						
Experimental	34	7.00	54.00	0 - 90	29.12	11.79
Control	41	10.00	55.00	0 - 90	37.55	9.92

Scale	<u>n</u>	Minimum	Maximum	Possible Min - Max	<u>M</u>	<u>SD</u>
Experience ^a						
Time 1	58	5.00	60.00	0 - 60	32.95	13.77
Experimental	54	0.00	54.00	0 - 60	33.65	14.78
Control						
Time 2	37	9.00	56.00	0 - 60	27.54	11.87
Experimental	40	3.00	60.00	0 - 60	30.50	13.10
Control						
Time 3	36	5.00	55.00	0 - 60	27.75	13.04
Experimental	41	4.00	58.00	0 - 60	31.80	13.49
Control						

Note. N varies according to the amount of missing data for each scale.

Note. ^a Six items after Item 12 deleted from the Experience sub-scale.

Ferrell, Grant, Chan, Ahn and Ferrell (1995) reported higher baseline scores for knowledge and experience among a sample of 50 family caregivers prior to three ‘pain instructional sessions’. In Ferrell and colleagues’ population the knowledge mean score was 53.2 with a standard deviation of 19.8 and the experience mean score was 38.8 with a standard deviation of 15.7. This means that at baseline this study population had more knowledge and better experiences in the area of cancer pain management at home than that of Ferrell and colleagues’ study population reported in 1995.

Missing Responses

No item had a greater than 5% incidence of missing responses for both instruments. After consultation with a bio-statistician, missing data were replaced with estimated means using the SPSS EM (expectation-maximisation) method to maximise the data available for analysis. This conservative method was chosen because it does not alter the mean for the distribution as a whole (Tabachnik & Fidell, 1996).

Data Screening

Data screening to check that variables met necessary assumptions for mixed between-within subjects analysis of variance (SPANOVA) resulted in a variety of actions being taken, as recommended by Pallant (2001). The two statistical assumptions for SPANOVA using multivariate tests are that the values of outcome variables are normally distributed and the population variance is homogeneous. These assumptions were met.

There were no significant differences in the mean scores between the control and experimental group at T1 for the three main outcome variables, knowledge, experience and attitudes, of pain management. Therefore, it appears that the randomisation method used was effective.

To what extent is the pain management intervention effective in improving the family caregivers' knowledge and experience of, and attitudes to cancer pain management?

Knowledge

Because internal consistency reliability estimates for the Knowledge sub-scale suggested that the items were not parallel and measured different facets of knowledge, a mixed between-within subjects analysis of variance (SPANOVA) was used to compare scores for each item on this sub-scale at each time point. The means and standard deviations are presented in Table 25. Figures that graphically demonstrate the trend for the nine items in the Knowledge sub-scale and the results of data analysis for all items can be found in Appendix HH.

Items 3, 4, 7 and 8 showed statistically significant effects for time ($p=0.02$, $p=0.00$, $p=0.02$ and $p=0.03$) respectively and Items 3 and 9 demonstrated a statistically significant interaction effect ($p=0.00$ and $p=0.01$) respectively when significance levels were set at ≤ 0.05 . Post hoc analysis of Item 3 reported a statistically significant main effect for time and group at Time 2 ($p=0.01$) and Time 3 ($p=0.00$). Most of the analyses reported a small to moderate effect size and the power for each of the 9 analyses for the Knowledge sub-scale

was below 0.80 indicating that the sample size was too small to detect a significant difference between the two groups. A summary of the analyses for the 9 Knowledge items can be found in Appendix HH.

Table 25

Descriptive Statistics for FPQ Knowledge with Statistic Test Scores for T1, T2, T3

Knowledge Questionnaire Items	<u>Experimental</u>		<u>Control</u>	
	n	<u>M (SD)</u>	n	<u>M (SD)</u>
1 Cancer pain can be effectively relieved**				
T1	38	2.39 (2.75)	40	3.40 (2.81)
T2	38	2.13 (2.44)	40	3.00 (2.53)
T3	38	1.92 (2.27)	40	2.92 (2.47)
2 Pain medicines should be given only when pain is severe				
T1	38	4.03 (3.75)	40	3.48 (3.52)
T2	38	3.00 (3.52)	40	3.30 (3.27)
T3	38	3.16 (3.26)	40	3.30 (3.14)
3 Most cancer patients on pain medicines will become addicted over time** ***				
T1	38	4.79 (3.41)	40	4.12 (3.18)
T2	37	2.03 (2.77)	40	4.28 (3.12)
T3	38	2.24 (2.22)	40	4.93 (3.08)
4 It is important to give the lowest amount of medicine possible to save larger doses for later when the pain gets worse**				
T1	38	6.24 (3.51)	40	6.05 (3.22)
T2	38	4.50 (3.83)	40	5.72 (3.26)
T3	38	4.42 (3.72)	40	5.45 (3.13)
5 It is better to give pain medications around the clock (on schedule) rather than only when needed				
T1	38	4.68 (4.17)	40	3.75 (3.59)
T2	38	4.50 (4.13)	40	3.43 (3.30)
T3	38	4.26 (4.08)	40	3.35 (3.19)

Knowledge Questionnaire Items	Experimental		Control	
	n	M (SD)	n	M (SD)
6 Treatments other than medications such as massage, heat and relaxation, can be effective for relieving pain				
T1	38	3.00 (2.60)	40	2.23 (2.13)
T2	38	2.32 (2.37)	40	2.85 (2.64)
T3	38	2.50 (2.30)	40	2.78 (2.26)
7 Pain medicines can be dangerous and can interfere with breathing				
T1	38	4.89 (2.89)	40	4.92 (2.95)
T2	38	3.29 (3.11)	40	4.70 (2.68)
T3	38	4.05 (2.93)	40	4.92 (2.52)
8 Patients are often given too much pain medicine				
T1	38	4.03 (3.28)	40	4.05 (2.57)
T2	38	2.71 (2.74)	40	3.65 (2.70)
T3	38	2.34 (2.45)	40	4.05 (2.75)
9 If the pain is worse the cancer must be getting worse				
T1	38	6.34 (3.02)	40	5.80 (3.27)
T2	38	4.34 (3.32)	40	6.30 (3.05)
T3	38	5.58 (3.18)	40	6.07 (2.84)

Note.** Denotes significant main effect for group for Item 1, $p=0.02$, Item 3, $p=0.00$, Item 4, $p=0.02$, when significance levels set at ≤ 0.05 .

Note.*** Denotes significant main effect for group for Item 3 when significance levels set at ≤ 0.005 , using the Bonferroni correction for multiple comparisons.

Results from this analysis indicate that the education program was most effective in improving family caregivers' knowledge about addiction and pain medications. However the experimental group demonstrated a sustained shift down in mean scores in all the FPQ knowledge items over time, suggesting some improvement in all the knowledge items for this group in contrast to the control group which displayed minimal change.

Experience

A mixed between-within subjects analysis (SPANOVA) was conducted to compare scores on the Experience sub-scale at Time 1 (prior to the intervention), at Time 2 (following the intervention) and at Time 3 (one-week follow-up). The means and standard deviations are presented in Table 26. There was no statistically significant effect for time, [Wilks' Lambda=0.932, $F(2,75)=2.74$, $p=0.07$] although the effect size was moderate (multivariate eta squared=0.068). The main effect for group [$F(1,76)=1.832$, $p=0.18$] and the interaction effect [$F(1,76)=0.048$, $p=0.83$] did not reach statistical significance.

Table 26

Descriptive Statistics for Cancer Pain Experience at T1, T2, T3

Time Period	n	<u>M</u>	<u>SD</u>
Time 1 (pre-intervention)			
Experimental	38	28.92	14.40
Control	40	32.55	15.06
Time 2 (post-intervention)			
Experimental	38	26.55	12.22
Control	40	30.07	12.98
Time 3 (1 week follow-up)			
Experimental	38	27.71	13.15
Control	40	31.90	13.63

The power for this analysis was 0.526, suggesting that the sample size was too small to detect a significant difference between the groups. Figure 3 shows that although both groups displayed improvements in experience scores between baseline testing (T1) and post intervention (T2), this outcome was not fully sustained at Time 3.

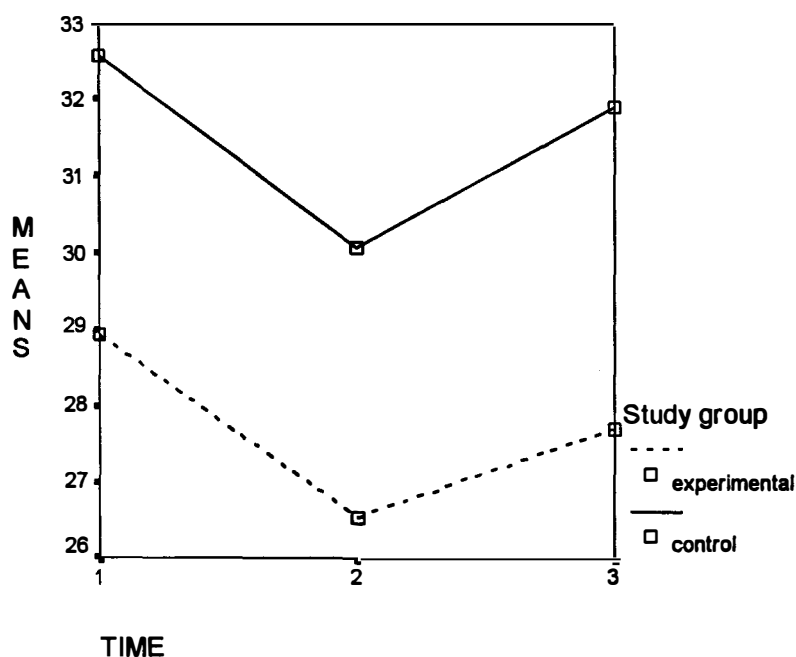


Figure 3. The estimated marginal means for Experience with cancer pain management scores for the control and experimental groups at Time 1, Time 2 and Time 3.

Attitudes

A mixed between-within subjects analysis (SPANOVA) was conducted to compare scores on the CPAQ at Time 1 (prior to the intervention), at Time 2 (following the intervention) and at Time 3 (one-week follow-up). The means and standard deviations are presented in Table 27. There was a statistically significant main effect for time, [Wilks' Lambda=0.892, $F(2,74)=4.47$, $p=0.01$] and a moderate to large effect size (multivariate eta squared=0.11). The main effect for group [$F(1,75)=2.332$, $p=0.13$] did not reach significance. The interaction effect [$F(2,74)=2.952$, $p=0.06$] did not quite reach statistical significance, indicating that the changes in scores for the two groups over time were not large enough to be significant, despite the trend towards improvement for the intervention group (see Figure 4.).

Table 27

Descriptive Statistics for Cancer Pain Attitudes at T1, T2, T3

Time Period	n	<u>M</u>	<u>SD</u>
Time 1 (pre-intervention)			
Experimental	38	32.21	15.47
Control	39	31.10	11.50
Time 2 (post-intervention)			
Experimental	38	24.82	15.29
Control	39	30.79	10.12
Time 3 (1 week follow-up)			
Experimental	38	26.45	17.05
Control	39	33.59	11.51

However the power of this test was less than 0.75 which may explain the non-significant result and indicates that a larger sample size would be required to demonstrate significance at the 0.05 level.

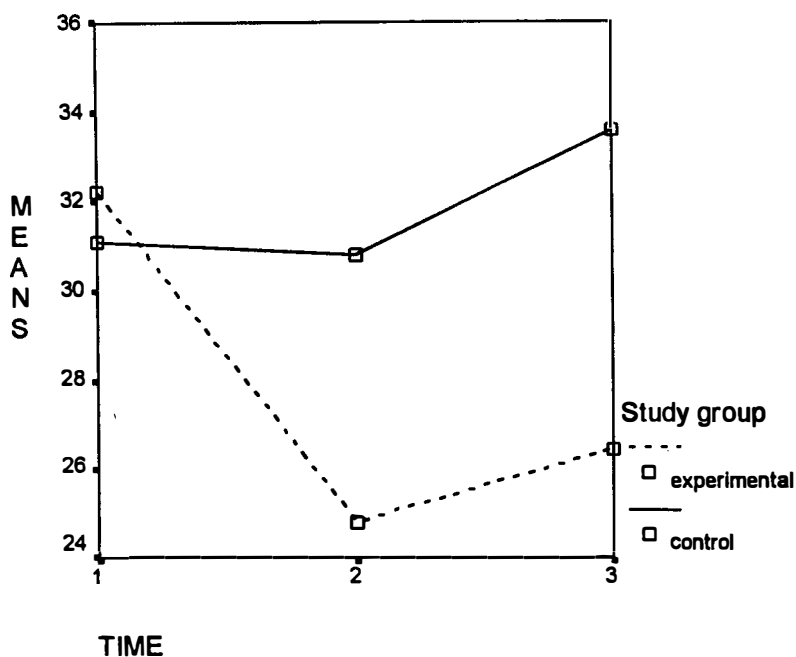


Figure 4. The estimated marginal means for Attitudes to cancer pain management scores for the control and experimental groups at Time 1, Time 2 and Time 3.

To what extent is the Daily Comfort Diary useful to family caregivers?

All of the original participants agreed to use the DCD at the commencement of the program. The DCD was used more frequently by the experimental group (45%, n=27) than the control group (26%, n=15). In the experimental group, 16 (26%) people returned the diary unused while 26 (45%) participants in the control group returned the unused diary. The remaining family caregivers in each group had family members who either deteriorated or died during the study (14 in the experimental group and 10 in the control group), or withdrew (3 in the experimental group and 9 in the control group).

Several family caregivers had an existing diary in which they had been writing appointment, medication and bowel information about their relative and didn't wish to double up. The researcher explained that the DCD was different from a usual diary in that it was specifically designed for pain management education and in all instances the family

caregivers agreed to use it. The 42 (36%) family caregivers who used the DCD expressed appreciation of the concept and valued what they described as their inclusion in the pain management team. Many family caregivers took the DCD with them to medical appointments or showed it to their home care nurse as an aid to remembering their relative's pain experience.

In summary, results from this third phase indicated that improvements in pain attitudes and specific areas of knowledge resulted in response to the intervention. Although no significant differences in the pain experiences were reported, the trend for both groups indicates that despite the fact that the patients' illnesses were progressing, the pain experience scores improved at Time 2. This may indicate that some transfer of knowledge and attitudes to pain management practices may have been realised through the home hospice service.

The original sample size proposed for Phase III of the study was 130 participants based on power calculations using data from Phase II that indicated that 65 participants in each group would allow detection of a difference of 25% with a power of 81%, with 95% confidence (Cohen, 1988). It was not possible to achieve that number of participants in the time available. All the statistical tests reported a power of less than 0.80. It is possible that the lack of significance, particularly in the area of knowledge and attitudes was due to the size of the sample in this study. Nevertheless, consistent trends showing improvement for the intervention group suggest that the PMP is a valuable resource for family caregivers.

CHAPTER 6

DISCUSSION

Introduction

This chapter will include a discussion of the findings from the study and the issues related to cancer pain management education in this palliative care family population.

Three specific findings emerged from this study. These were that

1. the PMP was effective in improving the family caregivers' knowledge of cancer pain management in the area of pain medication and addiction
2. PMP was effective in enhancing family caregivers' attitudes toward cancer pain management and
3. the PMP was found to be feasible, well received by participants and adaptable to individual family carer's learning needs.

Attitudes toward pain are complex and may be influenced by many long-standing beliefs and practices. Therefore, a shift in attitudes regarding use of opioids, comfort therapies and beliefs about the meaning of pain may be particularly difficult to attain. The fact that the simple and brief family education program was able to make a difference to family caregivers' attitudes indicates that the education was particularly effective and was able to address underpinning issues that might block or interfere with good pain management.

Improvements in knowledge about pain were notable in the areas of ability to relieve cancer pain, addiction and appropriate use of medication. A downward shift in mean scores in different causes of pain, addiction, appropriate use of opioids, and understanding

about correct and changing dose requirements also indicated improvement in knowledge in all these areas. These areas of knowledge are especially important when family members are providing care in the home and are responsible for managing complex pain and difficult and accelerating symptom distress. Therefore, the increase in knowledge in these areas is encouraging and suggests that the program was effective in key areas where pain management teaching is essential.

The shift in pain experience scores was in the predicted direction (ie, less pain experience), although the change did not achieve statistical significance. This lack of statistical significance may have been due to attrition (as more patients became ill in later stages or died during the study, limiting the numbers available for analysis). Lack of significance may also have occurred because the patients were becoming sicker, with possibly more pain and more related symptom distress (eg, nausea, shortness of breath, constipation). Therefore, a large decline in family caregivers' pain experience scores may not have been realistic given the ill health of this patient population. Results from the control group indicate that pain experience scores for these participants were similar to those of the experimental group over time. Given the declining health of the patients this seems clinically interpretable. Both groups demonstrated an improvement in pain experience scores between Times 1 and 2, with a slight increase toward baseline levels at Time 3, again, possibly reflecting illness progress. However the shift toward baseline by the experimental group was less than that of the control group. In this instance, even maintaining the pain experience scores may have been a positive achievement, rather than experiencing an increase in reported distress. These interpretations are offered cautiously, however, and warrant further study.

Results from this study have also revealed important issues that require consideration when providing family carer education related to pain management at such a stressful time. These issues are outlined below.

In relation to cancer pain education for family caregivers, eight key issues emerged in the course of implementing this study:

- ◆ timing of the education program,
- ◆ location for training,
- ◆ need for individual teaching approach,
- ◆ use of technology,
- ◆ refinements to outcome measures,
- ◆ rural and regional education issues,
- ◆ educational needs of special populations and
- ◆ education of families to manage other types of symptom distress.

Each of these will be discussed and specific recommendations to address these concerns will be provided in Chapter Seven.

Timing of Education Program

Although families in the study appear to have benefited from the education received, it appears that earlier teaching of this material has potential to better equip family caregivers for comforting their relative and may enhance the comfort care provided. Questions of when to provide education must be matched with the learner's readiness to receive the information. Although some family members interviewed in Phase I indicated that they would have liked to have received this information at the time of diagnosis, these statements were made retrospectively and must be considered cautiously. It is possible that family caregivers might not be able to receive information about pain management at a time when they are trying to integrate information about a new and difficult to accept diagnosis and treatment plan (Lewandowski & Jones, 1988; Rose, 1999). However, it is likely that families would be willing and ready to receive this type of education after the treatment program is under way and they are beyond the original crisis period of diagnosis (Grobe,

Ilstrup & Ahmann, 1981; Northouse & Peters-Golden, 1993; Pasacreta, Barg, Nuamah & McCorkle, 2000).

Location of Education Program Delivery

Decisions about where to provide this education program are closely linked to the timing of the training. At later stages of the illness trajectory, as was the case in this study, home was the preferred learning environment. Family members were hesitant to be apart from their relative and felt that the burden of travel to attend an educational session would be too great at this difficult time in the illness. However, it is possible that if the education is offered earlier in the illness trajectory, provision of education in the clinic setting might be more feasible (Pasacreta, Barg, Nuamah & McCorkle, 2000; Toseland, Blanchard & McCallion, 1995). Training in this type of setting would also be less expensive.

Need for Individual Teaching Approach

It appears that although the timing and venue for delivery of the program might vary, an individualised approach to the education would still be preferable. This would ensure that specific questions were addressed and that privacy and personal matters associated with symptom management and comfort care were sensitively addressed. Inclusion of information related to other associated symptoms might also be provided in this type of private forum and could allow the family caregiver to develop an individualised approach to patient comfort. There is a lack of literature in this area.

Benefits of Technology to Enhance Teaching

Use of the PowerPoint presentation and video were strengths of the program that facilitated consistency in teaching and helped to illustrate and reinforce the information provided. The possibility of using other types of technology to provide this type of training might also be considered. For example, provision of the information on a CD-ROM so that other family member could take the information home with them and share it with others is one suggestion. It is also possible that this type of education could be provided through public access television to allow health professionals to reach a wider audience, those in

remote and rural communities and individuals who might not be easily reached through clinic or home care settings.

Refinements to Outcome Measures

Although the use of the FPQ was a helpful and logical decision for measuring outcomes in this study, the instrument may benefit from some revisions. In particular, the sub-scale used to measure family caregivers' knowledge of pain may require additional items and further testing to determine if there are particular sub-domains of carers' knowledge that might be more fully measured. Additional items related to cancer pain relief and the pharmacokinetics of pain medication may be of benefit. Nunnally and Bernstein (1994) suggest that increasing the number of items in an instrument is a key tactic to making an instrument more reliable. Further testing of the knowledge sub-scale in an Australian context is warranted because of the complexity of the nature of knowledge and the possible impact of cultural variations (Murphy & Woods, 1996). The use of family caregiver experts rather than health professional experts to evaluate content validity may also go some way to improving the knowledge sub-scale of the FPQ. It is essential to ensure that sound, gold standard indicators for educational programs be developed to ensure that study results are comparable and carefully evaluated.

Rural and Regional Family Carer Education

Special attention to the needs of family caregivers in rural and remote areas of the country warrants consideration. Previous research has demonstrated that these family caregivers may feel particularly burdened and lack confidence about how to manage the patient's symptoms and comfort needs (Wilkes, White & O'Riordan, 2000). Families in these settings may have less access to palliative care or pain specialists and the patients in these areas may have less frequent assessment from health professionals. Therefore, the challenges of ensuring that pain management protocols and assessments of pain management needs are up-to-date are a particular issue for these families. Innovative approaches to providing pain education to these families are a priority that should be addressed. Approaches might include use of technology to enhance portability and accessibility of the program and development of "train the trainer programs" for rural community nurses, to more widely disseminate the program to families in different regions.

Educational Needs of Special Populations

The findings from this study could be particularly useful to the paediatric palliative care population, and in particular, the needs of parents of children with cancer to learn comfort measures and pain management approaches. There is an increasing awareness of the need for comprehensive care for dying children and their families (Wolfe, Holcombe, Klar, Levin, Ellenbogen and Salem-Schatz, 2000; Whiteley, Kristjanson, Degner, Yanofsky and Mueller, 1999) and a notable lack of evidence based literature to guide paediatric palliative care. Within the context of paediatric cancer, provision of palliative care is often of short duration (Wolfe et al, 2000). Therefore, access to key components of the palliative care model (ie supportive care that seeks to provide symptom control due to disease or treatment) is often required before a child even begins palliation (Chaffee, 2001). An education program for family caregivers of paediatric cancer patients could be developed and tested based on the PMP to meet the pain and symptom control needs of this under-researched group.

Other special populations that are likely require specific attention are those of non-dominant cultural groups. It is important to consider that many Australians may not have English as their first language and many family members may be unfamiliar with the dominant Anglo-Saxon culture that permeates health care delivery. Australia has large Greek, Italian, Vietnamese and Chinese communities that may benefit from this type of program. Therefore, approaches to translate and transfer this information in culturally sensitive ways are important to consider. The fundamental components of the family pain education program have been developed and would provide a valuable foundation for translation of the material into languages of families that might be most readily encountered by health professionals.

Family Caregiver Education for Management of Other Symptoms

Findings from this study provide a useful framework for developing symptom management education programs for family caregivers who are coping with other types of symptoms and medication management concerns. For example, dyspnoea has been reported to be one of the most distressing symptoms that patients experience (Tishelman, Degner & Mueller, 2000; Kristjanson, Sloan, Dudgeon, & Adaskin, 1996). Families who witness this

distress report anxiety themselves and uncertainty about how to manage this difficult symptom. Judicious use of medications, re-positioning, use of non-pharmaceutical techniques (eg, fans), may be helpful in alleviating this distress. The model developed in this study may therefore provide a sound framework for structuring family education for management of this symptom.

Another related and common symptom that causes patient distress is constipation (Campbell, Draper, Reid & Robinson, 2001; Economou, 2001; Mercadante, Casuccio & Fulfaro, 2000). Families might benefit from education and information about how to assess this problem early, how to manage the symptom with fluids, diet, exercise and medications.

A third symptom that may be addressed through family education programs would be management of fatigue of advanced cancer patients. This symptom may be particularly consuming of family caregiver energy and time and may interfere greatly with the patient's quality of life and ability to interact with loved ones. This symptom has been found to be associated with anxiety and depression and may limit the patient's ability to provide self-care. Some promising empirical findings are emerging to help patients manage this difficult symptom, using a balance of exercise and rest (Porock, Kristjanson, Tinnelly & Blight, 1999). Teaching families these approaches may help them to optimise the patient's energies and lessen the burden of this symptom on both the patient and family carers.

The findings from this study may also provide a framework for developing a family education program for the management of symptom clusters. The symptoms of pain, constipation and fatigue are common among advanced cancer patients (Coyle, Adelhardt, Foley and Portenoy, 1990; Donnelly, Walsh & Rybicki, 1995). Providing information and skills to families to manage this kind of symptom cluster may enhance their knowledge of pain and symptom control in a more integrated way.

Methodological Issues

Sampling Domain – Family Caregiver’s baseline knowledge, experience and attitudes.

The “typical” family caregiver in this study was twice as likely to be female as male, between 55 and 60 years old, have either completed secondary level education or a trade qualification, living on a low to moderate income (\$20,000 to \$50,000) and have no formal cancer pain management education. She/he is most likely to have been caring for a partner with cancer for one to 12 months or more. Approximately 61% (n=98) of patients had been living with cancer pain for one to six months.

In addition, most of the patients and families were enrolled in a 24-hour home hospice service where informal pain management education is conducted by a multi-disciplinary health care team. This may explain the better (lower) pain knowledge and experience scores reported by this study population in comparison to the family caregivers in Ferrell and colleagues’ (1995) study. In this Australian study many of the family caregivers had been enrolled with the home hospice service for four weeks or longer and had had time to have informally learned some basic pain management knowledge before recruitment. As well, the “better” experience reported by the study population may be explained by the presence of the home hospice team in terms of having had adequate time to develop and implement an effective pain management regimen thus allowing for recent past memories of pain management experience to be acceptable.

Psychometric Testing of the Instruments

The CPAQ demonstrated consistent internal consistency reliability in Phase II (Cronbach’s alpha coefficient, T1= 0.66, T2=0.74, T3= 0.84) and in Phase III (Cronbach’s alpha coefficient, T1= 0.71 for the whole group). The FPQ Experience sub-scale also demonstrated adequate internal consistency reliability in Phase II (Cronbach’s alpha coefficient, T1=0.73, T2=0.50, T3=0.80) and in Phase III (Cronbach’s alpha coefficient, T1= 0.78 for the whole group) when Item 12 was removed. All inter-item and item-to-total correlations for the CPAQ and the FPQ Experience sub-scale fell within the recommended ranges of 0.30 to 0.70 and 0.40 and 0.70 respectively.

The FPQ Knowledge sub-scale showed improved internal consistency in Phase II (Cronbach's alpha coefficient, T1=0.61, T2=0.79, T3=0.66) when Item 12 was deleted at Time 1 and Time 3. However, in Phase III at Time 1, the FPQ Knowledge sub-scale demonstrated poor internal consistency reliability (Cronbach's alpha coefficient = 0.42) despite the removal of Item 9. In Phase II, at all three time points, more than 50% of the FPQ Knowledge scores achieved item-to total correlations within the recommended range of 0.40 to 0.70. At Time 1, only 28% of inter-item correlations met the criteria (0.30 to 0.70), although these correlations improved at Time 2 (53.5%) and Time 3(42.8%).

All the instruments demonstrated adequate clarity, content validity and apparent internal consistency in Phases II and III of the study. The CPAQ and the FPQ Experience sub-scale performed adequately in all areas, while the FPQ Knowledge sub-scale performed adequately in all areas apart from its internal consistency reliability. The FPQ Knowledge sub-scale may benefit from the addition of more items related to knowledge about cancer pain management, further testing in an Australian hospice home care setting and the use of family caregiver experts to evaluate the instrument's content validity.

Theoretical Issues

Family caregiver beliefs about acceptable levels of pain and the extent to which cancer pain is manageable as the patient's disease progresses may impact on the variables being measured. In this population it is valuable to consider just what is achievable as any educational intervention is moving against the tide of the patient's advancing illness. The family caregiver pain management experience is likely to be multi-dimensional with probable relationships between pain and other symptoms that the patient may be suffering as opposed to the singular pain model in this study.

The conceptual model for this study illustrates the relationships between the family caregiver's perceptions of pain management at home and their social well-being in terms of their knowledge, attitudes and experience about the patient's pain. It also proposes a positive relationship between the implementation of a pain management education program for family caregivers on admission to a home hospice service and their social well-being. It is possible that that a stronger positive relationship may be obtained by implementing the education program at an earlier time for example, at disease recurrence, when the caregiver may have more energy to learn and the benefits may be more enduring.

Strengths of the Study

This randomised controlled trial is the first of its kind conducted in Australia in a palliative home care setting. The findings from this study confirm previous results of pain management interventions for family caregivers. The methodological design is sound and confirms the conceptual framework guiding the study. The pain management intervention developed from this research is reproducible, practical and feasible.

Limitations of the Study

The instruments used in this study are relatively immature especially in relation to their use in an Australian palliative care population. There are few instruments available for use in this population of family caregivers and these two tools reported adequate psychometric properties. In this study, despite the immaturity of the tools in relation to their use in this population, the results of the psychometric testing indicates that they performed adequately across all dimensions in which they were tested except Cronbach's alpha for the FPQ Knowledge sub-scale.

The research was also conducted in a narrow time frame close to the end of many patients' lives when there is commonly some escalation of symptoms and corresponding fatigue among family caregivers. While this was a challenging time in the participants lives in which to implement a randomised controlled trial there was a positive response from the patients and family caregivers.

CHAPTER 7

RECOMMENDATIONS AND CONCLUSIONS

Introduction

This final chapter will outline recommendations to address the issues that have been discussed in the previous chapter in relation to cancer pain education for family caregivers. The last section will provide the overall conclusion to the study.

The seven following recommendations are offered to address the issues in relation to cancer pain education for family caregivers.

Timing of Education Program

It is recommended that a study be undertaken to offer family pain management education to family members when the patient is first referred to a palliative care service or at time of disease recurrence.

Location of Education Program Delivery

It is recommended that a study to offer family pain education in a clinic based setting be undertaken to evaluate the feasibility and effectiveness of educating families in this type of setting.

Refinements to Outcome Measures

It is recommended that further psychometric studies be undertaken to refine and test outcome measures to assess the effectiveness of family pain education interventions.

Rural and Regional Family Caregiver Education

It is recommended that a study be undertaken to provide family pain management education to families in rural and remote regions of Australia using a range of innovative

approaches and appropriate technology. Public access television, satellite video link ups, Bulletin Boards and data bases eg Blackboard, where information can be down loaded are all possible approaches to use. A virtual hospice is also another approach to consider. A virtual hospice would involve a chat room where family caregivers could speak with health care professionals in a simulated hospice environment.

Educational Needs of Special Populations

It is recommended that a study to develop and test a paediatric pain education program for families of children with cancer be undertaken to evaluate the feasibility and effectiveness of educating this special group of families.

Educational Needs of Non-dominant Cultural Groups.

It is recommended that research be undertaken to translate the family pain management program into languages of various cultural groups within Australia to disseminate this knowledge and family care support more broadly.

Family Caregiver Education for Management of Other Symptoms

It is recommended that research be undertaken to develop and test family education programs to help families manage other types of symptom distress that patients may experience (eg, dyspnoea, fatigue, constipation). These education programs could target individual symptoms or clusters of commonly occurring symptoms experienced by palliative care patients.

Conclusion

In most instances family caregivers are the most constant caregiver, and yet, have usually been the least prepared for this role. Families who participated in this study were most appreciative of the opportunity to learn how to care for their ill relative. By undertaking a carefully constructed qualitative study it was possible to elicit the types of pain education families most needed to receive. Family caregivers were instrumental in instructing the researcher on important ways to teach this information. Some earlier

assumptions about how to provide this education were incorrect. For example, the original plan had been to hold group education sessions in a location close to the family caregivers' homes, but this was not acceptable to this study population. Family caregivers preferred to remain at home with their relative. By asking families specific questions about how they might best learn, the study was better able to meet their needs.

Use of technology to enhance the teaching was extremely useful, as was inclusion of the Comfort Diary. The message that families received through this study was that they are important partners in the patient's care. They received the message that their assessments of the patient's pain and comfort are important and the researcher endeavoured to empower them to provide comfort and use medications safely and confidently.

The capacity of families to learn and retain complex and detailed information at such a stressful time. Few of these family members had any formal pain management education, yet their motivation to learn and the type of the educational material provided appeared to have helped them to achieve some of their goals.

This study has identified some useful recommendations that would assist nurse researchers to build on the knowledge gained, extend the work and reach a wider population of families who might benefit from this type of teaching. This study has also demonstrated the importance of timing of pain education and the importance of accessible, convenient and individualised teaching methods.

The major conclusion from these results is that the PMP is a simple and effective intervention for addressing the needs of family caregivers to provide pain management in the home to terminally ill cancer patients. Three specific findings emerged from this study. These were:

1. The PMP was effective in improving family caregivers' attitudes toward cancer pain management.

2. The PMP was effective in enhancing the family caregivers' knowledge of cancer pain management in specific, focused areas.
3. The PMP was found to be feasible, well received by participants and adaptable to individual family caregivers' learning needs.

Although the primary motivation for conducting this work was to enhance the comfort care of the patients who rely on their family caregivers for pain relief and support; the program also appears to have relieved some of the burden and suffering of family carers. As one family member stated, "If I can comfort my father, I am comforted". The effects of this type of program therefore appear to be far-reaching and worthwhile.

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APPENDICES

Appendix A. Conceptual Definitions

Advanced Cancer Patient

An individual with cancer, who is receiving palliative care for the disease, and has an expected survival of six months or less.

Family Caregiver

The family caregiver may be the patient's spouse, partner, child, relative or friend who provides the majority of patient care in the home.

Appropriate Pain Management Interventions

Pharmacological and non-pharmacological interventions that reduce pain scores and improve patient comfort. For example, pain medication given regularly as prescribed, and/or heat therapy.

Pain Knowledge

Family caregivers' knowledge about basic pain principles such as causes of pain, pain relief using medication and comfort therapies, regular use of medication and addiction.

Experience of Pain

Family caregivers' perceptions of the patient's pain, their own distress about the patient's pain and their anticipation of the patient's future.

Attitude towards Pain

Family caregivers' concerns about analgesic medication, their expectations of pain relief, their beliefs in the effectiveness of comfort therapies and the impact of psychosocial and spiritual issues on the patient's pain.

Appendix B. Letter of ethical approval from Edith Cowan University



**EDITH COWAN
UNIVERSITY**

PERTH - WESTERN AUSTRALIA
CHURCHLANDS CAMPUS

Falcon Street, Churchlands,
Western Australia 6016
Telephone (08) 9273 8333
Facsimile (08) 9267 7066

12th July 1999

Committee for the Conduct of Ethical Research

Ms Lynn Oldham

Dear Ms Oldham

Code: 99-79
Title of Project: *Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Advanced Cancer Patients*

Thank you for your response to the matters raised by the Committee in its review of your proposal and for providing a copy of your amended disclosure statement to the caregivers who have been invited to participate.

Members have considered this additional information and I am pleased to advise that the project now complies with the provisions contained in the University's policy for the conduct of ethical research, and has been cleared for implementation.

Period of approval: From 12 July 1999 To 30 September 2001

With best wishes for success in your work.

Yours sincerely

ROD CROTHERS
Executive Officer

Attachment: Conditions of Approval

cc. Professor L. Kristjanson, Supervisor
Ms Toni Lampard, Administrative Officer, Research Services
Mrs A. Stevenson, Administrative Officer, Faculty R. & H.D.

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136 Jordanup Drive, Jordanup
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Appendix C. (Phase I) Letter to SCHCS seeking permission to conduct the study

22 July 1999

Dr Gill Lewin
Research Officer
Silver Chain Nursing Association
6 Sundercombe Street
Osborne Park WA 6017

Dear Gill

RE: Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Advanced Cancer Patients.

I am writing to request permission to access family caregivers, and their relatives with a diagnosis of advanced cancer who are currently receiving hospice care through Silver Chain for the above research project. I am primarily interested in family caregivers of advanced cancer patients who have pain. I am a Ph.D candidate at Edith Cowan University and have 15 years experience in hospice and palliative care. My principal supervisor is Professor Linda Kristjanson and Dr Sue Nikoletti and Dr Kevin Yuen are my co-supervisors.

The project has been funded through the Pharmaceutical Education Program therefore there are some funds available to cover expenses incurred by Silver Chain in the sampling process and mail out. Enclosed is a copy of the proposal which has been approved by the University Committee for the Conduct of Ethical Research.

My contacts are:

Telephone (home) [REDACTED]
(work): 9273-8164

Mobile: [REDACTED]

Email: l.oldham@cowan.edu.au

Yours sincerely

Lynn Oldham
Principal Investigator

Appendix D. Letter of ethical approval from SCHCS



Charity for the Dying

65 Grosvenor Street, Oldham Park,
65 Grosvenor Avenue, EC1A 7
Telephone: (0)2052320247
Facsimile: (0)204446136
Email: info@silverchain.org.uk

1 November 2000

Lynn O'Brien



Dear Lynn

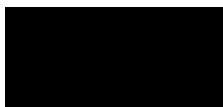
RESEARCH PROJECT TITLED "DEVELOPING AND TESTING A PAIN MANAGEMENT PROGRAM (PMP) FOR FAMILY CAREGIVERS OF ADVANCED CANCER PATIENTS"

I am writing to confirm that your application to conduct your research project using Silver Chain clients was approved in August 1999.

The project was discussed at the Professional Services Advisory Committee (a sub-committee of the Board of Management of Silver Chain) on 17 August 1999, and that whilst a number of concerns regarding methodological detail were expressed, it was approved on the basis that these concerns were addressed to my satisfaction and that the Hospice Manager (who unfortunately had not been available prior to the meeting to review the project proposal) also gave his approval for the project. My discussions later in the same week with yourself and with the Hospice Manager, then meant that this approval could be ratified.

As agreed at the commencement of the project, my department will continue to assist you at each stage of the project by selecting potential study participants and sending out a recruitment letter, and that this service will be charged for on a cost recovery basis.

Sincerely



Dr Gill Lewis
Research Manager

GL DW (G142)

Appendix E. Phase I – Letter to Family Caregivers and Patients requesting permission to release names

Date

Dear “Family caregiver name”

I am sending this letter on behalf of Lynn Oldham, an experienced palliative care nurse, and doctoral candidate and nurse researcher at the School of Nursing, Edith Cowan University. She is interested in learning how family caregivers manage pain symptoms experienced by their relative/friend in the home.

There are no known risks involved in participating in this study and it is anticipated that the discussion with Lynn may be helpful to you and your relative/friend.

I am writing to you, as the person who is most involved in caring for your relative / friend at home, to ask if you would be interested in talking with Lynn about how you manage caring for your relative/friend in the home. Your taking part would involve completing a short questionnaire (approximately 10 minutes) and participating in an interview with Lynn. She will ask you about what is important to you in caring for your relative at home. The interview will possibly take an hour of your time, and you and your commitments will guide Lynn.

If you are interested in talking with Lynn, please call her on 9273 8164, [REDACTED]

or [REDACTED].

Lynn will then provide you with further information about this study. You are not obliged to take part in this study and you may withdraw your involvement at any time.

If Lynn does not hear from you by (Date), she will assume that you do not wish to for any further information about the study.

Should you decide to take part, all information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by whether or not you decide to take part in this study.

Thank you for considering this request. If you have any questions about the research study Lynn Oldham can be reached on 9273 8164, [REDACTED]. Lynn’s supervisor Professor Linda Kristjanson can be reached at the University on 9273-8617.

Yours sincerely,
Gill Lewin
Research Director, Silver Chain Hospice Care Service

Appendix F. Phase I – Telephone Script

Hello Mrs/Mr Ms.....

Thank you very much for calling me.

How are you (listen to response as may be a difficult day)

(If it is not a good time to call I will tactfully end the conversation and offer to telephone at another time).

I am interested in learning how people in your situation (being a caregiver) manage caring for your husband/wife/friend/child at home.

“Would you be interested in meeting with me this week? Or is there another time that would be more suitable for you? We would need about an hour of your time and it would involve completing a short questionnaire and answering some questions about how you manage your relative’s pain. I would like to have a look at your relative’s medical records that are kept in your home, too, if your relative will give me permission. I am happy to meet you wherever you wish.”

If caregiver agrees on a time and place, an appointment will be made and the researcher will give the caregiver her telephone number in case any unforeseen circumstances arise.

“Thank you so much for agreeing to see me, I look forward to meeting with you and your husband/wife/ friend/child on day/date/time. I will give you my name and telephone number (Lynn Oldham on 9273 8164 (work) or [REDACTED] (home), and if you have any queries, please contact me”.

Appendix G. Phase I – Informed consent for the Family Caregiver

Study Title: Developing and Testing a Pain Management Program for Family Caregivers of Advanced Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Increasingly, cancer patients are receiving care in the community supported by families and home hospice services. Many family caregivers have little or no preparation for providing this type of care in the home. Pain management is consistently identified by family caregivers as their primary concern related to care and support of a loved one with advanced cancer. This study will provide information that will identify the needs of family caregivers in the home and will assist family caregivers to provide comfort measures for their ill relative.

I understand that there are no known risks in this study. I realise that the study will take approximately a hour of my time and will involve filling out a questionnaire about personal details such as age, occupation etc and answering some questions. I realise that the interview will be tape recorded.

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the care of my relative/friend will not be affected.

If I have any questions about the study or about being a participant, I know that I can call Lynn. I may reach her on [REDACTED]

I agree to participate in this study, and I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date

Participant's Signature

Investigator's Signature

Appendix H. Phase I – Permission to access Patient’s medical records in the home

Study Title: Developing and Testing a Pain Management Program for Family Caregivers of Advanced Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Lynn is a nurse who has worked in hospice and palliative care for 15 years. She is interested in learning how family caregivers manage caring for their relative/friend in the home. She believes that this study will provide information that will identify the needs of family caregivers in the home and will assist family caregivers to provide comfort measures for their ill relative. I understand that Lynn wishes to **look at, and retrieve information from my medical records kept in my home.**

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the quality of my care will not be affected.

If I have any questions about the study, I know that I can call Lynn. I may reach her on [REDACTED] (mobile), 9273 8164 (work) or [REDACTED] (home).

I agree to participate in this study, and to allow Lynn to retrieve information from my medical records kept here in my home. I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date

Participant’s Signature

Witness’s Signature

APPENDIX I. Phase I - Information for Health Professionals

Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Advanced Cancer Patients

Research investigating how family caregivers manages their ill relative or friend's pain in the home will commence on 20 September 1999. Lynn Oldham is undertaking this study. Lynn is a Registered Nurse and a doctoral student at Edith Cowan University. Lynn's Principal Supervisor is Professor Linda Kristjanson and other supervisors are Dr Kevin Yuen and Dr Sue Nikoletti.

Data collection will be undertaken in the patient's and family care giver's home. The primary family caregiver will be asked to provide socio-demographic information about herself/himself and the relative's/friends medical records retained in the home will be used to access socio-demographic data. The family caregiver will also be asked to participate in a taped interview with Lynn, lasting approximately one hour, where questions about managing the patient's pain will be explored.

The data collection period for this phase of the study will be from 20 September 1999 until the end October, 1999.

This is a three- phase project. Phase I will involve development of an education program for family caregivers using relevant literature and qualitative methods to elicit information about the components of a pain education program that would be helpful to families. Phase II will involve a pilot test of the education program and determine the extent to which outcome measures are sensitive and psychometrically sound. Phase III will involve a randomised clinical trial to test the intervention with a stratified random sample of family caregivers.

If you have any questions regarding this project you are invited to contact Lynn Oldham at (work) 9273 8164, (home) [REDACTED] or mobile [REDACTED].

APPENDIX J. Phase I - Interview Guide

I am interested in understanding what might be helpful to you in providing comfort for your relative. What is important to you in managing your relative's pain in the home?

1. Are there things you would like to learn about managing your relative's pain?
2. What do you know about managing cancer pain?
3. What do you think you need to know?
4. When would be the best time to learn more about pain management?
(At diagnosis / before discharge from hospital / in the home setting / on-going ?)
5. How would you like to learn about pain management?
(Information brochures / talking with nurses and doctors / brief, regular education sessions with other family caregivers outside the home/ other?)
6. What do you believe is important about relieving your relative's cancer pain?
(Why?)
7. What do you do to make your relative comfortable if he/she has pain?
(Give medicine/ comfort therapies/ re-posture/ pray /distract/ other)
8. What, do you believe, makes managing your relative's pain difficult?
9. What is the impact on you and your family when your relative is in pain?
(Feel inadequate/ out of control/ helpless/sad/ frustrated/ overwhelmed/ angry/ exhausted/ guilty/ despairing/ conflict)
10. Could you describe your relative's pain in the last two weeks?
11. What do you know about the pain medicine that your relative is taking?
(Strong/ addictive/ dangerous/ efficacious/ needs to be given regularly/ other)
12. What kind of help do the health care professionals give you in managing your relative's pain?
(Practical support/ emotional support/ other)
13. What are the benefits/burdens of managing your relatives pain at home?
15. Is there anything else you would like to talk about that we haven't discussed?

Thank you very much.

APPENDIX K. Phases I, II and III - Caregiver Demographic Form

SITE _____ ID _____

1. Gender male female
income(\$)

2. Primary caregiver yes no

3. Age (years) _____

4. Relationship to patient partner/spouse
 daughter
 son
 mother
 father
 friend
 other _____

5. Country of birth _____

6. Cultural background Australian
 British Isles
 European
 Aboriginal/ Torres Strait
 Asian
 Other (please specify)

7. Usual language spoken in home _____

8. Employment status not employed
 retired
 employed full time
 employed part time

9. Other commitments
Pre/School children (No.) _____
School/ Age children (No.) _____
Other. _____

10. Annual family

- < 10,000
- 10,000-20,000
- 21,000-30,000
- 31,000-40,000
- 41,000-50,000
- 51,000-60,000
- 61,000-70,000
- > 70,000

11. Postcode _____

12. Previous pain management education

yes no

If yes, please describe

13. Level of education

- Primary
- Secondary
- Trade
- University
- Other _____

APPENDIX L. Phases I, II and III - Patient Demographic Form

SITE _____ ID _____

1. Gender male female

2. Age (years) _____

8. Length of time since cancer diagnosis (months) _____

9. Length of time since onset of pain (months) _____

10. Primary pain site _____

3. Marital status married/defacto
 never married
 divorced/separated
 widowed

11. Primary pain type
 bone visceral neuropathic

12. Total number of pain types _____

4. Country of birth _____

5. Cultural background Australian
 British Isles
 European
 Asian
 Aboriginal/ Torres St
 Other

13. Current medications Delivery route
 opioid oral s/c IV IT PC
 other analgesics _____

6. Primary cancer diagnosis _____

14. Other current pain management modalities
 Physiotherapy
 Radiotherapy
 Surgery

7. Secondary involvement
 bone
 liver
 brain
 lung
 other _____

15. Current comfort therapies
 Aromatherapy
 Acupuncture
 Massage
 Psychotherapy
 other _____

APPENDIX M. Phases II and III - Teaching Plan for the PMP

Pain Management Program for Family Caregivers of Advanced Cancer Patients

Teaching Plan

- Structure:** Four sequenced education sessions using didactic/ interactive lectures, case studies, role-playing and video.
- Location:** The family home.
- Content:**
- Session 1: Pain types and assessment (Daily comfort diary)
 - Session 2: Pain management using medication (opioids and analgesics)
 - Session 3: Pain management using comfort therapies and teaching video
 - Session 4: Guidelines and support for family caregivers

SESSION 1: PAIN TYPES AND ASSESSMENT

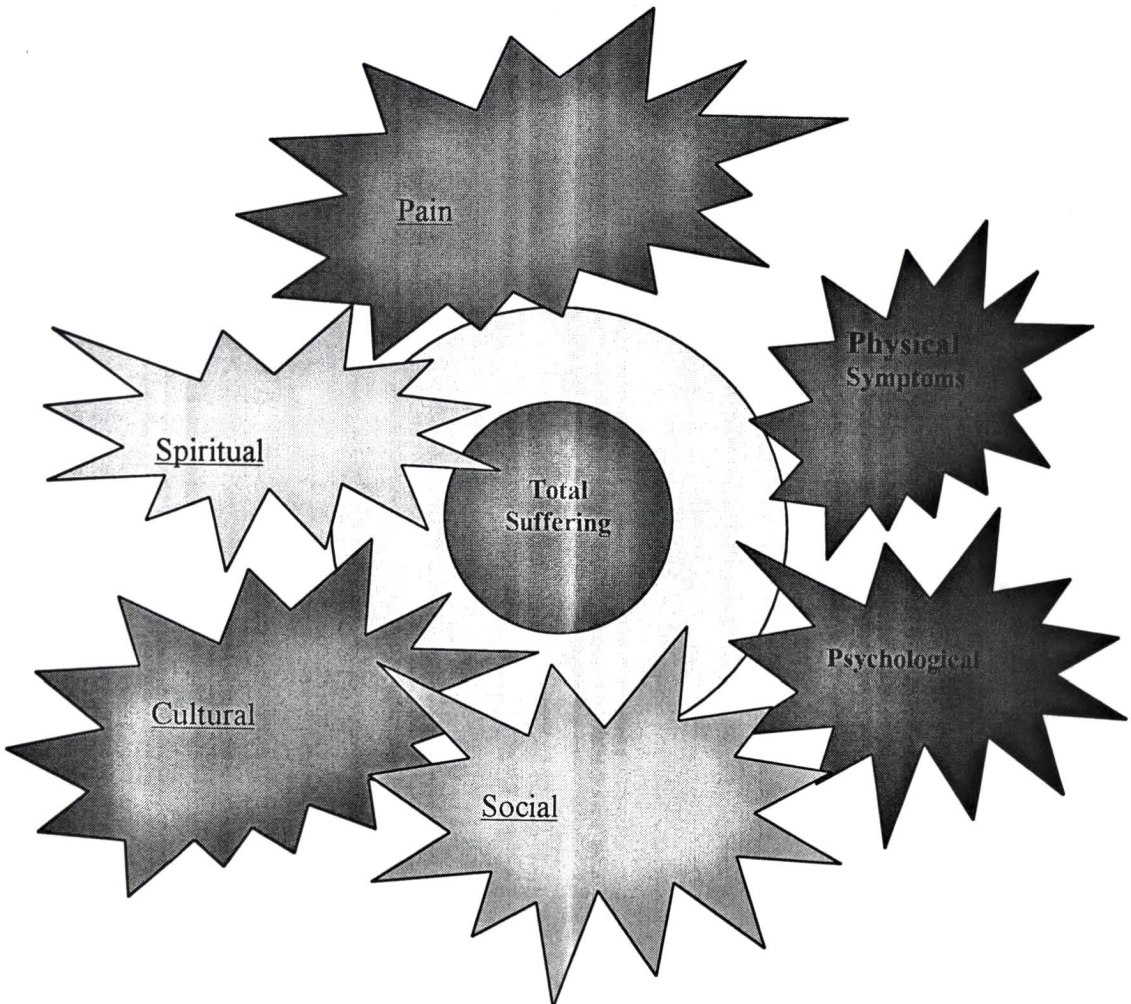
Overview of PMP for Family Caregivers

Understanding and Assessing Pain

Definitions: "Pain is what the patient/person says it is"
Discuss the concept of pain being not only due to physical problems but also due to emotional aspects such as anxiety, depression or fear. Consider the presence of spiritual and cultural pain.

(OVERHEAD)

Understanding Pain adapted from Woodruff, 1993.



Most cancer pain can be controlled and it may take some time to achieve good pain control. By understanding cancer pain and knowing how medication works on different pain types, you can help your family member to be comfortable.

Some of the problems that family caregivers have with managing cancer pain include not knowing what type of pain is causing the problem, not knowing how to assess the pain and not knowing which medication will be effective in relieving the pain.

This first session will look at pain types. It will show you how you can find out what type of pain your family member has and you can measure their pain

(OVERHEAD 2)

Table M1.

Pain types: mechanistic classification

	Pain 1	Pain 2	Pain 3	Pain 4
Where	Skin or just beneath skin Or Inside mouth, sinuses, urethra, bladder	Bones, joints, muscles Or Outside lining around liver, lungs etc	Inside hollow or solid body organs	Where nerves are squashed
Examples	Ulcers, gum ulcers	Bone disease, inflamed liver or swelling in the area	Deep in the abdomen or chest, kidneys	Spinal cord, side of chest
Feels like	Stinging, burning	Dull, aching	Dull, deep	Unusual sensations like pins and needles, tingling, burning, pain in numb area Shooting pain
Hurts more if you move	Not usually	Yes, patient usually likes to remain still	Movement may improve pain	Stretching may cause pain to start up

(Adapted from SCHCS – Guidelines to Pain and Symptom Control, March 1996)

(Perhaps here we could do a little role playing and miming the different pain groups, we could discuss who may have had some of these type of pains)

Acute and Chronic Pain

(OVERHEAD 3)

It is helpful to understand and recognise the difference between acute pain (the pain you would instantly experience if you dropped a brick on your foot) and chronic pain (such as the long-term pain of arthritis). People will behave differently depending on whether the pain is acute or chronic.

Usually people will respond to acute and chronic pain in some or all of these ways.

Table M2.

Pain responses

Acute Pain	Chronic Pain
Be obviously in pain	Pain may not be obvious
Tell you about the recent pain	May not tell you about the pain
Cry or groan	May just lie still, quiet – even sleep
Rub or hold the painful area	May focus on other things like TV or radio
Frown or look distressed	May have normal or blank facial expression
If in bed or chair, become increasingly restless	May appear or say he or she feels depressed

Adapted from McCaffrey and Pasero, 1999)

(Again, a little cameo pointing out the difference between acute and chronic pain)

How to Assess and Rate Pain

(OVERHEAD 4)

Ask your family member:

- ❖ Where is the pain?
- ❖ What does the pain feel like? (Eg. Burning, dull, aching, stinging etc)
- ❖ Is it the worst pain you have had (on a scale of 0 – 10, where 0 = no pain and 10 = worst pain) can you tell where this pain would fit?
- ❖ What makes the pain start? (Movement, waking up in the morning, breathing in)
- ❖ Is the pain always there? Or does it come and go?
- ❖ Have you got more than one pain? If yes, start again at (1) and ask through till (5).

If your family member is unable to describe the pain to you, look for changes in his/her usual behaviour, for example, distressed facial expressions, sensitivity to movement and /or restlessness. Table 2 of acute and chronic pain responses may be helpful in your assessment

Now, what to do with all this information... (give prescribed medication or comfort therapy) then use the Daily Comfort Diary to write down what you have done to manage your relative or friend's pain.

The Daily Comfort Diary

(OVERHEADS 5 AND 6)

The daily comfort diary has been developed to help you write down the pain information you have learned about your family member. It will help you see clearly where the pain is, how severe it is, what you did to make it better and whether the pain treatment is working. It will make it easier for you and your family member to describe your family member's pain to the doctors and nurses.

(Instructions on how to write in the diary and we will do one at the session)

Summary and end of Session 1

We will conclude the session with questions and discussion from the group.

SESSION 2 - MANAGING PAIN AND UNDERSTANDING MEDICATIONS

A brief review of last session, any concerns or issues.

In this session we will look at the medications that are commonly used to manage cancer pain and pain management principles. We will also look at some of the obstacles to achieving good pain management.

Medications commonly used to manage cancer pain

These medications are all called analgesics. They can be divided into opioid and non-opioid analgesics. Co-analgesics are another large group of medications which are not normally used for pain management, but which can contribute greatly to cancer pain management.

It is important to discuss your family member's medications with the doctor and nurse who are helping you care for your family member.

Opioid Analgesics

Opioids are drugs that are extracted from poppies and have been used for pain management for a very long time.

Morphine is the most commonly used drug for the management of cancer pain. **Codeine** is a similar type of poppy extract. **Oxycodone**, **pethidine**, **fentanyl**, **methadone** and **dextromoramide** (**palfium**) are semi-synthetic or synthetic opioids, which have the same effects as **morphine**. **Panadeine forte** is a mixture of codeine and **panadol** is also often used for **cancer pain management**. **Morphine** and pain management principles will be discussed further on in this session.

Non opioid analgesics

Paracetamol /panadol/panamax is the most commonly used non-opioid analgesic in advanced cancer pain management. It is usually taken 4 – 6 hourly and when necessary (PRN). Discuss the meaning of PRN

Co-analgesics

These include corticosteroids, non-steroidal anti inflammatories (NSAIDS), anticonvulsants, antidepressants, muscle relaxants and local anaesthetics. Co-analgesics are very useful medications for pain that is not relieved by Morphine, The following table shows some of the different groups of co-analgesic medication, their names and the way they work in cancer pain management.

Table M3.

Co-analgesics and the way they work

Medication	Name	Effects
Corticosteroids	Prednisolone (Prednisone) Dexamethasone	Reduces local heat, swelling, tenderness, compression of nerves May cause increase in appetite
Non steroidal anti inflammatories (NSAID)	Naproxen (Naprosyn) Indomethacin (Indocid) Ketoprofen (Orudis)	Lowers a raised temperature Reduces pain Modifies inflammation
Anticonvulsants	Sodium valproate (Epilim) Clonazepam (Rivotril) Carbamazepine (Tegretol) Phenytoin (Dilantin)	Blocks the “Shooting pain ” nerve message caused by to nerve compression
Antidepressants	Amitriptyline (Tryptanol) Doxepin (Dothep) Desipramine?	Blocks chemical message of pain caused by nerve compression or invasion
Muscle relaxants	Diazepam (Valium) Clonazepam (Rivotril)	Pain caused by muscle spasm Musculo-skeletal pain

Ways of taking analgesics for pain management

Most medication can be taken by mouth (orally). Oral medication is easy to take and usually costs less than other kinds of medicine. Most oral medication is in the form of tablets and sometimes liquids that you drink. If your family member finds it hard to swallow or cannot take tablets or liquids for some reason, there are other ways to get these medications.

These include:

Rectal suppositories - medicine that dissolves in the rectum and is absorbed by the body.

Patches that contain medicine and are placed on the skin. The medicine is then absorbed through the skin.

Injections – there are many ways of injecting pain medicine directly into the body. The most frequently used way for cancer pain, is by subcutaneous injection, often called a ‘butterfly’. The medicine is injected just under the skin using a small needle. The ‘butterfly’ can be attached to a syringe driver to give constant medicine.

More about Morphine

Morphine is the drug of choice for cancer pain. It is safe and effective in all stages of cancer pain management.

How Morphine Works

Describe how Morphine sits on receptors and blocks the pain message.

Discuss the need to keep the medicine at a constant in the blood stream to avoid breakthrough pain.

Taking Morphine

Morphine is usually taken by mouth as a mixture or as a tablet or capsule. For people who are unable to swallow, are vomiting, or unable tolerate morphine by mouth, it is possible to take morphine by injection. Table 4 shows the different ways of taking Morphine. (Overhead)

Taking Morphine regularly

It is important to take Morphine regularly for good pain management. If Morphine is ordered 4 hourly, give it 4 hourly. If it is ordered 12 hourly, give it 12 hourly. Morphine works if given regularly.

(Maintaining a constant level of morphine)

When people first start taking Morphine it may take a little time to get the right dose for the best pain management. (Adjustment time)

Morphine is available in Western Australia as a mixture (Ordine), slow release tablet (MS Contin), capsule (Kapanol) and an injectable solution (Morphine sulphate).

“Breakthrough” or “rescue” doses

Doses needed for intermittent pain or breakthrough pain – pain that occurs between regular dose times

Tasting Morphine mixture

Many people choose to mix Morphine mixture with a small or large amount of lemonade or orange juice. They do this because Morphine Mixture can taste bitter to some people.

Obstacles to achieving pain control

Some people have concerns about taking or giving Morphine for cancer pain management. Here are some common concerns expressed by some patients and family caregivers:

- ❖ **Concern:** You or your family member is afraid of addiction.
- ❖
- ❖ **Fact:** In fact, people who take Morphine for pain do not become addicted.

- ❖ **Concern:** You or your family member wishes to ‘save’ the Morphine and give it when the pain becomes severe.
- ❖ **Fact:** Taking the Morphine now will not make any difference to how well it will work in the future or when the pain gets worse. If pain is controlled now, you and your family member will be less worried and will know that the Morphine does work.

- ❖ **Concern:** Your family member doesn’t want to take the Morphine now because taking Morphine means he or she is dying. Only people who are close to dying take Morphine.
- ❖
- ❖ **Fact:** Morphine is not only used when people are dying. It is an extremely effective medication for many types of cancer pain at many stages of the illness.
- ❖
- ❖ **Concern:** People are unable to function “normally” if they are on regular Morphine
- ❖
- ❖ **Fact:** Many people are able to be alert and function normally when taking regular Morphine
- ❖
- ❖ **Concern:** Taking Morphine is dangerous for a person’s breathing.
- ❖
- ❖ **Fact:** When Morphine is taken for cancer pain at the correct dose there is no problem with breathing.

What (if any) problems or obstacles have you experienced with Morphine?

(Encourage discussion)

Some side effects of Morphine

Morphine has some side effects, but not everybody will get them. Most side effects happen when you begin to take the medicine and most will gradually go away.

Constipation

The most common side effect of Morphine is constipation (not being able to open your bowels) and it is important to discuss this with your doctor and nurse. Doctors usually prescribe a laxative or stool softener for people who take Morphine regularly.

Nausea and vomiting

If this happens, it is important to tell your doctor and nurse. It may only last for a day or two after starting the Morphine. The doctor can give you some medication to stop the nausea and vomiting.

Sleepiness

When people first start taking Morphine, they can feel very drowsy and sleep more than usual. This may last for a few days. Sometimes this happens because the person is finally getting his/her pain relieved and can sleep more easily.

It is important to discuss your family member's medications with the doctor and nurse who are helping you care for your family member.

Pain Management Questions

Ask your doctor and nurse what the pain management plan is for your family member. Ask them to explain:

- ❖ Which medication is for pain?
- ❖ If the medication dose doesn't work, can more "breakthrough" medication be given?
- ❖ What will happen if a dose is missed?
- ❖ Who can I ring in the night if pain increases?

Summary and end of Session 2.

SESSION 3- MANAGING PAIN USING COMFORT /COMPLEMENTARY THERAPIES

A brief review of the last two sessions including any concerns or issues that have emerged since the program started.

In this session we will look at other ways to manage cancer pain. These ways are often called comfort therapies and can be easily done at home. We will also look at ways of moving a person with cancer to avoid causing pain and discomfort and ways of relieving pain simply by re-positioning the person.

Comfort Therapies

Comfort therapies are often helpful in relieving pain. These treatments can be used along with your family member's usual medications.

It is important to discuss the comfort therapies you wish to use with the doctor and nurse who are helping you care for your family member

Hot and Cold

Heat – most people have used heat to relieve pain. Warm baths, showers, heat pads and hot water bottles relax muscles and give a feeling of comfort. Heat pads and hot water bottles should be covered with a soft cloth to prevent burning of the skin and electric heat pads should not be turned up too high for the same reason.

Cold – sometimes relieves pain better than heat. Cold packs also should be wrapped to protect the skin and prevent an unacceptable feeling of cold. Cold packs are good for inflammation and swelling.

Where to put the heat or cold

Heat or cold is usually put on the place where the pain is, but if you can't get to that spot or it is too tender to touch then heat or cold can be put

Around the pain place

- ❖ Between the pain and the brain
- ❖ Beyond the pain, which means the pain is between the brain and the heat or cold
- ❖ Opposite side of the body from the pain (McCaffrey and Pasero, 1999)

Use whichever is comfortable and works for your family member.

Hot/cold gel packs can be found at most pharmacies and large supermarkets.
Cost...

Massage

Gentle massage can be very helpful. Generally, massage movements are described as 'flowing'. It is practiced with one or two hands. Remove all rings, watches and bracelets, any thing that may scratch the skin that you are massaging. Apply some sweet almond oil or silicone cream to your hands, make sure your family member is comfortable and that you are too. With your hands, make a smooth flowing movement towards the heart and a lighter gentler return at the same pace. Keep the movements slow and rhythmical. For example, if you are massaging the feet, make a smooth flowing movement from the toes to the ankle and back to the toes.

(Offer to demonstrate on someone's feet or arm)

Distraction

Distraction simply means focusing on something other than the pain sensation. Distraction doesn't make the pain go away, but it can make it seem more bearable.

It is important to remember that when distraction does make the pain seem less fierce, it doesn't mean that the person didn't really have bad pain, it means that the distraction has worked and made the person's pain more bearable.

Distraction is helpful because not only can it make the pain seem less, it can give your family member a feeling of control over the pain.

Types of distraction can include:

- ❖ Practicing slow deep breathing
- ❖ Listening to music, TV
- ❖ Listening to a relaxation tape
- ❖ Using laughter. If you feel it's appropriate for your family member, ask if it would help to watch a favourite funny video, read a joke book or just share some funny family stories.

For further information about massage, distraction and other comfort therapies contact the following:

Cancer Foundation Helpline
Cancer Support Association

13 11 20
08 93843544

Movement and Cancer Pain

Helping people with advanced cancer move about can sometimes be painful for both the person who needs to move and the family caregiver that is helping. The following video will show you some useful ways to move a person in the following situations.

Moving a person in bed – re-positioning
Moving a person up the bed
Moving from bed to chair
Walking a person who is unsteady
Managing a fall at home

We will also discuss practical advice about giving medicine before movement begins, for example giving medicine a half-hour before attempting the morning shower.

Summary, questions and end of Session 3

SESSION 4 - SUSTENANCE AND SUPPORT FOR FAMILY CAREGIVERS

In the first three sessions we have looked at pain assessment and management, medications and their use in pain management, some of the complementary therapies used in pain management and the video on how to best move people with advanced cancer to avoid pain. This last session will look at ways to help you, the family caregiver to decide when you need to call for help with pain management. We will also consider practical ways to help you in your role as a family caregiver.

Deciding when to call for help with pain management

- ❖ Pain is increasing despite usual medication dose
- ❖ You have needed more than three 'breakthrough' doses in the last 12 hours
- ❖ A new type of pain is present, either in the same place or a new place
- ❖ Pain is consistently rated as 5 or higher in the last 12 hours
- ❖ Although not complaining of pain, your family member is very restless

Call your nurse or doctor

When you call, make sure you have your family members Daily Comfort Diary with you and that you know what medication has been taken. The nurse will need to know about the pain. It will help if you can tell the nurse:

- ❖ where the pain is
- ❖ what type of pain it is eg it is "burning or throbbing or stinging"
- ❖ how bad it is eg "the pain fits on the scale at 9, and is getting worse"
- ❖ when the pain started

- ❖ what made it start, if you know, eg “ he had a coughing fit or she tried to stand up”
- ❖ whether the pain is now always there or not
- ❖ whether it is a new pain
- ❖ whether the pain is stopping your family member from sleeping

It will also help if you can tell the nurse about your family member’s medications:

- ❖ what has been given for pain up to now, eg which pain medication and how much
- ❖ how many ‘breakthrough’ doses have been given, if any, since the pain began
- ❖ what comfort therapies you may have tried and how helpful they were

If your family member’s pain is being controlled using a ‘butterfly’ needle attached to a syringe driver (Graseby pump) check that

- ❖ the syringe is not empty
- ❖ the tubing is not kinked
- ❖ the plunger is firmly attached
- ❖ the battery is not flat – light flashing
- ❖ that the place where the needle goes into the skin is not red and swollen

Call your nurse if you have any of these problems

The family caregiver.

People who take on the role of caring for a loved family member with advanced cancer are rarely prepared. They are very committed and determined to do as much as possible and as well as possible, and they usually do. In this final session of the program, it may be helpful to look at some of the strategies that you can use to help you in your role, to prevent your own fatigue and to make sure that you stay as well as possible so that you can successfully care.

- ❖ Ask for help from family, friends and health care professionals
- ❖ Consider a cancer support groups
- ❖ Find out about volunteer services and access them
- ❖ Exercise if you find it helps
- ❖ Make sure you do rest
- ❖ Consider comfort therapies for yourself
- ❖ Avoid neglecting your diet – nourish yourself
- ❖ Organise visitors so you are not overwhelmed by numbers

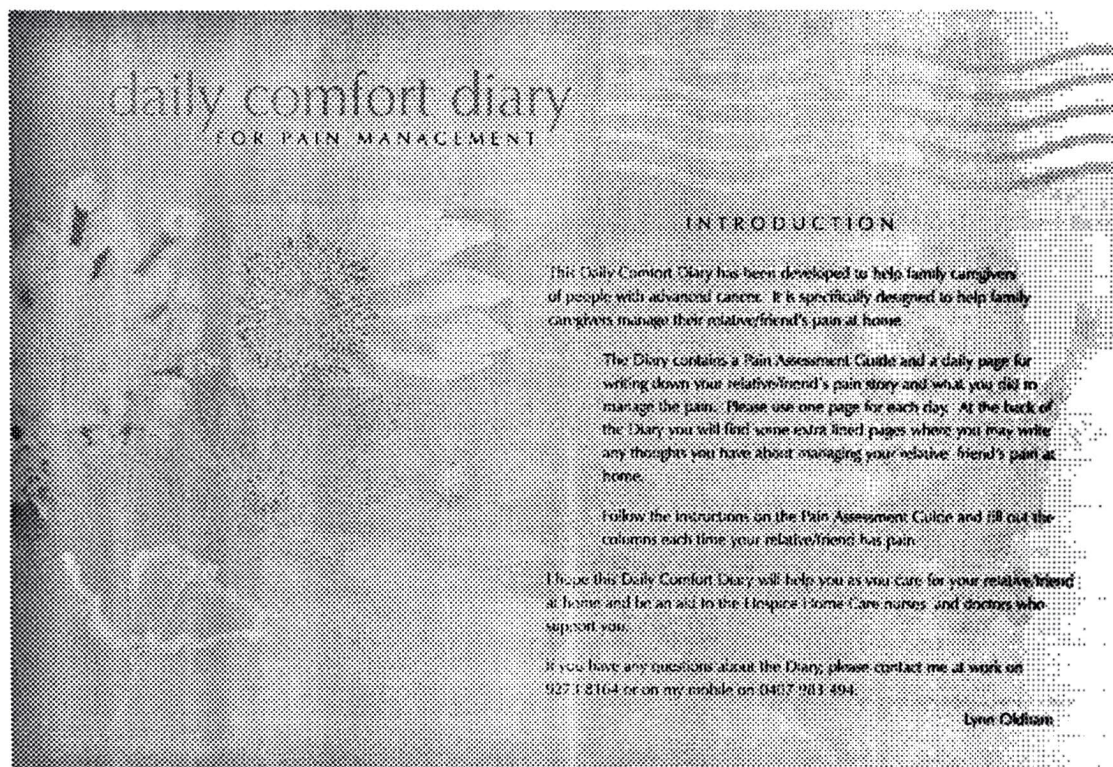
(Some family caregivers leave a note on their front door, saying ‘thanks for calling, we are resting, but please leave a note and I will phone you soon’).

In this session, we will discuss strategies that people have used and if they wish, we will help each member of the group to plan his or her own strategy.

Summary and end of session 4.

Appendix N. Phase II and III - Daily Comfort Diary

Page 1



daily comfort diary
FOR PAIN MANAGEMENT

INTRODUCTION

This Daily Comfort Diary has been developed to help family caregivers of people with advanced cancer. It is specifically designed to help family caregivers manage their relative/friend's pain at home.

The Diary contains a Pain Assessment Guide and a daily page for writing down your relative/friend's pain story and what you did to manage the pain. Please use one page for each day. At the back of the Diary you will find some extra lined pages where you may write any thoughts you have about managing your relative/friend's pain at home.

Follow the instructions on the Pain Assessment Guide and fill out the columns each time your relative/friend has pain.

Please this Daily Comfort Diary will help you as you care for your relative/friend at home and be an aid to the Hospice Home Care nurses and doctors who support you.

If you have any questions about the Diary, please contact me at work on 0273 8164 or on my mobile on 0437 983 494.

Lynn Okham

pain assessment guide

FOR USE WITH THE DAILY COMFORT DIARY

Use this guide to help you fill out each column when your relative/friend has pain.

"TIME" Write down the time.

"PAIN LOCATION"

Use these figures to locate and record where your relative/friend's pain is:

- Each body area has a number. Write the appropriate body area number in your Daily Comfort Diary.
- If pain is experienced in more than one area, write all the body area numbers that show pain in your Daily Comfort Diary.

For example, if pain is felt in the right forearm, you will write "25" in the column. For pain in the left thigh, you will write "18" in the column. Please use a separate line for each pain location.

"TYPE OF PAIN"

Some of the words you might use to describe pain are: stinging, burning, dull, aching, deep, throbbing, shooting, tingling, numb, like pins & needles, hurts at the lightest touch.

Use whichever word your relative/friend says best describes his/her pain, which may be a word not listed above.

"HOW SEVERE IS YOUR RELATIVE/FRIEND'S PAIN?"

In this column, write down the number between 0 and 10 which best measures your relative/friend's pain.

Example: Your could say to your relative/friend "if no pain = 0, and the worst pain you have ever had = 10, what number would you use to measure your pain now?"

"WHAT DID YOU DO TO EASE PAIN?"

Just describe here whatever you did to relieve the pain. Some of the things you may do are:

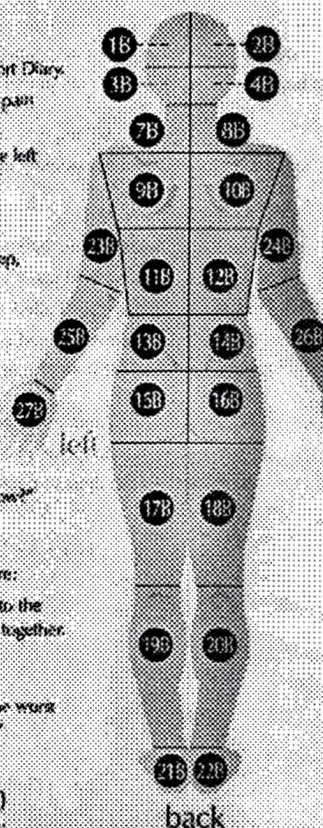
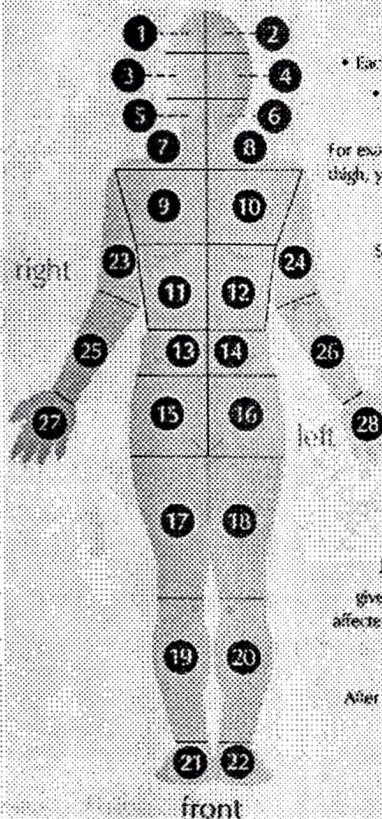
give regular medication, give breakthrough medication, change position, apply hot/cold pack to the affected area, use distraction (TV, music, visitors, deep breathing), massage the painful area, pray together.

"HOW SEVERE IS THE PAIN AFTER HALF AN HOUR?"

After half an hour, ask your friend/relative the same question as before: "if no pain = 0, and the worst pain you have ever had = 10, what number would you use to measure your pain now?"

Write this number in the column provided.

0 1 2 3 4 5 6 7 8 9 10
no pain worst pain



Appendix N (cont)

Page 3

daily comfort diary
FOR THE FAMILY CAREGIVER

0 1 2 3 4 5 6 7 8 9
no pain

today's date each day covers the full 24 hour period, please record all incidents of pain experienced in that time using the guide provided.

TIME	TYPE OF PAIN	WHAT DID YOU DO TO EASE THE PAIN?

Appendix O. Phase II and III - Video for Family Caregivers



Appendix P. Phase II - Letter to Family Caregivers and Patients requesting permission to release names

Date

Dear "Family caregiver name"

I am sending this letter on behalf of Lynn Oldham, an experienced palliative care nurse, and doctoral candidate and nurse researcher at the School of Nursing, Edith Cowan University. She is interested in learning how family caregivers manage pain for their relative/friend in the home.

I am writing to you, as the person who is most involved in caring for your relative / friend at home, to ask if you would be interested in talking with Lynn about how you manage caring for your relative/friend in the home. Your taking part would involve completing a short questionnaire (approximately 10 minutes) and participating in a pain education program with Lynn. This will probably involve approximately four hours in total, and you will be able to learn about ways to provide comfort care for your ill relative/friend. The education sessions will be held at (location) and if you need assistance to get there or a sitter at home while you are absent, Lynn will help you arrange a volunteer. There are no known risks involved in participating in this study and it is anticipated that the program will be helpful to you and your relative/friend.

If you are interested in talking with Lynn, please call her on 9273 8164, [REDACTED]

[REDACTED]

Lynn will then provide you with further information about this study. You are not obliged to take part in this study and you may withdraw your involvement at any time.

Should you decide to take part, all information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by whether or not you decide to take part in this study.

If Lynn does not hear from you by (Date) she will assume that you are not interested in any further information about the study.

Thank you for considering this request. If you have any questions about the research study Lynn Oldham can be reached on 9273 8164, [REDACTED]. If you would like to discuss any aspects of the study, Lynn's supervisor, Professor Linda Kristjanson can be reached at the University on 9273-8617.

Yours sincerely,

Dr Gill Lewin
Research Director, Silver Chain Hospice Care Service

Appendix Q. Phase II - Telephone Script

Hello Mrs/Mr Ms.....

How are you (listen to response as may be a difficult day)

(If it is not a good time to call I will tactfully end the conversation and offer to telephone at another time).

Thank you for calling. I am interested in helping people in your situation (being a caregiver) manage caring for your husband/wife/friend/child at home and I believe that you are interested in talking with me?"

"Would you be interested in meeting with me this week? Or is there another time that would be more suitable for you? I would like to discuss the study with you and your relative/friend and collect some information from you. We would need about half an hour of your time and it would involve completing a short questionnaire and then I will describe the pain education program with you particularly in terms of the "when" and "where". I would like to have a look at your relative's medical records that are kept in your home, too, if your relative will give me permission. I am happy to meet you wherever you wish."

If caregiver agrees on a time and place, an appointment will be made and the researcher will give the caregiver her telephone number in case any unforeseen circumstances arise.

"Thank you so much for agreeing to see me, I look forward to meeting with you and your husband/wife/ friend/child on day/date/time. I will give you my name and telephone number, Lynn Oldham on [REDACTED] (home) 9273 8164 (work) and [REDACTED] (mobile), and if you have any queries, please contact me".

Appendix R. Phase II - Informed consent for the Family Caregiver

Study Title: Developing and Testing a Pain Management Program for Family Caregivers of Advanced Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Pain management is consistently identified by family caregivers as their primary concern related to care and support of a loved one with advanced cancer. Lynn is interested in learning how family caregivers manage caring for their relative/friend in the home. She believes that this study will assist family caregivers to provide comfort measures for their ill relative.

I understand that the study will involve filling out a short questionnaire and taking part in some education sessions about pain management.

I understand that these sessions will be held at our home and will take approximately four hours of my time altogether. I realise I will also be asked to complete a daily comfort diary about my relative/friend during this time.

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the care of my relative/friend will not be affected.

If I have any questions about the study or about being a participant, I know that I can call Lynn. I may reach her on 9273 8164 (work) or [REDACTED] (home) or [REDACTED] (mobile). I know that I can contact Professor Linda Kristjanson at the University (9273-8617) if I wish to discuss any aspects of the study.

I agree to participate in this study, and I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date

Participant's Signature

Investigator's Signature

Appendix S. Phase II - Permission from Patient to access Patient's medical records in the home and to obtain information from the Family Caregiver about the Patient's pain.

Study Title: Developing and Testing a Pain Management Program for Family Caregivers of Advanced Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Lynn is a nurse who has worked in hospice and palliative care for 15 years. She is interested in learning how family caregivers manage caring for their relative/friend in the home. She believes that this study will assist family caregivers to provide comfort measures for their ill relative. I understand that Lynn wishes to look at, and retrieve information from my medical records kept in my home. She will also ask my caregiver to complete a diary about my pain and it's treatment. This diary will be seen by Lynn.

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the quality of my care will not be affected.

If I have any questions about the study, I know that I can call Lynn. I may reach her on 9273 8164 (work) or [REDACTED] (home) or mobile [REDACTED]. I know that if I wish to discuss any aspects of the study, that I can contact Professor Linda Kristjanson at the University on 9273-8617.

I agree to participate in this study, and to allow Lynn to retrieve information from my medical records kept here in my home. I will also allow Lynn to ask my caregiver to complete a diary about my pain and it's treatment. I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date	Participant's Signature	Investigator's Signature
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Appendix T. Phase II - Information for Health Professionals

Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Advanced Cancer Patients

This study is being undertaken by Lynn Oldham. Lynn is a Registered Nurse and a doctoral student at Edith Cowan University. Lynn's Principal Supervisor is Professor Linda Kristjanson and other supervisors are Dr Kevin Yuen and Dr Sue Nikoletti.

Phase I of the research investigating how family caregivers manage their ill relative or friend's pain in the home has been completed. Thank you all for your very valuable assistance during this phase.

Phase II will commence in1999. This part of the study will involve a pilot test of the education program, derived from the Phase I data, and will determine the extent to which outcome measures are sensitive and psychometrically sound.

The education sessions will be held at (location) on (time and place). The primary family caregiver will be asked provide socio-demographic data about herself/himself and the relative's/friends medical records retained in the home will be used to access socio- demographic data. The family caregiver will also be asked to participate in four pain education sessions with Lynn, lasting approximately 1 ½ hours each, complete a daily comfort diary for their relative and also fill out pain knowledge, experience and attitude questionnaires at several points during this phase of the study.

Phase III of this study will involve a randomised clinical trial to test the pain management program with a stratified random sample of family caregivers.

If you have any questions regarding this project you are invited to contact Lynn Oldham on [REDACTED] (home), 9273 8164 (work) or mobile [REDACTED]

Appendix U. Family Pain Questionnaire

Below are a number of statements about cancer pain and pain relief. Please circle a number on the line to indicate your response.

Knowledge

1. Cancer pain can be effectively relieved

0 1 2 3 4 5 6 7 8 9 10
agree disagree

2. Pain medicines should be given only when pain is severe.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

3. Most cancer patients on pain medicines will become addicted to the medicines over time.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

4. It is important to give the lowest amount of medicine possible to save larger doses for later when the pain is worse.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

5. It is better to give pain medications around the clock (on schedule) rather than only when needed.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

6. Treatments other than medications (such as massage, heat, relaxation) can be effective for relieving pain.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

7. Pain medicines can be dangerous and can interfere with breathing.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

8. Patients are often given too much pain medicine.

0 1 2 3 4 5 6 7 8 9 10
agree disagree

9. If pain is worse, the cancer must be getting worse.

0 1 2 3 4 5 6 7 8 9 10
 agree disagree

Experience

10. Over the past week, how much pain do you feel your family member has had?

0 1 2 3 4 5 6 7 8 9 10
 no pain a great deal

11. How much pain is your family member having right now?

0 1 2 3 4 5 6 7 8 9 10
 no pain a great deal

12. How much pain relief is your family member currently receiving?

0 1 2 3 4 5 6 7 8 9 10
 no pain relief a great deal

13. How distressing do you think the pain is to your family member?

0 1 2 3 4 5 6 7 8 9 10
 not at all a great deal

14. How distressing is your family member's pain to you?

0 1 2 3 4 5 6 7 8 9 10
 not at all a great deal

15. To what extent do you feel you are able to control the patient's pain?

0 1 2 3 4 5 6 7 8 9 10
 a great deal not at all

16. What do you expect will happen with your family member's pain in the future?

0 1 2 3 4 5 6 7 8 9 10
 will get better will get worse

Appendix V. Cancer Pain Attitude Questionnaire

Below are a number of questions about cancer pain. Please circle a number on the line to indicate your response.

1. How concerned are you that if your family member receives narcotics for cancer pain relief, that he or she will become addicted to those drugs?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
										concerned

2. How concerned are you that if your family member takes narcotics early in the disease, there will be nothing to control their pain later?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
concerned										concerned

3. How concerned are you that if your family member takes narcotics for cancer pain, that he or she will not be able to lead a normal life because of the medications?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
concerned										concerned

4. How concerned are you that if your family member takes narcotics, he or she will have side effects?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
concerned										concerned

5. How much relief from cancer related pain should your doctor attempt to provide for your family member ?

0	1	2	3	4	5	6	7	8	9	10
none at all										complete relief

6. How much pain relief do you believe your family member can expect with appropriate treatments?

0	1	2	3	4	5	6	7	8	9	10
none at all										complete relief

7. How effective do you think non-medical treatments (heat, cold, relaxation, imagery, hypnosis and exercise) are for helping relieve cancer pain, when used in combination with narcotics?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely effective

8. How reluctant are you for your family member to receive larger doses of narcotics for cancer pain because you are concerned about side effects?
- 0 1 2 3 4 5 6 7 8 9 10
not at all extremely reluctant
9. How important is it to you to address spiritual, emotional and family issues in managing your family member's pain?
- 0 1 2 3 4 5 6 7 8 9 10
not at all extremely important

(Adapted from Elliott, Elliott, Murray, Braun & Johnson, 1996)

Appendix W. Phase III - Information Booklet

Title: Developing and Testing a Pain Management Program for Family Caregivers of Cancer Patients

I am seeking family caregivers who are currently caring for a friend or relative with cancer at home who may wish to take part in this study.

Why is this study important?

Increasingly, cancer patients are receiving care in the community supported by families and hospice/palliative care services. However, it seems that little or no preparation is provided to family caregivers who assume this supportive role, often for 24 hours per day. Pain management is consistently identified by family caregivers as their primary concern related to care and support of a loved one with cancer. I believe that by building the pain management knowledge and skills of family caregivers, their relative/friend with cancer will have an improved quality of life, the caregiver burden may lessen and the wellbeing of both the family caregiver and the person with cancer will improve.

Who is doing this study?

My name is Lynn Oldham, I am an experienced palliative care nurse, doctoral candidate and nurse researcher at the School of Nursing, Edith Cowan University. My doctoral project involves the development and testing of a pain management program specifically for family caregivers who care for their relative/friend with cancer, in the home. I would like to tell you the story so far...

What is the study about?

The program has been developed in three stages.

The first stage involved interviewing family caregivers who, at the time of interview, were caring for their friend or relative at home. I wanted to find out what is important to families and what would be helpful at this time in their lives. This information was then combined with current pain management knowledge and my own clinical experience to develop the pain management program for family caregivers.

The second stage of the study was to test the education program and also to make sure that the questionnaires I am using are suitable, easy to do and measure effectively. Thirty three family caregivers of cancer patients at home agreed to take part in the pain management program and they found it to be helpful. This stage was completed just before Christmas.

I am now preparing for stage three of the study and I would love to hear from anyone who is interested in taking part, or even if you are just interested in finding out more.

What will be expected of family caregivers during Stage Three?

I need 130 family caregivers who are caring for their relative/friend at home in the Perth metropolitan area. I will need to randomly allocate these people into two groups. One group will be offered the pain management program, the diary and the video. The other group will be offered the diary. Both groups will be asked to complete a questionnaire at three different times; at the beginning of the study, when the education program has been completed and one week later. The questionnaire is short and takes about five minutes to do. Both groups will also be asked for some information about their age, gender and other demographic information. The education sessions will be held in your home, if you wish, and at a time that is suitable to you. If you are among the group who do not participate in the pain education program, I am hoping to be able to offer it to you when the study is completed.

What is the pain management program?

The pain management program consists of four sessions. The sessions deal with understanding and assessing pain, managing pain and understanding medications, some comfort therapies, knowing when to ask for help with pain management, and support strategies for the family caregiver. Each session usually takes an hour. I have also developed a diary for recording patterns of pain, as well as management strategies. A short video is included which is designed to help family caregivers when moving their relative/friend in or out bed, walking with someone who is unsteady and what to do if someone falls.

What is the impact of the study on families?

At the beginning of this study I was concerned that the program might feel like yet another draw on families' time and energy but this has not been the case. All the education sessions in the pilot test took place in the family home at a time that suited the family circumstances.

Voluntary participation and your right to refuse

It is important for you to know that you don't have to take part in this study, and if you decide not to be involved, your current and future care will not be affected in any way. If, after agreeing, you later change your mind, you may withdraw your consent at any time, simply by telling my research nurse or me. We would then destroy any records containing your information.

How will your privacy be protected?

If you do decide to take part in the study, all information that you give me will be kept strictly confidential. To protect your privacy and ensure that personal details are kept confidential, I will remove your name from my research records as soon as they are transferred to the research files. At this time, names will be replaced with code numbers. All records will be stored for five years in a secure location in the university office and will then be destroyed. You will not be identifiable in any reports resulting from this research study. No information about you or your family will be shared with the health professionals who are caring for your relative/friend.

Are there any risks involved in this study?

There are no known risks involved in taking part in this study and I hope that the program will be helpful to you and your relative/friend. If however, your participation raises questions or concerns that you wish to discuss with a health professional, please contact me and I will be happy to assist you with a referral to an appropriate health professional.

Who can you contact if you have questions about the study?

If you are interested in talking with me, please phone me Lynn Oldham, on 9273 8164 (Edith Cowan University), [redacted] (home) or [redacted] (mobile). You can also e-mail me at l.oldham@cowan.edu.au. My supervisor, Professor Linda Kristjanson (9273 8617) will also be pleased to answer any questions you may have.

Who has given permission for this study to proceed?

The Edith Cowan University Ethics Committee, the Silver Chain Hospice Care Professional Services Advisory Committee, Hollywood Private Hospital Research and Ethics Committee and the Cancer Support Association of WA have approved this study.

Will the results of this study be helpful to others?

When the project is finished, it will be available to all interested health care services in the hope that it will be a resource for all family caregivers of cancer patients at home.

Thank you for taking the time to read this information sheet. I look forward to hearing from you.

Appendix X. Phase III - Letter to Family Caregivers from SCHCS

13 March 2001

«Title» «Initials» «Surname»
«Number» «Address»
«Suburb» WA «Postcode»

Dear «Title» «Surname»

Lynn Oldham, an experienced palliative care nurse, is currently studying for her PhD at Edith Cowan University. The objective of Lynn's research is the development of a Pain Management Education program for the carers of individuals for whom pain is a significant symptom.

I believe pain has at one time been a problem for your friend/relative that is currently a client of Silver Chain's Hospice Care Service. I am therefore writing to ask whether you are interested in helping Lynn with her research.

If you are interested in talking with Lynn, please call her on (University) 9273 8164, (Home) [REDACTED] or (Mobile) [REDACTED]. Lynn will then provide you with further information about her project. You are not obliged to take part in this study and you may withdraw your involvement at any time.

Should you decide to take part, all information you give will be kept strictly confidential. No information about you or your family will be shared with health professionals caring for you. The care you receive will not be affected by whether or not you decide to take part in this study.

If Lynn does not hear from you within the next two weeks she will assume that you are not interested in any further information about the study.

Thank you for considering to participate in a project that will produce a program of great benefit to carers of the terminally ill.

Sincerely

[REDACTED]

Dr Gill Lewin
Research Manager

GLDW (04.07)

Appendix Y. Phase III - Invitation to Family Caregivers for the Cancer Support Association Website and Newsletter

PAIN MANAGEMENT PROGRAM FOR FAMILY CAREGIVERS OF CANCER PATIENTS AT HOME

**Edith Cowan University (Western Australia)
and
Cancer Support Association of Western Australia Inc**

Cordially invite you to take part in a Ph.D Nursing Research Study that has been approved by the Edith Cowan University Ethics Committee and the Silver Chain Hospice Care Professional Services Advisory Committee.

If you are currently caring for a relative or friend with cancer, at home and would like more information and wish to become involved, you are invited to contact:

**Ms Lynn Oldham
Telephone (08) 9273 8164
Mobile [REDACTED]
E-mail l.oldham@cowan.edu.au**

or

**Professor Linda Kristjanson
Telephone (08) 9273 8617**

All information received will be treated in confidence.

Abstract

Development and Testing of a Pain Management Program for Family Caregivers of Cancer Patients

A three phase study is being conducted in the Perth metropolitan area to develop and test pain management interventions that will provide family caregivers of cancer patients with information and skills to manage their relative's or friend's pain.

Phase I involved the development of an education program for this group of families. Relevant literature and information gained from interviews with family caregivers were combined to build an education program that would be helpful to families. The pain management program (PMP) consists of four sequenced, interactive education sessions, a Daily Comfort Diary and a video.

In Phase II the PMP was tested to determine the extent of the reliability, validity and consistency of the instruments. The instruments are two brief questionnaires which are completed a three time points in the program. The feasibility and acceptability of the program to family caregivers was also evaluated. Thirty three family caregivers have taken part in this phase and the results show that the PMP is both feasible and acceptable and the instruments are reliable, valid and consistent

In Phase III, a randomised clinical trial will be carried out with 130 family caregivers to test the pain management program. This will involve randomly assigning family caregivers to one of two groups. One group will be offered the PMP, the Daily Comfort Diary and the video and the other group will be offered the Daily Comfort Diary. Both groups will be asked to complete the two questionnaires at three time points.

As more families are choosing or are being expected to care for cancer patients at home, their knowledge about how to provide pain management becomes increasingly important. This study has the potential to improve the cancer patient's quality of life, to lessen the caregiver burden and improve caregiver well being. The study may also help to reduce the inappropriate use of pain management medications and hospital admissions.

**Please note that the Ethics Committee of Edith Cowan University requires that no respondent is identified when research data is published.
Confidentiality is assured.**

Appendix Z. Phase III - Telephone Script

Hello Mrs/Mr Ms.....

“How are you?” (listen to response as may be a difficult day)

“Thank you very much for calling about the pain management study.”

“Would you be interested in meeting with me this week? Or is there another time that would be more suitable for you? I would like to discuss the study with you and your relative/friend and collect some information from you. We would need about half an hour of your time. If you consent to participate in the study, it would involve completing a short questionnaire and then I will describe the pain education program with you particularly in terms of the “when” and “where” and how you will be assigned to a group. I would like to have a look at your relative’s medical records that are kept in your home, too, if your relative will give me permission. I am happy to meet you wherever you wish.”

If caregiver agrees on a time and place, an appointment will be made and the researcher will give the caregiver her telephone number in case any unforeseen circumstances arise.

“Thank you so much for agreeing to see me, I look forward to meeting with you and your husband/wife/ friend/child on day/date/time. I will give you my name and telephone number, Lynn Oldham on 9273 8164(work), [REDACTED] (home) and [REDACTED] (mobile), and if you have any queries, please contact me”.

Appendix AA. Phase III - Informed Consent for the Family Caregiver

Title: Developing and Testing a Pain Management Program for Family Caregivers of Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Approved by the Edith Cowan University Ethics Committee, the Silver Chain Care Professional Services Advisory Committee, the Cancer Support Association of WA, the Sir Charles Gairdner Nursing Research and Scientific Committee and the Hollywood Private Hospital Research and Ethics Committee.

Pain management is consistently identified by family caregivers as their primary concern related to care and support of a loved one with advanced cancer. Lynn is interested in learning how family caregivers manage caring for their relative/friend in the home. She believes that this study will assist family caregivers to provide comfort measures for their ill relative.

I have read the information booklet about the study. I understand that if I agree to take part in this study, I will be allocated to one of two groups, the education group or the control group. If I am chosen for the education group, I understand that the study will take approximately four hours of my time. It will involve filling out a several short questionnaires at different time points, and taking part in four education sessions about pain management. I understand that these sessions will be held in my home or at a venue suitable to me. I realise I will also be asked to complete a daily comfort diary about my relative/friend during this time, with his/her permission.

I understand that if I am chosen for the control group, it will involve filling out several short questionnaires at different time points. I also understand that when the study is completed (add time when known), the education program will be offered to me.

I know that my participation in this study is strictly voluntary. I know that I have the right to withdraw at any time and that the care of my relative/friend will not be affected.

I have had the opportunity to discuss the study with Lyn or research nurse and I am satisfied with the answers I have received.

If I have any questions about the study or about being a participant, I know that I can call Lynn. I may reach her on 9273 8164 (work), [REDACTED] I know that if I wish to discuss any aspects of the study that I can contact Professor Linda Kristjanson at the University on 9273-8617.

I agree to participate in this study, and I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date

Participant's Signature

Investigator's Signature

Appendix BB. Phase III - Permission to access Patient's medical records in the home

Title: Developing and Testing a Pain Management Program for Family Caregivers of Cancer Patients

Principal Investigator: Lynn Oldham RN, BN (Hons)

Approved by the Edith Cowan University Ethics Committee, the Silver Chain Care Professional Services Advisory Committee, the Cancer Support Association of WA and the Hollywood Private Hospital Research and Ethics Committee.

Lynn is a nurse who has worked in hospice and palliative care for 15 years. She is interested in learning how family caregivers manage caring for their relative/friend in the home. She believes that this study will assist family caregivers to provide comfort measures for their ill relative.

I have had the opportunity to discuss the study with Lynn or research nurse and I am satisfied with the answers I have received. I understand that Lynn wishes to look at, and retrieve information from my medical records kept in my home. I am aware that my family member will keep a diary about my pain and it's treatment and that this diary will be given to Lynn as part of the research study. I have been assured that Lynn will return the diary to me, if my family member wishes to keep it, as soon as all the information from the diary has been added to the research data.

I know that my **participation in this study is strictly voluntary**. I know that I have the right to **withdraw at any time** and that my care will not be affected.

If I have any questions about the study, I know that I can call Lynn. I may reach her on 9273 8164 (work), [REDACTED] I know that I can discuss any aspects of the study with Professor Linda Kristjanson at the University on 9273-8617.

I agree to participate in this study, and to allow Lynn to retrieve information from my medical records kept here in my home. I also agree to my pain diary being given to Lynn. I have received a copy of this consent form. I have been assured that my identity will not be revealed while the study is being conducted or when the study is published.

Date

Participant's Signature

Investigator's Signature

Appendix CC. Phase III - Information for Health Professionals

Title: Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Advanced Cancer Patients

This study is being undertaken by Lynn Oldham. Lynn is a Registered Nurse and a doctoral student at Edith Cowan University. Lynn's Principal Supervisor is Professor Linda Kristjanson and other supervisors are Dr Kevin Yuen and Dr Sue Nikoletti.

Phases I and II of the research investigating how family caregivers manage their ill relative or friend's pain in the home has been completed. Thank you all for your very valuable assistance during this phase.

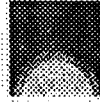
Phase III will commence in January 2001. This part of the study involves a randomised clinical trial to test the education program with two groups of family caregivers. One group will receive the pain management program and the control group will be offered the same program at the completion of the study.

The education sessions will be held either in the family home or a venue suitable to individual families. All the primary family caregivers will be asked to provide socio demographic data about herself/himself and the relative's/friends medical records retained in the home will be used to access socio-demographic data. The family caregivers who are selected to the education group will also be asked to participate in four pain education sessions with Lynn or her research nurse Jo Hale, lasting approximately one hour each. All family caregivers will be asked to complete a daily comfort diary for their relative and also fill out pain knowledge, experience and attitude questionnaires at several points during this phase of the study.

Thank you all for your on-going support for this research study.

If you have any questions regarding this study you are invited to contact Lynn Oldham on (work) 9273 8164, (home) [REDACTED] or mobile [REDACTED]

Appendix DD: (Phase III) Letter of ethical approval from Hollywood Private Hospital



HOLLYWOOD PRIVATE HOSPITAL

February 8, 2001

Ms I. Oldham
School of Nursing and Public Health
Edith Cowan University
Pearson St
CHURCHLANDS WA 6009

Dear Ms I. Oldham

Re: Hollywood Private Hospital - Research Ethics Committee Application
REFERENCE NUMBER: HPH096

Developing and testing a Pain Management Program (PMF) for family Caregivers of advanced cancer patients

I am pleased to advise you that at the Hollywood Private Hospital Research Ethics Committee meeting held on February 6, 2001, approval for the above proposal was granted, subject to the following:

Revision of Appendices XXIV (Informed Consent - Family Caregiver - Phase III) and XXV (Permission to Access Patient's Medical Records in the Home - Phase III).

The Committee felt that these documents should not be written using the first person when referring to the Principal Investigator. Following our telephone discussions regarding this matter and the subsequent provision of revised documents by you via e-mail, full approval for your study can now be confirmed.

The approval includes:

- Research Proposal
- Caregiver Demographic Form (Appendix X)
- Patient Demographic Form (Appendix XI)
- Daily Comfort Log for the Family Caregiver (supplied in the form of a diary)- Appendix VII)
- Family Pain Questionnaire (Appendix XVIII)
- Cancer Pain Attitude Questionnaire (Appendix XIX)
- Patient Comfort and Pain control (Appendix XX)
- Information Booklet Phase III (Appendix XXI)
- Telephone Script - Phase III (Appendix XXIII)

Appendix DD (cont)

The approval also includes the revised Consent Documents

- Informed Consent Family Caregiver - Phase III, Version 2, dated 8th February, 2001 (as supplied in your e-mail dated 8th February, 2001)
- Permission to Access Patient's Medical Records in the Home - Phase III, Version 2, dated 8th February, 2001 (as supplied in your e-mail dated 8th February, 2001)

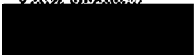
I have attached the revised consent documents that are approved to ensure there is no confusion regarding which consent forms may be used in the study.

The Hollywood Private Hospital Research Ethics Committee operates in accordance with the NH&MRC National Statement on Ethical conduct in Research involving humans. In accordance with the NH&MRC National Statement on Ethical Conduct in Research Involving Humans (June 1999) monitoring requirements, the committee requires that annual reports be submitted for all approved projects. In addition, the committee must be advised in writing immediately in the event that any of the following circumstances arise:

- Proposed changes or modifications that are made to the original protocol
- Serious or unexpected adverse effects on participants enrolled in the trial
- Unforeseen events that may affect continued ethical acceptability of the project

Please quote the project reference number (HPH098) in all correspondence addressed to the committee. On behalf of the committee, I wish you well with your project. Please contact me on 9346 8571 or at trobb@ramsayhealth.com.au if you have any queries.

Yours sincerely,


TANYA ROBB
Research Facilitator

Appendix EE. Phase III - Letter of ethical approval from Sir Charles Gairdner Hospital



METROPOLITAN HEALTH SERVICE



SIR CHARLES GAIRDNER HOSPITAL

1st May 2001

Professor Linda Kristjansson
Associate Dean
Research and Higher Degrees
School of Nursing and Public Health
Edith Cowan University
Pearson Street
Churchlands, WA 6009

Dear Linda

"Developing and Testing a Pain Management Program (PMP) for Family Caregivers of Cancer Patients".

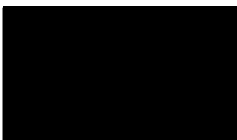
The Nursing Research Scientific Sub-Committee (NRSS) met on the 17th April 2001 to review your proposal. I have great pleasure in advising you that the committee approved your proposal subject to the following suggestion:

That consideration be given to following the Zelen method of recruitment whereby informed consent for the intervention is sought after randomisation. Ethics approval should be sought from the original source (Edith Cowan University)

You may commence your study once Nursing Research have ethics approval documentation from Edith Cowan University.

The Nursing Research Scientific Sub-Committee requests a review of the studies approved by the Committee annually to establish progress. You will be asked to provide an up to date synopsis of your study on a proforma sheet sent to you at a later date.


Yours sincerely



DE TWIGG
EXECUTIVE DIRECTOR OF NURSING SERVICES
cc. Lynn O'Dhau, PhD candidate, School of Nursing and Public Health:
Edith Cowan University.

Hospital Avenue, Nedlands, Western Australia 6009
Telephone +618 9346 1333 Facsimile +618 9346 3159 T.E.Y. Line +618 9346 1400
Website: <http://www.sugh.health.wa.gov.au>

Appendix FF. Phase III - Letter of permission to recruit from the Cancer Foundation of Western Australia Inc. A. H. Crawford Lodge



CANCER FOUNDATION
of Western Australia Inc

Patron His Excellency Lieutenant General John Sanderson, AC
Governor of Western Australia

1 June 2001

Ms I. Oldham
PhD Candidate
School of Nursing and Public Health
Faculty of Communication Health and Science
Edith Cowan University
Pearson Street
Churchlands WA 6014

Dear Ms Oldham

Following our recent conversation I am happy to confirm that you may make contact with guests at our A H Crawford Lodge in order to invite them to participate in your study "Developing and Testing a Pain Management Program for Family Caregivers of Cancer Patients".

As you are aware, the Cancer Foundation does not have a role in the health care of its guests at A H Crawford Lodge. Would you kindly contact our Coordinator of Administration Ms Ann Holmes, to assist you with circulating relevant information during the study period.

With best wishes for the success of this important study.

Yours sincerely



Ellen Nightingale
Director
Cancer Services Division

40 Verdine Avenue, West Perth, Western Australia 6005
Telephone (08) 9212 4222 Facsimile (08) 9212 4224
www.cancerwa.com.au
SBN 11 730 871 561

Appendix GG. Phase III – Family Caregiver Characteristic Comparisons between Groups

Table FF4

Family caregiver characteristics in the experimental and control groups

Characteristic	Experimental Group (n=60)	Control Group (n=57)	Sig		
Age(years)	Range Mean	19-87 60.54	Range Mean 13-82 57	0.192	
Gender	Female	39(65%)	Female	39(68%)	0.844
Relationship to pt	Partner Daughter Son Mother Friend Other	48(80%) 7(12%) 1(2%) 2(3%) 0(0%) 2(3%)	Partner Daughter Son Mother Friend Other	46(81%) 4(7%) 1(2%) 1(2%) 2(4%) 3(5%)	0.651
Language	English	59(98%)	English	56 (98%)	1.00
Education	Primary Secondary Trade University Post grad	7 (12%) 26 (44%) 21 (36%) 5(9%) 0(0%)	Primary Secondary Trade University Post grad	3 (5%) 32 (56%) 18 (32%) 3 (5%) 1(2%)	0.417
Employment	Not employed Retired Fully employed Part employed	14 (23%) 34 (57%) 8 (13%) 4 (7%)	Not employed Retired Fully employed Part employed	14 (25%) 28 (49%) 7 (12%) 8 (14%)	0.592
Income	<20,000 21,000 –50,000 51,000 –70,000 71,000-85,000 Not stated	12(25%) 19(32%) 10 (20%) 5 (10%) 3 (6%)	<20,000 21,000 –50,000 51,000 –70,000 71,000-85,000 Not stated	6 (11%) 19(36%) 17 (32%) 7 (13%) 4 (8%)	0.387
Previous pain management experience	No	54 (90%)	No	53 (95%)	0.557

Note: Chi square test for independence was used to compare family caregivers' categories between groups.
Independent samples t-test was used to compare family caregivers' ages between groups.

Appendix HH. Patient Characteristic Comparisons between Groups

Table GG5

Patient characteristics in the experimental and control groups

Characteristic	Experimental Group (n=59)	Control Group (n=53)	Sig		
Age (years)	Range Mean	35-88 65.90	Range Mean	33-79 61.57	0.059
Gender	Female	30(59%)	Female	22(41%)	0.375
Secondary cancer	No	25(42%)	No	22(41%)	0.890
Time diagnosis	<6 months 6-12 months >12 months	4(7%) 50(85%) 5(9%)	<6 months 6-12 months >12 months	10(19%) 38(70%) 6(10%)	0.130
Onset of pain	No pain Within 6 months Within 12 months	9(16%) 13(22%) 23(40%)	No pain Within 6 months Within 12 months	11(20%) 15(28%) 17(32%)	0.654
No. pain types	0 1 2 3	11(19%) 22(37%) 24(41%) 2(3%)	0 1 2 3	9(16%) 23(43%) 20(37%) 2(4%)	0.947
Opioids	Yes	41(66%)	Yes	37(69%)	1.00
Physiotherapy	No	55(93%)	No	53(98%)	0.415
Radiotherapy	No	35(54%)	No	29(54%)	1.00
Chemotherapy	No	52(88%)	No	38(70%)	0.035

Note: Chi square test for independence was used to compare patients' categories between groups. Independent samples t-test was used to compare patients' age between groups.

Appendix II. Phase III - Graphic Representation and Data Analyses of Knowledge Sub-scale Items for T1, T 2 and T3

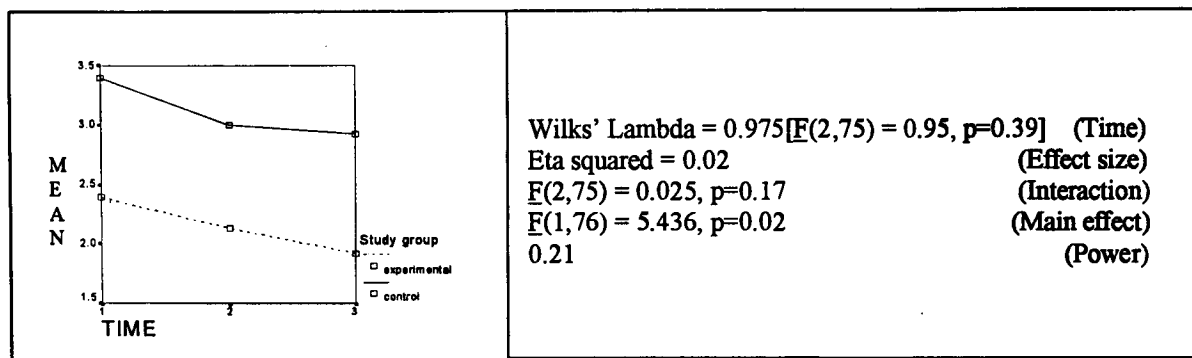


Figure 5. Mean scores for T1, T2 and T3 for Item 1: Cancer pain can be effectively relieved

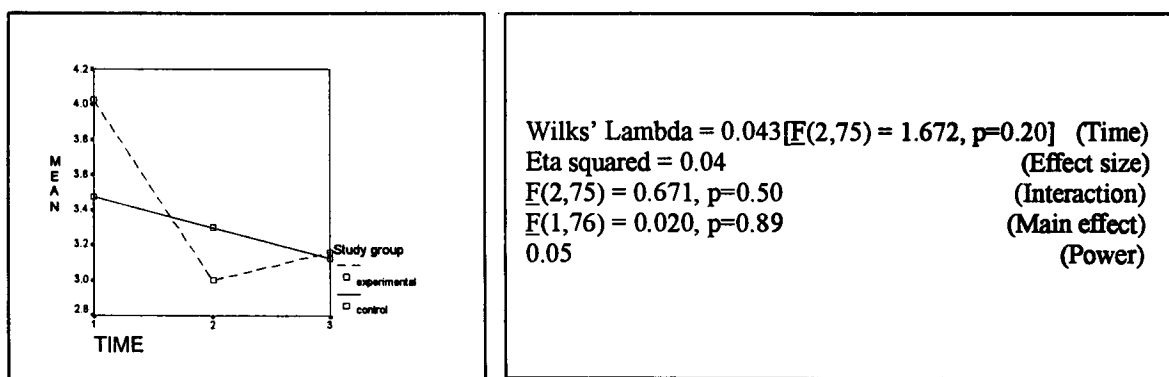


Figure 6. Mean scores for T1, T2 and T3 for Item 2: Pain medicines should be given only when pain is severe

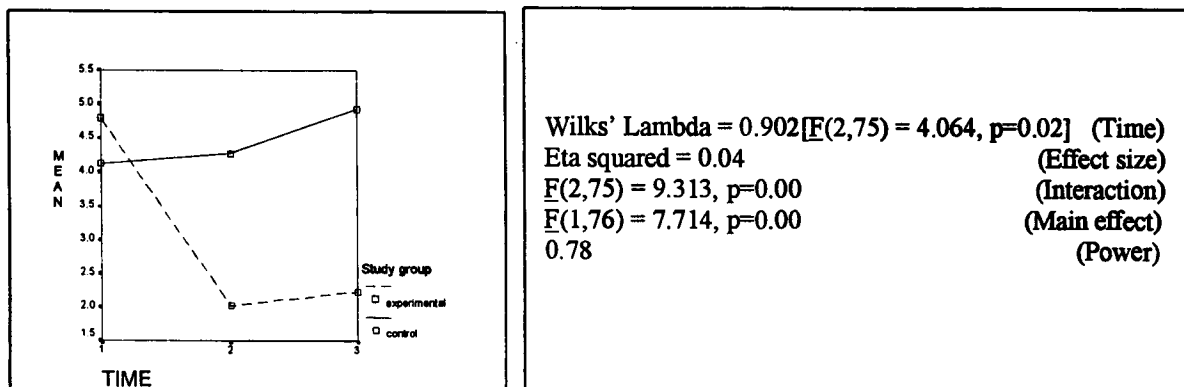
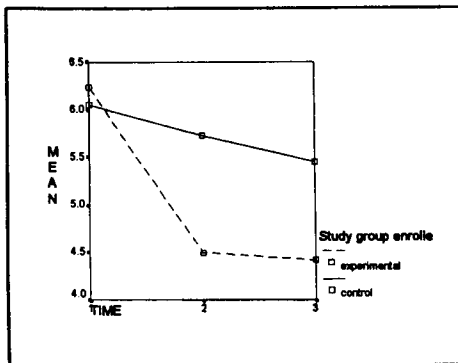


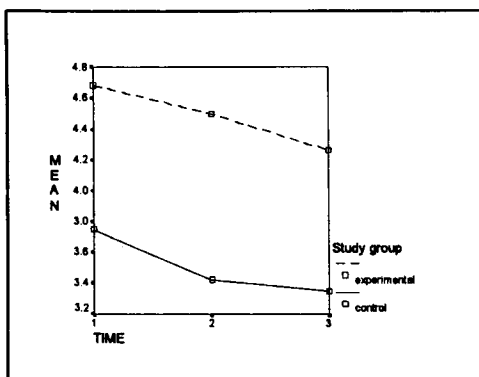
Figure 7. Mean scores for T1, T2 and T3 for Item 3: Most cancer patients on pain medicines will become addicted over time

Appendix II (cont.)



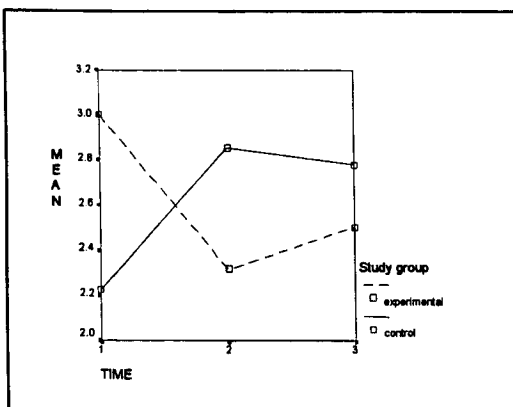
Wilks' Lambda = 0.882 [$F(2,75) = 4.995, p=0.00$] (Time)
 Eta squared = 0.12 (Effect size)
 $F(2,75) = 1.668, p=0.20$ (Interaction)
 $F(1,76) = 1.164, p=0.02$ (Main effect)
 0.19 (Power)

Figure 8. Mean scores for T1, T2 and T3 for Item 4: It is important to give the lowest amount of medicine possible to save the larger doses for later when the pain gets worse



Wilks' Lambda = 0.989 [$F(2,75) = 0.427, p=0.65$] (Time)
 Eta squared = 0.01 (Effect size)
 $F(2,75) = 0.025, p=0.98$ (Interaction)
 $F(1,76) = 2.066, p=0.16$ (Main effect)
 0.30 (Power)

Figure 9: Mean scores for T1, T2 and T3 for Item 5: It is better to give pain medications around the clock (on schedule) rather than only when needed



Wilks' Lambda = 0.999 [$F(2,75) = 0.021, p=0.98$] (Time)
 Eta squared = 0.001 (Effect size)
 $F(2,75) = 2.062, p=0.13$ (Interaction)
 $F(1,76) = 0.01, p=0.98$ (Main effect)
 0.05 (Power)

Figure 10. Mean scores for T1, T2 and T3 for Item 6: Treatments other than medications such as massage, heat and relaxation can be effective for relieving pain

Appendix II (cont.)

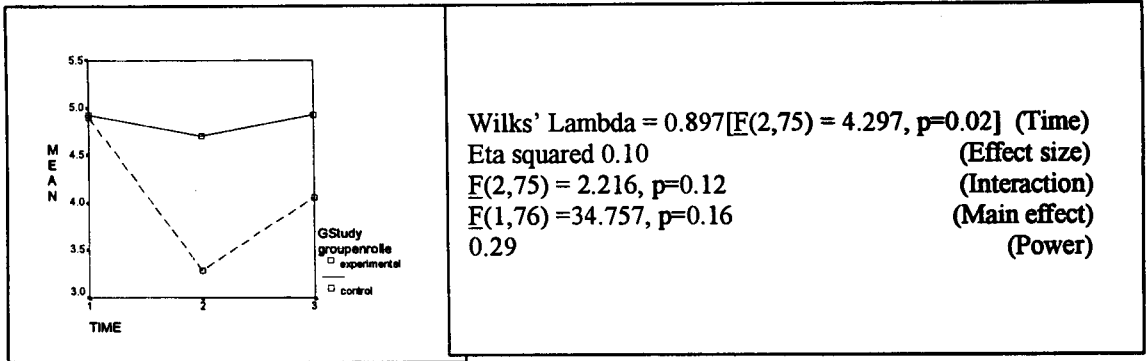


Figure 11. Mean scores for T1, T2 and T3 for Item 7: Pain medicines can be dangerous and can interfere with breathing

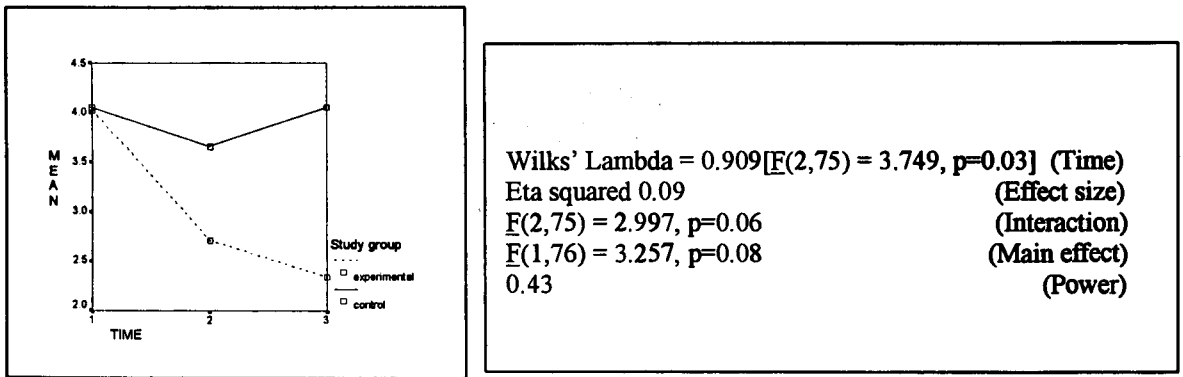


Figure 12. Mean scores for T1, T2 and T3 for Item 8: Patients are often given too much pain medicine

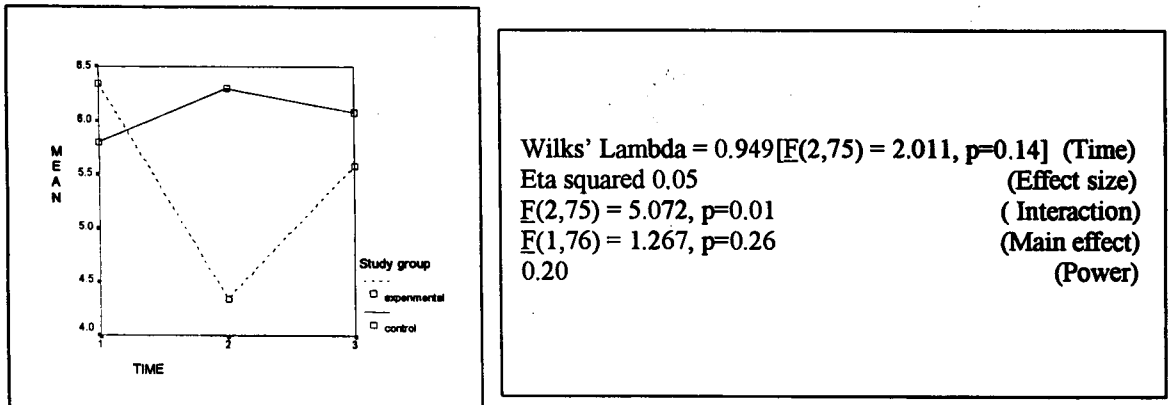


Figure 13. Mean scores for T1, T2 and T3 for Item 9: If the pain is worse the cancer must be getting worse