# THE FAMILY MEETING AS AN INSTRUMENT FOR THE SPIRITUAL CARE OF PALLIATIVE PATIENTS AND THEIR FAMILIES

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# CHAPTER ONE

# INTRODUCTION AND OUTLINE OF THE THESIS

## Why this Study?

Spiritual care has been widely accepted as an important aspect of the holistic care of palliative patients and is certainly very consistent with hospice philosophy. Palliative Care Australia (2000) has identified this area of care as being a priority for research. Substantial research, aimed at identifying the spiritual needs of patients, has been published, although in most cases this does not extend to the needs of family members and carers. This research particularly includes the development of measuring scales to assess patient spiritual needs. Many of these have been found to have limited usefulness being very narrow in their view of spirituality.

A lack of clarity about the definition of spirituality and the fact that this field of study is not easily objectified, both add to the difficulties. In this study a very broad view of spirituality (discussed in more detail in chapter 2) has been taken. In particular it is acknowledged that religious practice is part of spiritual expression for some people but is not for many others.

Family Systems Theory, a widely accepted theory of family functioning (Hoffman, 1981) proposes that the experience of trauma (such as terminal illness and death) of one member of the family impacts on the functioning and needs of the whole system and on every member of that system. Consistent with this view are the World Health Organisation National Cancer Control Programmes: Policies and Managerial Guidelines (2002) which stress that the needs of the patients' family members and caregivers should be addressed in the provision of palliative care. A small number of researchers (Kissane & Bloch, 2002; Waldrop, Milch, & Skretny, 2005) have investigated family member needs following diagnosis of a terminal disease in one of its members and, the impact of working with family groups, rather than just the patient, on bereavement outcomes. They have found that for many participants improved outcomes are observed.

A search of published, proposed or utilized models of spiritual care of palliative patients identified only one which included the whole family unit. Murphy's family meeting model was applied for a number of years in a hospice setting in the USA and has been described in some detail (Murphy, 1999), although the efficacy of this model has ever been formally assessed. It is probable that the complex nature of family interventions, along with the well published difficulties of undertaking research involving palliative care patients, are contributing factors to the paucity of studies in this field, which have included family units. It is evident from this search that further research in this important area of care within palliative care services is clearly indicated.

## Aim of the Study

This research study was undertaken in order to assess the efficacy of Murphy's family meeting model.

Practice orientated research is only relevant if it considers not only the benefits and disadvantages of the intervention for patients and family members, but also investigates the needs of the staff who would implement it. This study therefore aimed to ascertain staff participants' views of the implications for staff, of implementing this model of care in regular service. There was a focus on their needs for training, time availability and self care.

This study also aimed to investigate other possible barriers to the inclusion of this model in regular service as perceived by all stakeholders.

## Objectives of the Study

In order to achieve the above aims of this study the following research questions were posed:
What was the experience of patient participants of a family meeting conducted according to Murphy's Family Meeting Model?

- What was the experience of family member participants of this meeting?
- What were staff members' observations of the impact of this meeting on participating patients and family members?
- What are stakeholders' views about the suitability of this intervention for inclusion in regular palliative care service offerings?

## Significance of the Study

This study is original research and is believed to be the first in-depth assessment of a family meeting intervention intended to facilitate the spiritual care of palliative patients and their family members. Another study, Family Focused Grief Therapy (Kissane and Bloch, 2002), which worked with families as a unit has been well evaluated but focuses on bereavement outcomes with particular emphasis on psycho-social issues.

While further research, beyond this study, is likely to be needed before Murphy's (1999) or an other similar family meeting intervention can be implemented into regular palliative care service as an instrument of spiritual care, it is hoped that extending the knowledge of the benefits and challenges of caring for families as a unit, rather than just individual patients, can open the way for more holistic care of families living with the terminal illness of a family member.

It is also significant that this study investigates the perceived needs of staff members in implementing this program and the other expected practical barriers to its implementation

## Researcher’s Position

Religion has always been a part of my life having been raised by strict, rather fundamentalist Christian parents. While I decided long ago that this particular perspective was not for me, I have always had a consciousness of myself, and all human beings, as spiritual beings. This process has been aided by a lifetime of exposure to multi-cultural settings, and awareness that spirituality can be expressed through a variety of religious practices, and in many cases also in ways that are not recognised as related to any conventional religion. I have for the last seventeen years been an active member of a small Christian church which has a broad understanding of the spiritual nature of the human being and accepts that there is no one way to express this that is ‘right’ for everyone. For the last eleven years I have been an ordained person within this community.

In the last twenty five years my educational studies, qualifications and my professional experience have been focused around counselling, pastoral care and teaching. Initially this was within the context of a school environment and then more recently in various community locations focusing on pastoral care and grief and bereavement issues. The counselling work has been with both individuals and family groups. In the last five years my work has also included teaching at a postgraduate tertiary level in courses such as ‘Grief and Spirituality’, ‘Issues in Death and Dying’ and

‘Counselling in Palliative Care’. My training has also included self awareness training, especially in the area of death, my own mortality and that of others.

My interest in palliative care has arisen in part from my past experience of being involved in the care of dying parents. My conviction, that death is a transition, for both the one who is dying and those who are left and who must continue to live without the physical presence of their loved one, has also contributed to my interest in this field. This transition, whether it is regarded as moving from one mode of living to another or from physical life to nothingness, can I believe, be made smoother and less traumatic if all aspects of those involved are tended to, including spiritual needs.

I see my process in providing this care as being to understand the individual’s and family groups’ perspective of spirituality and its expression, and to facilitate care from this view point. While being aware of my own spirituality and its expression is important, my purpose is never to impose those views and practices on others.

## Outline of the Thesis

This thesis is presented in the following eleven chapters. These chapters can be divided into four main areas of interest:

Setting the Scene

Chapters 2 and 3 set the scene for the thesis by positioning the study in the context of available literature and discussing the philosophical underpinning and methodology utilized in the investigation of the research questions which are stated above.

### The Methods Used

Chapters 4, 5 and 6 outline the methods used in this study. They include a description and explanation of recruiting processes, data collection and data analysis.

### The Results

Chapters 7-10 inclusive present in detail the results of this study, identifying the main themes from the perspective of patients, family members and staff participants.

### Study Outcomes

Chapters 11 and 12 discuss the results of the study in the light of current literature and in relation to the research questions investigated in this study. Implications for practice, limitations of the study and recommendations for further research are also presented.

Generally this dissertation is written in the third person but in those parts of the work where the researcher's own experience is examined, the first person is used.

## Summary

This chapter has outlined the reasons for choosing to do this study and has described the aims, objectives and significance of the study. The researcher's background, which is seen to have had a significant impact on her current position in relation to spiritual care in the palliative care setting, is also presented. The structure of the thesis is outlined.

# CHAPTER TWO

# WHAT DOES THE LITERATURE SAY?

## Introduction

The Spiritual Care Work Group of the International Work Group on Death, Dying and Bereavement (1990) made the fundamental assumption that dying is more than a biological process and is in fact a “human, social and spiritual event” (p.75). It is now widely accepted that the spiritual care of palliative patients, near end-of-life, and their families is an important part of their total care within the palliative care system, and that the provision of this care is a multi-disciplinary task (McGrath, 1999; Milligan, 2004; Strang, Strang, & Ternestedt, 2002; Thomson, 2000; Wesley, Tunney, & Duncan, 2004). A negative correlation between spiritual well-being and anxiety and depression has been identified (McCoubrie & Davies, 2006). William (2006) , in a recent review of qualitative literature on perspectives on spirituality at the end of life, concluded that the “fundamental importance of spirituality at end-of-life’ (p.407) had been confirmed. Palliative Care Australia (2000) has also listed spiritual care as a key area for research in palliative care.

There are a number of issues of concern relating to the provision of spiritual care in the palliative care setting. These include:

- A lack of clarity about the concept of spiritual care.
- The assessment of patient spiritual needs.
- The development, implementation and evaluation of spiritual care programs.
- The provision of suitable staff training.

Development and implementation of spiritual care programs that meet the needs of patients and family members would seem to be of prime importance if the holistic outlook of palliative care is to be supported. The purpose of this literature review was therefore to identify the spiritual needs of palliative patients and their families, determine what is considered most important in the provision of spiritual care, identify spiritual care programs which have been proposed or implemented and to identify any programs whose efficacy has been assessed.

## Background

Recent literature in the area of spiritual care has generally differentiated between spirituality and religiosity (Koenig, McCullough, & Larson, 2001; McGrath, 1999; Walter, 2002; Wright, 2002). Some still use the terms religious and spiritual interchangeably (Gall & Cornblat, 2002; Grey, 1996). Rumbold (2003) points to the confusion and misunderstanding that can arise when these terms are used interchangeably. In a recent study Edmondson, Park, Blank, Fenster and Mills (2007) demonstrated that religious well-being and existential (or spiritual) well being were conceptually and statistically distinct from one another and that they impacted on health related quality of life differently. In a thematic review of literature relating spirituality and health in palliative care, Sinclair, Pererira and Raffin (2006), suggested that spirituality was emerging as a concept largely devoid of religion.

The problems of definition and of outcome measures still remain despite a reported increase of 600% in publications relating to the role of religion and spirituality and health in the period 1993 – 2002 (Stefanek, MCDonald, & Hess, 2005). A thematic analysis of 73 articles, published between 1991 and 2000, in which the nature of spirituality had been investigated or a definition offered, revealed the themes of existential reality (with a sub-theme of meaning/purpose of life);

transcendence; connectedness; and power/force/energy (Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004). A study of the essence of spirituality revealed four constitutive patterns and ten themes, some of which are also related to the concept of finding meaning (Chao, Chen, & Yen, 2002)

For the purposes of this study, the concept of spirituality is understood to be consistent with the 'transcendent' approach to spirituality, as described by Coyle (2002) . This transcendent approach incorporates both a transpersonal connectedness to a higher power or consciousness and an intrapersonal connectedness that focuses on the potentialities of self. As Coyle (2002) points out, some proponents of the 'transcendence' concept of spirituality favour the transpersonal aspect only (Abrums, 2000; Benzein, Norberg, & Saveman, 1998). Others favour the intrapersonal approach (Chandler, Holden, & Kolander, 1992; Dyson, Cobb, & Forman, 1997) while some are able to embrace the broader understanding that incorporates both transpersonal and intrapersonal aspects (Fry, 1998; Grant et al., 2004; Tanyi, 2002). This latter view suggests that the transpersonal and intrapersonal are not mutually exclusive. Both these aspects give rise to a knowing that emerges from different sources i.e. a higher power and contemplation of inner resource respectively. In the transpersonal perspective truth involves a connectedness to the sacred and having faith while in the intrapersonal this connectedness is to self, others and a sense of the divine within. Both offer a way of finding meaning and purpose in living and dying. The discovery of this meaning and purpose includes the experience of hope, motivation, empowerment, guidance, meaningful relationships and a sense of self-identity.

Religion, on the other hand is defined as an organised system of beliefs, practices, rituals and symbols which may facilitate closeness to a higher power and guide behaviour and relationships with others (Koenig et al, 2001). Some people express their spirituality through religious practice.

The method of review will now be discussed.

## Method

A systematic search of the literature was undertaken to identify studies which had been implemented with the aim of identifying specific spiritual needs of palliative patients and their families, as expressed by staff, patients and carers. Information was also sought relating to the implementation and assessment of spiritual care programs in the palliative care field.

Keyword search terms were developed via a search matrix and the terms spirituality, spiritual care, palliative care and terminal illness were entered into the Pubmed MESH data base to find relevant terms to assist in developing the search strategy. The search query was entered as follows: (spiritual care OR pastoral care OR spiritual therapies OR spirituality Or chaplain* OR religion OR spiritual counsel* OR spiritual dimension* OR holistic nursing) AND palliative care OR palliative patient* OR terminally ill OR hospice OR hospice care OR nursing homes OR nursing home OR home care) AND humans. As indicated, four truncated search terms were used these being chaplain*, spiritual counsel*, spiritual dimension* and palliative patient*. The following data bases were searched: Pubmed, PsycINFO, Nursing and Allied Health (CINAHL)-CD, and ERIC.

Key paper references were also scanned for similar studies and key authors. Literature from 1985 onwards was considered for this review. In the main, however, it was found that the most significant literature had been published since 1995.

The search yielded the following numbers of publication references: Pubmed 2529, PsycINFO 329, CINAHL 1373, ERIC 10. These publications were scanned and relevant papers selected for further review using the following two criteria:

- peer reviewed journal
- abstract indicated relevance to this study

A total of 502 articles were selected for closer review and downloading to the electronic reference manager Endnote Windows version 9.0 (2005) (ResearchSoft, 2005). Using the same search terms, alerts were set on the above data bases and with key journals, for relevant new publications that might arise during the study. During the period since the original literature search a total of 88 articles arising from these alerts, have been selected for closer review.

Further searches were conducted using three data bases – Pubmed, PsycInfo and CINAHL -utilising the following terms: “JAREL spiritual well-being scale” and “Functional Assessment of Chronic Illness Therapy - spirituality subscale” (FACIT_Sp), respectively. The resulting articles were scanned using title and abstract where available to assess their relevance to palliative care patients and their families. Apart from the authors who developed the tool no studies utilising the JAREL spiritual well-being scale in palliative care studies were found. A total of 10 studies were identified which reported on utilising the FACIT_Sp assessment tool.

Author citation searches, using Web of Science, available at (http://portal.isiknowledge.com/portal.cgi?DestApp=WOS&Func=Frame), were conducted for the following authors of suggested spiritual care programs for palliative patients, to determine if there were reports on the utilisation and assessment of these programs: Gordon, T., Highfield, M., Hunt, J., Paton, L., Friedemann, M., Emblen, J. and Murphy, N.M. The search revealed no assessment studies of any of these spiritual care programs.

In view of the lack of reports relating to the assessment of spiritual care programs, a search was undertaken in order to review the literature dealing with the assessment of other primary health care programs. Following a lead from the Primary Health Care Research and Information Bullletin (2003), a search query “realistic evaluation” was run on Pubmed (13 ), PsycINFO (2) and CINHAL (10) and a total of five items were selected for further consideration.

## Results

For clarity of presentation the results of this literature review were divided into six main themes. This list is not intended to convey a hierarchical order of importance but rather a development of thinking.

- What are the spiritual needs of palliative patients and their families?
- How have these needs been assessed?
- What is considered important in the implementation of spiritual care?
- What specific spiritual care programs have been implemented?
- Focus on the patient only or on the family as a unit?
- How has the efficacy of spiritual care programs been assessed?

## What are the Spiritual Needs of Palliative Patients and Their Families?

There have been numerous attempts to clarify the nature of the spiritual needs of palliative patients. Sinclair et al. (2006) point out however, in their thematic review of the literature relating to spirituality in palliative care shows that most of the studies related to the needs of patients, but did not consider the needs of either family members or staff.

Kellehear (2000) maintains that a fundamental concept of spirituality is the human desire to transcend suffering and hardship and has proposed a multidimensional model of spiritual needs, which incorporates three major areas of transcendence; situational, moral and biographical, and religious. Based on his review of the literature, Kellehear (2000) has identified a number of key themes within each of these areas of transcendence. These are illustrated in Table 1.

***Table 1:*** *Dimensions of Spiritual Need*

| Situational Transcendence | Moral and Biographical Transcendence | Religious Transcendence |
|---|---|---|
| Purpose | Peace & reconciliation | Religious reconciliation |
| Hope | Reunion with others | Divine forgiveness and support |
| Meaning and affirmation | Prayer | Religious rites/sacraments |
| Mutuality | Moral and social analysis | Visits of clergy |
| Connectedness | Forgiveness | Religious literature |
| Social presence | Closure | Discussion about God, eternal life and hope |

(Kellehear, 2000 p.153)

A total of twelve articles describing studies involving palliative patients, carers and staff, undertaken to determine the nature of the spiritual needs of patients and families from the perspective of the above stake holders, were reviewed. All were studies completed and published subsequent to Kellehear's work described above. The findings of this review are summarised in Table 2.

*Table 2: Spiritual Needs of Palliative Patients and Carers*

| **Author** | Population | Method | Spiritual Needs Identified |
|---|---|---|---|
| 1. | 11 adult palliative patients – USA (Hart et al 2003) | Qualitative - ethnography | to be treated as a whole person with sensitivity, doctors willing to discuss spiritual issues, no preaching |
| 2. | 19 hospice patients – USA (Hermann, 2001) | Qualitative | 29 needs in 6 themes:<br>religion, relationships, control finishing business, experience nature, hope |
| 3. | 12 adult survivors of haematologic malignancy – Australia (McGrath, 2002) | Qualitative | Meaning, connection with life, relationships |
| 4. | 12 adult survivors of haematologic malignancy – Australia (McGrath, 2003) | Qualitative | to talk about spiritual issues, to be listened to, finding meaning |
| 5. | 95 cancer patients - USA (Miller, Pitman & Strong, 2003) | Quantitative self admin. questionnaire FACT-G* | 59% physicians should ask about spiritual needs, 61% physicians should offer help with taking to family about dying |
| 6. | 20 inoperable lung c<br>20 heart failure patients - Scotland (Murray, Kendal, Boyd, Worth & Benton, 2004) | Qualitative | spiritual needs independent of religion, need to talk but only when a relationship has developed. |
| 7. | 13 terminally ill patients – Netherlands (Proot et al., 2004) | Qualitative – Grounded Theory | Closure, religious rituals, hope |
| 8. | 6 hospice patients – USA (Stephenson, Drauker & Martsoff, 2003) | Qualitative | Beliefs, values, life story, connections, meaning |
| 9. | 141 nursing staff – Sweden (Strang, S., Strang, P. & Ternestedt, 2002) | Questionnaire – some open-ended questions | inner peace and harmony, meaning, religious practice, relationships, freedom/self responsibility |
| 10. | 21 cancer patients and 7 carers – USA<br>(Taylor, 2003) | Qualitative | relating to ultimate other, hope & gratitude, give & receive love, review beliefs, find meaning,<br>religious rituals |
| 11. | 19 adult cancer patients – Australia<br>(Thomas & Retsas, 1999) | Qualitative – Grounded Theory | finding meaning |
| 12. | 16 palliative care patients, staff and volunteers with first hand experience – UK<br>(Wright, 2002) | Qualitative – Phenomenology | to be treated as an individual,<br>forgiveness, religious practice,<br>relationships, story telling,<br>to be listened to |

* Functional Assessment of Cancer Therapy

The spiritual needs identified by the authors In Table 2, fall broadly within six categories which are: the need to be treated as a whole person, the need to have people willing and able to listen to them, the need for closure, religious needs, the need for effective relationships and the need to find meaning.

Similar needs were identified by Lin and Bauer-Wu (2003) in their integrative literature review and meta-analysis of forty-three articles. The studies they reviewed were undertaken in fourteen countries, by researchers from a variety of disciplines, investigating the psycho-spiritual well-being of cancer patients. Their review included studies published between 1985 and 2001 and so no doubt was based on some of the same material examined by Kellehear (2000). They noted the following four themes, which fall within the domain of spirituality as defined in this study: relationships and connectedness with others, a sense of faith, a sense of empowerment which included sense of joy and inner peace, a sense of personal value, fulfilling life business and living with meaning and hope. Lin and Bauer-Wu (2003) also identified two other themes and four sub-themes within the theme ‘sense of empowerment’ which have not been detailed here as they are considered to be of a psychosocial nature rather than spiritual. Sinclair et al. (2006) in their thematic review of spirituality literature in palliative care also reported the identification of similar spiritual needs.

## How Have Spiritual Needs Been Assessed?

Arising from these studies (most of which are qualitative in nature), which aimed to identify palliative patient’s spiritual needs, is the work of those researchers who have attempted to produce and validate spiritual assessment tools for use by palliative care staff. These have frequently been confined to a few questions which are religion based (Davies, Brenner, Orloff, Sumner, & Worden, 2002; Dudley, Smith, & Millison, 1995; Govier, 2000). There are however, a small number of assessment tools that are based on a much broader understanding of spirituality and spiritual needs. One such example is the JAREL Spiritual Well-Being Scale, a 21 item Likert-type scale (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996). This literature search however, found very few examples of studies in which the JAREL Spiritual Well-Being Scale had been utilised and none dealing specifically with palliative care participants.

The Functional Assessment of Chronic Illness Scale – Spirituality subscale (FACIT-Sp) (Daugherty et al., 2005; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002; Wasner, Longtaker, Johannes-Feg, & Borasio, 2005) is another spiritual assessment scale, the use of which has been more widely reported. Peterman, Fitchett, Brady, Hernandez and Cella, (2002) acknowledged three important limitations of FACIT-Sp as being: apparent significant demographic differences in scores; ceiling effects - especially in relation to the faith subscale; and the possibility that it does not address some aspects considered by some people to be important in spirituality such as forgiveness, generosity and love. Peterman et al. (2002) also reported that work was in progress on a twenty-three item version (FACIT-Sp-Ex). However, this literature review found no published work relating to this new version.

Other attempts to provide a measure of spiritual needs which were identified included: the Spiritual Well-Being Questionnaire (SWBQ) (Gomez & Fisher, 2003) – no evidence of application to palliative care; a comprehensive instrument (Galek, Flannelly, Vane, & Galek, 2005) – no evidence of trial or evaluation and the Moral Authority, Vocational, Aesthetic, Social and Transcendent (Mor-VAST) Model of assessment (Skalla & McCoy, 2006) – no evidence of evaluation and validation. The Spiritual Needs Inventory has recently been developed by Hermann (2006) . While showing promise the author indicates that further testing is needed. Two studies have been identified which have utilised this inventory of spiritual needs (Hampton, Hollis, Lloyd, Taylor, & McMillan, 2007; Hermann, 2007)

Issues relating to the application of some of the assessment scales discussed above, such as when they should be utilised, who should administer them and their suitability for very ill or distressed patients, have been reported (McSherry & Ross, 2002). These authors concluded that spiritual assessment in all its forms has not been adequately worked through. More recently Chochinov and Cann (2005) in their summary of evidence relating to interventions to enhance the spiritual aspects of dying, point out that ‘although quantitative approaches may suit particular protocols, qualitative methods may provide a greater understanding of spirituality and religiosity and enable the subjective reporting of experiences for which robust measures are only starting to emerge’ (p.S-112). These authors also suggest that future research in this important domain should engage a broad spectrum of skills and perspectives and be conducted across a broad band of international locations and settings.

There is clearly considerable interest in the subject of identifying and assessing the spiritual needs of palliative patients and their families. Common themes, relating to the nature of spiritual needs in this population, have emerged from numerous studies. The fact that spirituality is a very individual thing (Carroll, 2001; Narayanasamy, 2004; Tan, 2005) has however contributed to the difficulty of developing reliable and non-invasive spiritual assessment tools and interventions.

## What is Considered Important in the Implementation of Spiritual Care?

A number of aspects have been identified as important in the provision of spiritual care, whether as part of formal spiritual care programs or in the more general care of palliative patients.

As already indicated there are a number of challenges associated with the successful development and implementation of spiritual care programs, which encompass a broad understanding of the nature of spirituality. Among these are a lack of clarity of the concept of spirituality and the pressures to quantify a very subjective domain. These two issues have already been addressed in this literature review. Appropriate training for staff members of multi-disciplinary teams, to adequately and confidently meet the spiritual needs of patients and families is important, but is perceived to be lacking by many staff (Baldacchino, 2006; Brayne, Farnham, & Fenwick, 2006; Chibnall, Bennett, Videen, Duckro, & Miller, 2004; Highfield, Taylor, & Amenta, 2000; Milligan, 2004; Rose, 1999; Wasner, Longtaker, Johannes-Feg, & Borasio, 2005; Wesley, Tunney, & Duncan, 2004). The increasing acceptance of a concept of spirituality which may or may not include religious practice and the declining number of people in most western societies who are educated in and participate in religious practice points to the need for a non-religious language of spirituality to enable communication between patients, staff and families on spiritual matters. This has been recognised as most important in both assessing spiritual needs, and in providing appropriate spiritual care (Byrne, 2002; McGrath, 2002; Stanworth, 1997). Work has also been done towards recognising the spiritual needs of palliative patients through the symbols and metaphors of their language and art work (Stanworth, 2004).

A number of other general qualities have also been identified as important attributes for staff, in the recognition of spiritual needs, and the provision of spiritual care. Several authors have discussed the importance or self-awareness of staff in relation to their own spirituality and ideas and feelings about death, as well as their ability to attend to their own spiritual needs (Govier, 2000; Jackson, 2004; Ladbrook, 1998; Murphy, 1999; Narayanasamy, 1999; Stanworth, 2004). Other attributes that are considered to be important are: the ability to be with a person , rather than to do for them (Stiles, 1990) , to be comfortable with silence (Stanworth, 2004), and the ability to really listen (Harrington, 1995; Narayanasamy, 2004; Stanworth, 2004).

This ability to listen may well extend to creating the time and opportunity for the patients and families to tell their story, this having been found to be very important in the expression and resolution of spiritual needs (Friedemann, Mouch, & Racey, 2002; Kleinman, 1989; LeFavi & Wessels, 2003; Murphy, 1999; Stanworth, 2004; Taylor, 1997). Other authors discuss the therapeutic role of narrative analysis in the provision of care (Abma & Widdershoven, 2005; Caldwell, 2005; Carlick & Biley, 2004; Kuhl & Westwood, 2001).

Another attribute seen as important in the assessment of spiritual needs and the provision of spiritual care is the opportunity, and the ability of staff to refer particular patients to members of the team who have specialised knowledge and skills in spiritual care (Gordon & Mitchell, 2004; Heilferty, 2004; Taylor, Amenta, & Highfield, 1995). Gordon and Mitchell (2004) discuss a pilot study in which they trialled the Spiritual and Religious Care Competencies for Specialist Palliative Care Program developed by Marie Curie Cancer Care. This model of spiritual care and assessment is based on the individual competence of all health care professionals to deliver spiritual care, and is presented as an alternative to the search for a definition of spirituality and spiritual care and the development of assessment tools.

There is general agreement that there are a number of characteristics that are related to the ability to implement spiritual care in an effective manner. These include an awareness of one's own spirituality and spiritual needs, an ability to listen effectively, a work culture that allows for extensive periods of listening to stories and the inclusion of team members with specialised skills in the provision of spiritual care.

## What Specific Spiritual Care Programs Have Been Developed?

There is a dearth of literature that outlines specific spiritual care programs and reports on their implementation. The programs identified in this literature review fall broadly into three categories:

- General frameworks within which a consciousness of providing spiritual care within the general care of the patient can be achieved.
- Those that refer to overall spiritual care programs which include assessment of needs and strategies for meeting them which are uniformly applied.
- More specific programs that are designed to meet some spiritual needs and are intended to be used selectively in conjunction with the approach that attempts to integrate spiritual care into all aspects of care by acknowledging the value of effective listening, good staff self awareness, willingness of staff to engage in conversation on spiritual matters and appropriate referral to relevant spiritual guides.

There was also some literature that discussed palliative care programs, purported to be holistic in approach, and giving mention to spiritual care, but with the only evidence of this actually occurring being the statement that there was a chaplain on the team (Nelson & Walsh, 2003).

Three examples of general frameworks within which, a consciousness of providing spiritual care within the general care of the patient, were found. The Sacred Circle (Paton, 1996) is a conceptual frame-work for exploring or explaining spiritual issues. It is a 4 part circular process of change.

- Via Positiva (the wonder and power of creation, the role of beauty, transcendence and inspiration)
- Via Negativa (dare to enter the darkness, the acknowledgement of pain, suffering, loss, encouraging prayer and meditation)
- Via Creativa (gateway to compassion, process of discovery that works towards solutions to problems)
- Via Transformativa (creativity leads to new possibilities, growth and transformation

A second example is described by Friedemann, Mouch and Racey (2002) and uses the Framework of Systemic Organisation, advocating a balance between spirituality and control within the patient system, to give a framework for spiritual care. The authors acknowledge that this requires a caring and trusting relationship between patient and the health-care professional, and self awareness on the part of this professional. It is a patient driven approach. It is suggested that although assessment of spiritual needs can be made using scales such as JAREL, individual informal assessment by caring skilled people is considered more appropriate. This way of working incorporates the notion that assessment and intervention are intertwined and so encourages the use of story telling both as a means of revealing specific needs while at the same time addressing others.

A third example in this category is called the Strengthening Transcendent Meaning Model (Emblen & Pesut, 2001). This model is based on five areas of spiritual assessment and intervention intended to be appropriate for all individuals regardless of religious or spiritual belief and to lead to the finding of transcendent meaning. The five areas are: authority and guidance, experience and emotions, community, rituals and practice, vocation and consequence. Some suggestions are made for questions to be asked to facilitate understanding of each area and interventions that may be helpful.

The literature review also identified four overall spiritual care programs which include assessment of needs and strategies for meeting them, which are offered to all patients. The most frequently cited, but also the earliest published, of these is the JAREL Spiritual Well-Being Scale. It is designed to assess spiritual needs of patients and also suggests some interventions such as affirmation (listening to discover “gifts” and blessings to be affirmed finding positive ways to approach the seemingly negative), therapeutic communication (discovering strengths and areas of pain and loss which nurses may use as a process for meeting these needs). It also proposes that sometimes silence and presence are more important than speaking. It suggests that listening (for meaning) reminiscence (exploring the meaning of significant life events, unfolding concerns, completing unfinished business) and referral (only after discussion with patient and only if they agree) may also be important in meeting needs.

Highfield (2000) also developed an outline for the provision of spiritual care to cancer patients.  The main features of this program include:

- clarity about the nature of spirituality and religion,
- the gathering of data relating to religious practice and other spiritual expression in three areas of spiritual need fulfilment which are: religion/values, personal beliefs and practices
- self assessment by nurses of their own spiritual and religious values
- fostering a relationship with patients of care and trust
- some suggested questions for facilitating the gathering of data
- designing a plan of care to deal with unmet needs
- documentation of needs and plans

- creating a work environment in which there is a climate of spiritual care.

A third general model for the provision of spiritual care is the Trent Hospice Audit Group (THAG) model (Hunt, Cobb, Keeley, & Ahmedzai, 2003). This involves three levels of ongoing assessment of spiritual need:

- routine basic information for all patients at admission
- multidisciplinary assessment sensitive to spiritual issues expressed by patient or carers, or observed by staff members
- specialist assessment (usually by the chaplain) to explore in depth issues. It is suggested that the Royal Free Interview Questionnaire (M. King, Speck, & Thomas, 2001) be used for this purpose. This is an eighteen item questionnaire exploring religious and spiritual beliefs.

Documentation to record the levels of assessment done, the plan to be implemented for this patient and who will lead its implementation, are matters considered important. The developers of the THAG model, on the basis of feed-back, have suggested that levels 1 and 2 may be combined and that there is a need to cover a wider range of existential issues for use at the third level of assessment. Further evaluation of this program carried out by Hunt, Keeley, Cobb and Amedzai (2004) makes no reference to the evaluation of spiritual care.

The Competency Model (Gordon & Mitchell, 2004) proposes a 4 level competency framework based on knowledge, skills and actions that outline the level of spiritual and religious care to be offered by all staff and volunteers according to their level of competency. This model seeks to integrate spiritual care into all care rather than assess it as an individual element of care. The importance of staff self-awareness of their own level of competency is emphasised. The four levels are described as follows:

- Level 1 – all staff and volunteers who have casual contact with patients and families –an awareness of religious and spiritual needs, basic skills of awareness, communication and relationship and ability to refer.
- Level 2 – staff and volunteers whose duties require contact with patient and families – enhanced level 1 competency with increased knowledge of how spiritual needs may be identified.
- Level 3 – members of multidisciplinary team. – a higher level of ability in the areas described for level 2. This category moves into formal assessment of spiritual needs and developing care plans and it includes confidentiality issues and recording.
- Level 4- those whose primary responsibility is spiritual care. In addition to level 3 competencies, staff at level 4, need to be able to manage and facilitate complex patient and family needs and to liaise with external sources and provide training and resources for other levels.

The most recently published model, which incorporates spiritual assessment and care of palliative patients, along with a range of physical, psychological and social issues, is the Dignity Model which is designed to be used selectively in conjunction with the approach that attempts to integrate spiritual care into all aspects of care (Chochinov et al., 2005; Chochinov et al., 2006). This model includes the intervention known as Dignity Therapy. Patients are invited to discuss issues that matter most to them and that they would want remembered. Sessions are transcribed and edited and the final version is then returned to the patient.

Murphy's (1999) family meeting program is designed to meet some spiritual needs, and as with the Dignity Model above is intended to be used selectively in conjunction with the approach that attempts to integrate spiritual care into all aspects of care. The family meeting is described by Murphy, as being in many ways a sacred event. It is a time for making peace, discharging old resentments, giving thanks and saying goodbye. Murphy (1999) has developed a five-part paradigm to guide families through this process:

- The story of the Wound (told by the dying member)
- Worries and Fears
- Roots – bringing out memories from the shadows
- The family speaks
- The Blessing

A very important aspect of this model is its flexibility. The lack of prescriptive detail makes it suitable for working with a broad spectrum of family situations. However this flexibility does require skill on the part of the facilitator, particularly an ability to observe and respond appropriately to emotional expression and other non verbal cues. For this reason Murphy stresses the importance of appropriate training and care of staff. No evidence was found that the efficacy of this model, as an instrument of spiritual care, has been assessed.

It is acknowledged, that despite the paucity of publications relating to the provision and evaluation of programs designed to meet the spiritual needs of palliative patients and their family members, some spiritual care, both formal and informal, is being made available to this population. This would be particularly true for those who have active involvement in a religious community. However, grey literature which may have provided further information about these types of spiritual care, was not considered in this review.

## Focus on the Patient Only or on the Family Unit?

There is increasing evidence that to work with the whole family rather than to focus attention entirely on the patient, especially in a palliative care setting where the family members are often closely involved in the care of the patient, has better outcomes for both patient and family members (Kissane & Bloch, 2002; Nadeau, 1998; Parkes, Relf, & Couldrick, 1996; Waldrop, Milch, & Skretny, 2005). The WHO National Cancer Control Programs: Policies and managerial guidelines (2002) has stressed that the needs of the patients' family members and caregivers should be addressed in the provision of palliative care. This premise is based on the notion that families are systems and that the illness or death of one member alters the balance of the system, has impact on all other parts of the system and requires the negotiation of a new balance within the system (Hoffman, 1981; Kemp, 1995).

Kissane and Bloch (2002) have pointed out that 'a family is conventionally defined as a group of persons linked by kinship, which can be established through lines of descent that connect blood relatives, or through marriage' (p.9). These authors do, however, indicate that with changing social circumstances clinicians generally accept family as being that which is presented by the patient. Kristjanson and Aoun (2004) suggest that the usual practice in palliative care systems is to regard the family as the 'unit of care' (p. 360) rather than just the patient. Broader definitions of the family, are now widely used, such as that quoted by Kristjanson and Aoun (2004, p.360) from the Canadian Palliative Care Association (1998).

> The family is defined as those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage /contract), and the family of choice and friends (not related biologically, by marriage/contract).

A number of researchers who have undertaken work to investigate the impact of illness, death and grief on the family system were identified in this literature search. Rando (1984) reported that the degree to which families are able to redefine themselves in the face of the death of one of their members is dependent on the level of family functioning and their ability to enter into dialogue with each other.

Parkes, Relf and Cauldrick (1996) expressed the view that assessment of family risk begins from the first contact with the family and requires that health professionals get to know the family, their characteristics and issues (p.106). They also reported that problematic relationships including secrets, unresolved conflicts and poor communication increase the chance of complicated grief. They found that family members who are prepared emotionally and have a sense of having done everything they could do, cope much better with bereavement (p.100).

Nadeau (1998) found that during the bereavement process both individual and family meaning was re-negotiated and that the ease with which this occurred depended on the openness and level of communication within the family. The importance of family communication for the mental health of cancer sufferers was also identified by Mallinger, Griggs and Shields (2006) . Other authors, (Cohen et al., 2006; Northouse, 2005; Tanyi, 2006) have reported studies in which positive outcomes were achieved in working with families and carers as opposed to just patients.

Kissane and Bloch (2002) have undertaken a major study leading to the development of a model of family-centred care during palliative care and bereavement. This process involved the screening of families (as opposed to individuals) on the admission of the patient to the palliative care service, in order to identify families at risk of complicated grief. They found that some family types were at much greater risk, and of those at risk some had the capacity to benefit from family grief therapy interventions and others did not.

In a recent review of literature relating to working with families in end of life situations King and Quill (2006) indicate that while comprehensive palliative care must involve working with the family unit, numerous dynamics around communication and problem solving operate in family systems. For this reason one way of assessing needs and meeting them will not be appropriate for all families.

The increasing interest in spiritual care, especially in the palliative care context, has generated a number of attempts to offer models of care and interventions designed to facilitate this care. Most of these interventions focused on the spiritual care of the patient and in a few cases also considered the care of family members individually. The proposed methods of providing spiritual care identified in this review included those that attempted to integrate spiritual care into the general care of the patient, those that prescribed a one method for all approach and those that offered an intervention to be selectively used for assisting in the meeting of spiritual needs of the patient (Chochinov et al. 2005; Chochinov et al. 2006; Murphy 1999). The latter of these focuses on the family as a unit (Murphy 1999).

## How Have These Programs Been Evaluated and What Other Options for Evaluation Have Been Utilised in Health Care Programs?

With the move to evidence based care throughout the health system and the consequent increased emphasis on accountability and evaluation of all domains of care (Catterall, Cox, Greet, Sankey, & Griffiths, 1998), the evaluation of spiritual care programs is also very important if this domain of care, already established as essential in the palliative care setting, is to assume it's rightful place in the total care system.

The author citation searches carried out for all of the proposed spiritual care programs discussed in the section above, revealed no published evidence that there had been an independent evaluation of any of these programs to date, apart from the Dignity Model (Chochinov et al. 2005; Chochinov et al. 2006). The impact of Dignity Therapy on some measures of psychosocial and spiritual distress has been measured. It was found to be a helpful intervention in meeting some of the spiritual needs of patients. Dignity Therapy, originally developed from data derived from a qualitative research study has been validated with the use of a 22 item questionnaire which incorporated questions relating to psychological, physical, existential and social well-being.

Gordon and Mitchell (2004) have discussed the pilot study of the education program for the Competency Model but to date there is no published data relating to evaluation of the implementation of the model in a palliative care setting.

In view of the lack of evidence of evaluation of spiritual care programs to date, and the unsuitability of available spiritual needs assessment tools for the evaluation of a complex intervention such as a family meeting, it was evident that a different approach to evaluation was needed. Realistic Evaluation was considered as a framework for designing suitable evaluation methods for spiritual care intervention programs. Journal Watch (Service, 2003) has quoted other authors as follows, in describing realistic evaluation:

> "The question asked by realistic evaluation is 'What works, for whom, in what circumstances and why?' (Pawson & Tilley, 1997; Tilley, 2000) This compares with the questions asked by traditional experimentation, which are 'Does this work?' or 'What works?' Realistic

> evaluation is a form of theory driven evaluation which aims to understand causal mechanisms and the conditions under which they are activated to produce specific outcomes" (p.8).

Pawson and Tilley (1997) discuss the complex nature of many interventions and hence their unsuitability for evaluation in terms of simple variables. They argue that before an evaluation can be designed, consideration has to be given to the contexts within which the intervention operates and the mechanisms by which it may bring about change. Only when these have been hypothesised can decisions be made as to exactly which outcomes are likely and how these can be measured. In complex scenarios this evaluation will inevitably involve a variety of research methods. Other authors (Byng, Norman, & Redfern, 2005; Redfern, Christian, & Norman, 2003; Slade, Kuipers, & Priebe, 2002) have discussed the implementation of realistic evaluation as a framework for designing evaluation programs in a variety of settings including mental health programs, prison education programs and the impact of interventions on the prevalence of crime in housing estates. Slade, Kuipers and Priebe (2002) express the view that mental health services will only move towards being rationally planned, developed and evaluated when research agenda look towards an understanding, rather than an explanation, of what aspects of a social program produce change; in what way, for which people and in what context.

It is clear from this literature review that despite the big surge in interest in this area in recent years there is still a paucity of literature relating to the implementation and evaluation of spiritual care programs.

# Discussion

Identifying the spiritual needs of palliative patients and their families is clearly an essential beginning point in the provision of spiritual care. Whether or not one accepts Kellehear's (2000) tenet that the fundamental concept of spirituality is the desire to transcend, the specific needs he identified within each dimension of his multi-dimensional model are consistent with, and inclusive of, those spiritual needs identified in the more recent studies summarised in Table 2. The spiritual needs identified by Lin and Bauer-Wu (2003) and by Sinclair et al. (2006) are also encompassed by Kellehear's model.

These spiritual needs identified by Kellehear (2000), are also those that could be anticipated if we accept that the nature of spirituality is accurately represented by Coyle's (2002) transcendent approach to spirituality, as described in the "Background" section of this chapter. For the purpose of this study, Kellehear's model of needs will be used as guide to understanding the degree to which spiritual needs are being met by spiritual care programs, already being offered, or being proposed.

Attempts have been made to develop spiritual needs assessment tools, driven by the need for an easy to apply means of determining individual spiritual needs and the increasing pressure to apply the rigours of research to all areas of practice, including spirituality which is clearly a very subjective domain (McGrath, 1997).

A number of characteristics have been identified as important in the implementation of spiritual care in the palliative setting. It would seem that most spiritual care programs consist of an overall consciousness of the importance of spiritual care. Supplementary to this is the encouragement, though often not by formal training, of the development by staff of the general qualities described, in the hope that spiritual care will be integrated into all aspects of care for palliative patients and their families.  There is also a general acknowledgment that specialist knowledge and skills are required for the implementation of comprehensive spiritual care.

The studies cited would suggest that it cannot be assumed that all staff having contact with palliative patients and their families possess the appropriate skills for the integration of spiritual care into the general care of the patient.  With this in mind it would seem that the Competency Model proposed by Gordon and Mitchell (2004) may be a useful tool for increasing staff awareness of their competency level and identifying possible needs for further training.  It is also evident that if spiritual care is to embrace a broad understanding of spirituality, as discussed above, the traditional stereotype of the specialist spiritual care provider as being a Christian chaplain of one denominational background or another, may need expansion.

One of the first criteria for assessing the value of a suggested spiritual care program would be the degree to which it takes into account the perceived spiritual needs of the population it is designed to serve.  Using Kellehear’s (2000) Model of Needs, as discussed above, it can be observed that the spiritual care programs discussed vary considerably in relation to the degree to which each attempts to meet patient spiritual needs, as revealed by the author’s outline of the program.  Another important area in the implementation of a spiritual care program is an awareness of the staff skills that will be required to implement this program.  Table 3 categorises the spiritual care programs reviewed in relation to the identification of patient spiritual needs which are to be met and the needs of staff and the skills required for program implementation.

***Table 3:Degree to which Spiritual Care Programs Identify Spiritual Needs to be met and Staff Needs Considered.***

| | Client Needs to be Met Specified but not Comprehensive | Some General Areas of Client Needs to be Met Only | Client Needs to be Met Not Specified at All |
|---|---|---|---|
| Required Staff Skills Specified | Murphy (1999) | Nil | Gordon (2004) |
| Some Mention of Required Staff Skills | *Friedemann et al. (2002) if JAREL scale used.<br>Hungelmann et al. (1996)<br>Chochinov et al (2005) | Highfield (2000a) | * Friedemann et al. (2002) if JAREL not used. |
| Required Staff Skills not Considered | Hunt et al. (2003) if using RFIQ** | Paton (1996)<br>Emblem & Pesut (2001) | Nil |

*classification depends on method of assessing needs chosen

** Royal Free Interview Questionnaire (King, Speck & Thomas 2001)

It should be noted that only Murphy’s family meeting model took any account of working with the family as a unit. Although not all needs described by Kellehear (2000) are mentioned by Murphy (1999) in relation to his described intervention, it would seem to offer the possibility of meeting all spiritual needs depicted in Kellehear’s model, with the probable exception of visits by clergy (although some clergy would be suitable guides), religious literature and philosophical discussion about God, eternal life and hope (although elements of these may well be included with families for whom this was important).

In the current climate of evidence based practice in all areas of the health care system it is clear that no program can be considered adequate or incorporated into an overall care program until it has been appropriately assessed.  As no evidence was found of the evaluation of any of the proposed spiritual care programs, with the important exception of the Dignity Therapy Model (Chochinov et al., 2005), clearly a large gap exists in this area of the research into the spiritual care of palliative patients and their families.  The “reasonable evaluation” concept offers a suitable means of designing an evaluation program for a complex area of research such as the evaluation of a spiritual care program. Clearly many variables need to be considered in designing such an evaluation. Some examples of these, based on the “what works, for whom, in what circumstances” paradigm described by Pawson and Tilley (1997), would include:

- Circumstances - home care, hospice care, hospital care
- For whom - Patients (what age, sex, nearness to death, expressed spiritual needs, religious background if any, family circumstances), Family members (what relationship to patient, nature/closeness of the relationship, expressed spiritual needs, age, sex, etc), Staff (role of staff, degree of interaction with patient and/or family, training in skills identified as necessary for spiritual care, attitude to spiritual care etc)
- What works - What does working mean? What will be measured? Can the cause of the difference between working and not working be identified?
- In such a complex evaluation process more that one type of research method would be needed, a range of studies which is beyond this particular work.

## Conclusion

Although there is still conjecture about the definition of spirituality and its relationship to religion, the understanding now generally accepted, is a broad view of spirituality, which embraces religious expression as one aspect of spiritual expression that is important for some people. Numerous attempts have been made to develop ways of assessing the spiritual needs of patients and from these some models of spiritual care have evolved. Some of these are much more comprehensive than others, both in terms of needs they seek to meet, and awareness of staff skills required for their implementation. Murphy’s (1999) family meeting model, while making no claim to be universally applicable, took into account the needs of clients, the skills required by staff for the implementation of the intervention and also embodies the notion that families (in their broadest sense) are systems and that the illness and approaching death of one of its members impacts on the rest of the system.

Despite the work done on the identified models for the implementation of spiritual care, apart from the Dignity Model, there was no evidence found that any of these had been evaluated in a palliative care situation. Clearly this constitutes a significant gap in the literature. The concept of “reasonable evaluation” offers one suitable method from which to begin the assessment of spiritual care programs.

This study will endeavour to begin to fill the gap in the literature which has been identified by assessing the family meeting model proposed by Murphy (1999) as an instrument of spiritual care in a palliative care setting. A more detailed account of this model is presented in Chapter 5. The methodology underpinning this investigation will be explained in the next chapter.

# CHAPTER THREE – THE PHILOSOPHICAL PREMISE:

# HERMENEUTIC PHENOMENOLOGY

## Introduction

The key purpose of this study is to investigate the experience of palliative patients, and their family members, of participating in a family meeting used as an instrument of spiritual care and conducted according to Murphy's model. Crucial to this investigation is the expression, telling the story, of the essence of their experience. The stories are then interpreted so that the investigator can come to an understanding of the essence of their experience. Hermeneutic Phenomenology, which refers to both a philosophy which underpins this qualitative study, and a research methodology has been selected as a basis for the investigation of the research questions which were outlined at the end of chapter one.

There are four basic elements to the qualitative research process. Crotty (Crotty, 1998) identifies and defines these as follows:

> *Methods* – the techniques and processes used in the collection and analysis of data which are appropriate for the research question under study.
>
> *Methodology* – the strategy or plan, the process of the design that lies behind the choice of particular methods and links these methods to the desired outcome
>
> *Theoretical Perspective* – the philosophical stance informing the methodology and providing a context for the process
>
> *Epistemology* – the theory about knowledge and how it is gained that underpins the theoretical perspective and hence the methodology of the study (Crotty, 1998), p.3).

This chapter outlines the epistemology and theoretical perspectives out of which hermeneutic phenomenology has arisen. It also reviews the historical influences which informed the development of Paul Ricoeur's theory of interpretation, utilised in the analysis of data in this study, including the philosophies of Husserl, Heidegger and Gadamer. The relevance of this research methodology to human science research in general, and to the particular research questions that are addressed in this study are also discussed.

## Epistemology and Theoretical Perspective

As Maynard (1994) points out 'epistemology is concerned with providing possible philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate' (p.10). The epistemological perspective of constructionism claims that meanings are constructed by human beings as they interact with a world which they are interpreting, and that in order for this to occur there must be beings who are capable of interpreting (Crotty, 1998). Meaning is therefore constructed, rather than created, and is transmitted through social interaction. This implies that from a constructionist viewpoint, knowledge (or truth) is neither completely objective nor completely subjective. The researcher and the study participants remain separate conscious individuals through out the research. However, as the researcher focuses their conscious attention to the objects of the research (in the case of this study, the patient, family member and staff participants and their experience of the family meeting), there is an interaction between them from which neither can be completely objective. The meaning of, or the truth about the experience of the family meeting, is constructed both by an interaction between the researcher and each individual present, but also between the family members taking part in the meeting.

Interpretivism is one of the theoretical perspectives or philosophical stances informed by the epistemology of constructionism. In interpretivism the emphasis is on interpreting experienced or observed phenomena, rather than on explaining in the sense applied in natural science (Crotty, 1998). There are a number of theoretical perspectives that claim to come under the general umbrella of interpretivism but the one which was selected as most appropriate for the purposes of this study is Hermeneutic Phenomenology.

Both ‘hermeneutics’ and ‘phenomenology’ have been variously defined, but for the purposes of this study they are taken to have the following meanings:

> <u>Hermeneutics:</u> This is the “art and science of interpretation” (Ezzy, 2002) especially as it applies to text.
>
> <u>Phenomenology:</u> This is the study of the essence of a phenomenon as it presents itself in lived experience in the world (Crotty, 1998).

The evolutionary process by which hermeneutics and phenomenology came together to form a new theoretical perspective and research methodology, known as Hermeneutic Phenomenology will be outlined in the following section.

## Towards a Hermeneutic Phenomenology

### Edmund Husserl

From the time of the French philosopher Descartes (1596-1659) to Edmond Husserl (1859-1938), the work of philosophers was dominated by epistemology, the search for the foundations of knowledge. In this time much was written about the so called Cartesian Model of Duality, of mind-body split or subjective-objective duality (Koch, 1995) . Husserl argued however, that living subjects do not simply react to external stimuli but rather respond according to their own perception of what these stimuli mean.  He introduced the term ‘life world’ which was understood as being what is experienced pre-reflectively (Husserl, 1931) .  Husserl, widely acknowledged as the father or founder of phenomenology, considered the three key notions of intentionality, essences and bracketing as essential to phenomenology.

For Husserl the key to the study of a phenomenon was through consciousness and, as he saw it, access to the structures of consciousness was not a matter of induction or generalisation but rather a result of grasping the phenomenon.  This grasping was an intentional process, one in which the mind is intentionally directed towards objects of study. Husserl described his notion of intentionality as an indispensable starting point for phenomenology (Husserl, 1931),  p.245).  He proposed that in this process one could come face to face with the ultimate structures of consciousness and he identified these ultimate structures as the essences that made the object or experience unique.

However, the identification of the essences requires, according to Husserl’s theory, phenomenological reduction, or “to set aside all previous habits of thought, see through and break down the mental barriers which these habits have set along the horizons of our thinking …. to learn to see what stands before our eyes” (Husserl, 1931), p.43).  Bracketing, as this process has become known, is not a doubting of the existence of the things bracketed but rather is an attempt to avoid being influenced by judgements about them (Hopkinson, Wright, & Corner, 2005; Husserl, 1931). Through the process of bracketing Husserlian Phenomenology claims objectivity of interpretation. The philosophers Heidegger and Gadamer, among others, however, did not agree that this objectivity was possible or even desirable.

## Martin Heidegger

Martin Heidegger (1889-1976), who worked with Husserl for a time, later claimed the right to build further on his understanding of phenomenology. Rather than focusing on epistemological questions of knowing, of being in the world but separate from it, as Husserl did, Heidegger took an ontological stance, a focus on the nature of being or the nature of existence, to the point of considering ontology and phenomenology to be inseparable.

> Phenomenology is our way of access to what is to be the theme of ontology, and it is our way of giving it demonstrative precision. Only as phenomenology is ontology possible (Heidegger, 1967), p.60).

Heidegger embarked on a phenomenology of human being, or as he termed it Dasein. He used this term Dasein to denote the essential nature of the human being, which includes the ability to inquire into the nature and possibilities of Being (Heidegger, 1967, p.27). His primary question was 'what is it like to be a human being who is both in and of the world?' In defining phenomenology he acknowledged that this word is derived from two Greek words, *phainomeno* translated "phenomenon" and *logos* (Heidegger, 1967). Heidegger in his analysis of the origins of the word phenomenology comes to the conclusion that "phenomenon" as used in this context, signifies "that which shows itself in itself" (p.51). It is evident that the word *logos* has been translated in various ways but Heidegger points to Aristotle's claim that *logos* is discourse "that lets something be seen from the very thing which the discourse is about" (Heidegger, 1967, p.56). In combining the meaning of these two words he concluded that *phenomenology* means, "to let that which shows itself be seen from itself in the very way in which it shows itself from itself." The beginning of this journey towards *"Being"* is a pre-understanding, which we all possess, which he calls the 'fore-structure'. As (Crotty, 1998) points out, arriving at this pre-understanding is already a phenomenology and "its further unfolding, together with the manifestation of Being itself and the unveiling of other phenomena in the light of Being, remains a phenomenological process throughout" (p.97).

However, to speak of revealing and unveiling, has connotations of description, interpretation and of language and hence of hermeneutics. Heidegger's use of the word 'hermeneutics' was certainly not original or unique but as he suggests in his book 'Being and Time' (1967), life is like a text. For Heidegger, hermeneutics was not a body of rules for interpreting text, nor a methodology of the human sciences as Dilthey understood it. Rather, as (Crotty, 1998) explains, 'Heidegger's hermeneutics starts with a phenomenological return to our being, which presents itself to us initially in a nebulous and undeveloped fashion, and then seeks to unfold that pre-understanding, make explicit what is implicit, and grasp the meaning of Being itself' (p.97). This more enlightened understanding of Being then enriches our existence in the world and becomes a part of our fore-understanding of future experience. This of course makes reference to Heidegger's version of the Hermeneutic Circle.

'This circle of understanding is not an orbit in which any random kind of knowledge may move; it is the expression of the existential (relating to existence) fore-structure of Dasein itself' (Heidegger, 1962), p.195). From Heidegger's perspective fore-structure or pre-understanding is a fact of our being in the world and it is not something we can eliminate, or bracket as Husserl claimed. Heidegger asserts that there is nothing which can be encountered without reference to a person's background and pre-understanding and that we cannot have a life in the world except through acts of interpretation (Heidegger, 1962). The practical implication of this is that interpreters participate in making the data (Koch, 1995).

In this study the presence of the facilitator of the family meeting, their style of facilitation, their impact on and interaction with each individual interviewee, as well as their process of interpretation, are all a part of the creation of a new understanding of the experience of the family meeting.

## The Relevance of Heideggarian Hermeneutic Phenomenology for Human Sciences Research.

In recent years hermeneutic phenomenology, as attributed to Heidegger, has been utilized in human sciences research in various disciplines such as in nursing (Evans & Hallett, 2007; Koch, 1995; Todres & Wheeler, 2001), in mental health (Barnable, Gaudine, Bennett, & Meadus, 2006; P. Thomas, Bracken, & Leudar, 2004) in the study of the experience of hope (Dickerson, Boehmke, Ogle, & Brown, 2006) and the experience of grief (Fielden, 2003). Hermeneutic phenomenology, being the process of interpreting the description (text) of human experience, in order to understand the central nature of that experience, is therefore a very suitable research methodology for human sciences research.

However, the work of Husserl and Heidegger, while providing a very appropriate philosophical foundation for research in the social sciences that seeks to investigate the meaning of lived experience, from the perspective of those who are living it, lacks clarity of process. This makes it difficult to assign the degree of rigour to the work which is demanded in an era that has been dominated by the positivist paradigm for which “truth” can only be identified by processes regarded as totally objective. The work of Gadamer (1900-2002) and Ricoeur (1913-2005), further developed Heidegger’s ideas, in the areas of method and interpretation of Hermeneutic Phenomenological research, in a direction that has addressed this difficulty

## Hans-Georg Gadamer

Gadamer, a student of Heidegger, is known more for his hermeneutics than for his phenomenology, stating in the introduction to his well known text “Truth and Method” (1989), that these studies were concerned with the problem of hermeneutics (Gadamer, 1989). In this text he deals with the obsession for the development of objective method in human sciences and his approach, is an attempt to overcome this and to ask what is going on in methods, what is occurring during the research process (Koch, 1995)? Like Heidegger, although perhaps even more strongly, Gadamer believed that it was impossible for researchers to completely separate themselves from their prejudices, or in Heideggarian terms from their fore-understanding. Two key aspects of Gadamer’s thinking were that we stand in tradition and that tradition is irrevocably linked to language. Two pivotal concepts that he discussed, in connection with this thinking are: his understanding of discourse and the concept of ‘the fusion of horizons’.

From Gadamer’s perspective the interaction between researcher and participant, or between reader and text is a constant discourse, conducted in a manner that remains always open to the possibilities. In this sense interpretation is a collaborative process. Entering into this process is also what Gadamer calls the fusion of horizons. He sees this process of being one of constant mediation between the past (tradition, culture, experience) and the present ‘horizon’ of the interpreter. This means that as soon as we really open ourselves to a question, our historical understanding (the one that we have as a result of all our previous experience or knowledge of the question), is immediately superseded by the impact of the present horizon, our exposure to the experience, views and understandings of those with whom we interact in that moment.

> Thus the movement of understanding is constantly from the whole to the part and back to the whole (Gadamer, 1989, p.291).

In other words our understanding is continually expanding as we continually expose it to dialogue with text or research participants, a concept which is cognisant with Heidegger's Hermeneutic Circle.

## Paul Ricoeur

Ricoeur, who, as already indicated, was a contemporary of both Heidegger and Gadamer, is probably best known for his theory of interpretation which arose from his work, primarily released in a series of publications during the 1970's, some of which will be referred to later in this chapter. The development of this theory, and his more general contribution to hermeneutical phenomenology, was as he himself acknowledged, the outcome of the interaction of his own thinking with that of Husserl, Heidegger, Gadamer, the French philosopher Gabriel Marcel and others.

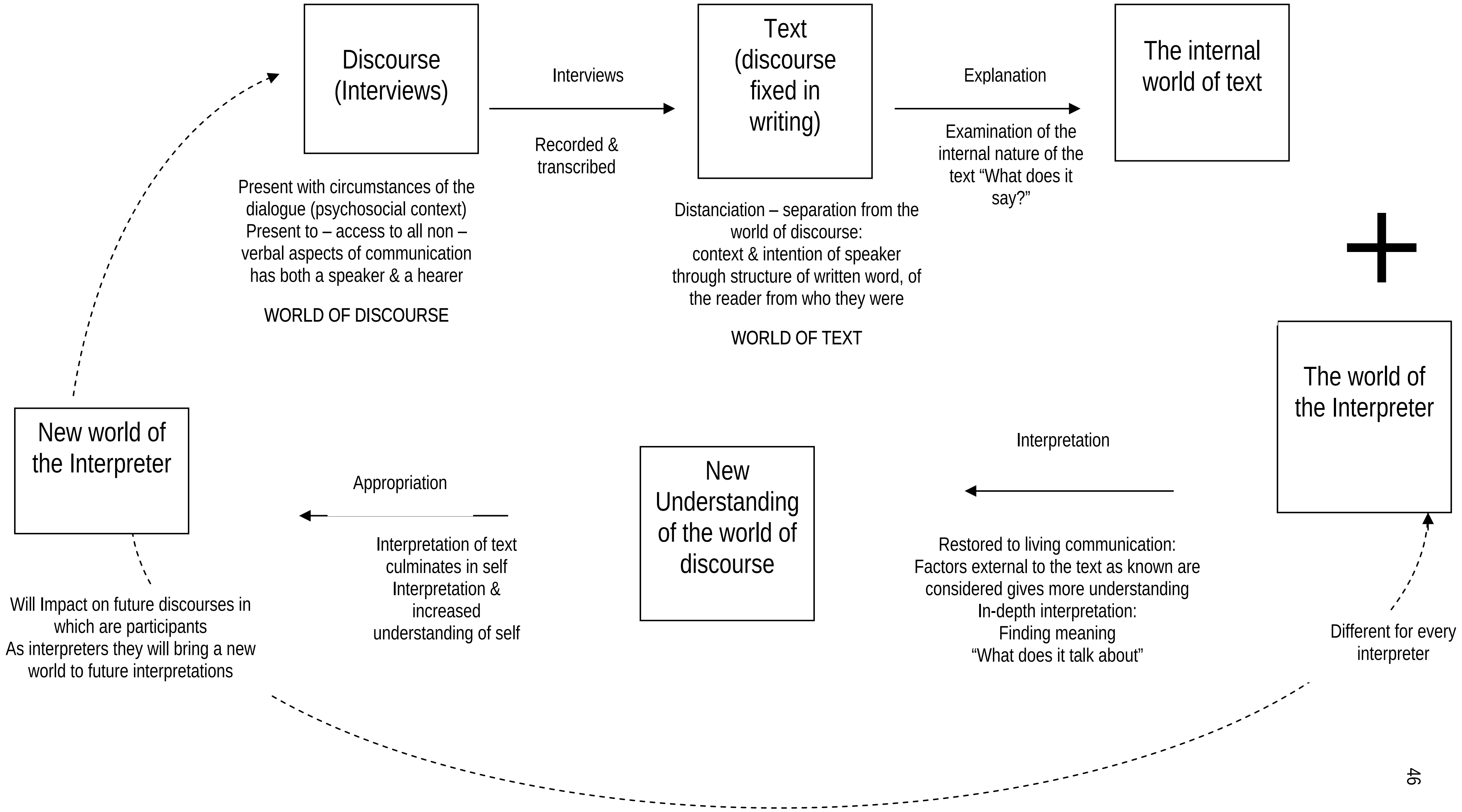
Ricoeur, more than any other cemented the connection between hermeneutics and phenomenology which had been put forward by Heidegger. As Thompson points out in his introduction to Ricoeur (1981, p.21), despite the increasing focus on hermeneutics in Ricoeur's later writings, the mutual affinity between hermeneutics and phenomenology provided the philosophical basis for much of his work. Ricoeur described this connection as follows.

> On the one hand, hermeneutics is erected on the basis of phenomenology and thus preserves something of the philosophy from which it never the less differs: *phenomenology remains the unsurpassable presupposition of hermeneutics.* On the other hand, phenomenology cannot constitute itself without *hermeneutical presupposition* (Ricoeur, 1981, p.101).

Arising from Ricoeur's hermeneutical critique of Husserl's idealistic presentation of phenomenology, are a number of key concepts, which need to be understood in order to grasp and apply his Theory of Interpretation. These include his understanding of text and ‘distanciation’ and his concept of appropriation.

These concepts will be discussed in more detail below but in order that they can be viewed in the context of the overall process of interpretation as Ricoeur proposes it, his Theory of Interpretation is present in diagrammatic form in Figure 1 (p.46). As will be observed as the detailed discussion of the concepts unfolds, this diagrammatic representation is inevitably an over simplification of his theory of interpretation.

Figure 1 – Ricoeur's Theory of Interpretation



## Text and Distanciation

Fundamental to an understanding of Ricoeur's theory of interpretation is a grasp of his concept of text. Central to this understanding is his concept of distanciation - a standing separate from or being objective in relation to the text. Ricoeur, (1981, p.145) begins his argument, by stating that "text is discourse fixed in writing." His discussion of the nature of the relationship between speech and writing, and the role of the writer and the reader compared to that of the relationship between participants that occurs in the situation of a spoken discourse, leads in the first instance to the conclusion that:

> The emancipation of the text from the oral situation entails a veritable upheaval in the relations between language and the world, as well as in the relation between language and the various subjectivities concerned (that of the author and that of the reader) (Ricoeur, 1981, p.147).

Ricoeur's argument is further progressed as he points out that in the case of speech, those who are involved in the discourse, are present in the same psycho-social circumstances of the dialogue and also have the opportunity to be conscious of the non-verbal aspects of the dialogue. This is no longer achieved when text takes the place of "live" discourse (Ricoeur, 1981), p.148). This is also consistent with Gadamer's contention that the hermeneutical task is to discern the 'matter' of the text and not the psychology of the author. To this extent Ricoeur agrees with Gadamer.

In his further discussion of the text as a relation of speech to writing, Ricoeur endeavours to make clear which traits of discourse are altered by the passage from speech to writing. He argues, based on the work of the French linguist Emile Beneniste (Ricoeur, 1973), p.131), that discourse is an event that occurs at a particular point of time and in this sense is not preserved entirely unchanged when committed to written form such as interview transcripts. He also points out that discourse refers back to its speaker and that it not only has a world (a particular context) but it also has an “other”, a hearer to whom it is addressed. He argues also that the other pole that constitutes discourse as an event is that of meaning, particularly meaning that endures. In seeing discourse as an event there is a separation of the action of saying from what is said.

> Just as language in actualizing itself in discourse goes beyond itself in the speech event, so speech in entering into the process of understanding goes beyond itself in meaning (Ricoeur, 1973, p.132).

There is also an autonomy in relation to the intention of the author, as the text no longer necessarily coincides with what the author wanted to say - the language they use even in live dialogue does not necessarily convey what they intended to say. This is even more likely when the discourse has become text.

What has been discussed so far can also be related to the context of this study. When analysing the transcripts of interviews with the participants of this study several months after the interview took place, even with reference to field notes, it is not possible to entirely recreate the event. What remains is an impression only of the language of the interview. Some of the inflections of tone and nuance may be recaptured in listening to the audio recording but nonverbal cues are certainly absent, leaving the interview transcripts as the only concrete link to participant’s expression of their experience. So in coming to an interpretation of the participant’s experience the researcher is dependent on the text from which, to a degree, they have become distanced.

This immediately points to the third way in which the autonomy of the text is introduced by writing in that the audience is now potentially anyone who can read, and so, the audience is also now distanced from the social and psychological context of the original intended audience. This latter point is not totally applicable to the stage of my reading of the interview transcripts (or text) in the sense that I was a participant in the original spoken discourse, and hence not distanced from the psychosocial context of the discourse. But, again with the passage of time since my experience of the 'live' discourse, the psychosocial context of each individual interview, limited to some extent at the time anyway, is now even less clear. The autonomy of the text in the sense that Ricoeur describes here would, however, certainly exist for all other readers of the original text and of my discussion of that text.

In the context of this study what is said in the transcript text is more than the sum of the structure of the language, and the understanding that is taken on by the interpreter goes beyond what is talked about by the interviewee.

As (Geanellos, 2000) points out, however, it is important not to confuse distanciation (a standing separate from or being objective in relation to the text) with objective knowledge because Ricoeur's theory, while acknowledging the distance between the self and the other, also affirms that the knower and the known are linked. In his essay entitled *The Hermeneutical Function of Distanciation (*Ricoeur, 1973) Ricoeur stresses that in his view text displays “a fundamental characteristic of the historicity of human experience (incidentally also at the root of Gadamer's, 1989 work), namely “that it is communication in and through distance” (p.130). He organises his discussion of this concept around four themes: 1) the text as a relation of speech to writing (discussed above), 2) the text as a structured work, 3) text as the projection of a world and 4) text as the mediation of self understanding.

The second theme of Ricoeur's discussion of distanciation is that of 'discourse as a work'. He identifies three distinctive traits of the notion of a work: 1) a work is a sequence longer than a sentence 2) a work is submitted to a form of codification that is applied to its composition or we can say it has a literary genre 3) a work has a unique style which relates it to the individual. Ricoeur believed that the objectification of discourse in a work, and the structural characteristics of the composition, joined to distanciation by means of writing, raises serious questions about the opposition between understanding and explanation raised by Dilthy (Ricoeur, 1973, p.139). The relationship between understanding and explanation will be discussed further below. Ricoeur is adamant however, that this objectification of discourse in the structure of a work does not obscure the fundamental purpose of the discourse, which is, 'someone saying something to someone about something' (p.138). In the context of this study the text (discourse transcriptions) are an attempt by each individual participant to say something to the interviewer about their experience of the family meeting in the context of their life, either with a terminal illness or with a family member who has a terminal illness.

This then leads our discussion to Ricoeur's third modality of distanciation which is connected with what he calls 'the world of text'. Discourse is applied to a reality and expresses the world but it does this in the context of a reference or a reality which is common to the speaker and their audience. Ricoeur argues that if hermeneutics can no longer be defined as a search for another person and their psychological intentions which are hidden behind the text, and neither is it understanding merely reduced to identification of language structures, then 'to interpret is to explicate a sort of being-in the world which unfolds in front of the text' (Ricoeur,1973, p.140). Here he joins Heidegger's theory (*Being and Time)* which suggests that understanding is not understanding of others but instead becomes a structure of being-in-the-world.

> What is to be interpreted in a text is a proposed world, a world that I might inhabit and wherein I might project my ownmost possibilities (Ricoeur, 1973, p.140).

This is very closely connected to Heidegger's hermeneutical circle in that the interpreter's 'innermost possibilities' are projected on the unique world of each text to create a new picture or understanding of a possible world, in the consciousness of the interpreter.

In the interviews, or discourses that are the subject of this study, both the interviewer and the interviewee share a common experience of being present at a family meeting at the same time. There is therefore, some degree of commonality in 'the world of text' which is the subject of the discourse. This same degree of commonality in the world of text applies to each of the interviews, however each discourse remains unique, even those with different participant members of the same family meeting, because what each speaker attempts to express is related to their own unique experience and pre-understanding. The process of interpreting each text (or discourse) ideally creates in the interpreter a new understanding of the world of being part of a family meeting of the type implemented in this study.

The fourth, and what Ricoeur describes as the most fundamental distanciation which is associated both to the act of writing and the act of reading, is what he calls the 'distanciation of the subject from himself' (Ricoeur, 1973, p.141). If we are to take seriously the distanciation by writing and the objectification by the structure of the work, as discussed above, then we can no longer, as Ricoeur points out, hold to the notion of understanding that Dilthey proposed – that understanding is a grasping of an alien life expressing itself through writing. Ricoeur's conclusion is that 'in the last analysis the text is the mediation by which we understand ourselves' (Ricoeur, 1973, p.141). This leads to his concept of 'appropriation', one which is fundamental to Ricoeur's theory of interpretation.

Before we enter into a discussion of appropriation, two other hypotheses of Ricoeur in relation to text should be mentioned – those of metaphor and action as text. As they are not particularly relevant to this study they will not be discussed in detail.

## Action and Metaphor as Text

Ricoeur argues that his theory of interpretation of text can be applied to the interpretation of action. In the first instance he claims that meaningful action can become an object of science, without loosing its meaningfulness, through a process of objectification similar to that already explained in relation to text.

> Like the speech act, the action event… develops a similar dialectic between its temporal status as an appearing and disappearing event, and its logical status as having such-and-such identifiable meaning or "sense content"  (Ricoeur, 1991), p.152).

In the same way that text is detached from its author, action is detached from the perpetrator of that action.

Ricoeur (1976)  argues that the common unit of both metaphor and text is the sentence, which as Thompson (1981)  points out, is a view which opposes the traditional view of metaphor as being a figurative word which is substituted for a literal one.  On the basis of this connection between metaphor and discourse, Ricoeur proposes that from the viewpoint of 'explanation', the analysis of metaphor is a good guide to the analysis of text.  He also suggests that from the perspective of 'interpretation' the analysis of text provides a key to the analysis of metaphor.

This is significant in the interpretation of text such as interview transcriptions, to the extent that interviewees make use of metaphor in attempting to convey the essence of their experience, in this case of the implemented family meeting.

Let us now consider the key concept of Ricoeur's theory of interpretation, that of 'appropriation'.

## Appropriation

Ricoeur (1981) defines the term 'appropriation' in the following way:

> By 'appropriation' I understand this: that the interpretation of text culminates in the self interpretation of a subject (*the interpreter)* who thenceforth understands himself better, understands himself differently, or simply begins to understand himself (p.158).

He argues that if the objectification of meaning (as discussed in relation to distanciation) is a necessary mediation between the writer and the reader, then this mediation calls for a process which he calls the 'appropriation of meaning'. A process of understanding which includes appropriation, is a temporal event, set in a particular time frame, and so is the counterpart of the timeless distanciation already discussed.

> Above all, the characterisation of interpretation as appropriation is meant to underline the 'present' character of interpretation (Ricoeur, 1981, p159).

Ricoeur warns, however, of the possible errors that can arise in the concept of appropriation, especially in relation to the primacy of the interpreter which was promoted by philosophers such as Descates, Kant and Husserl. He claims that in their thinking, the 'role of the subject (*the interpreter)* seems to imply that appropriation is a form of constitution of objectivity in and by the subject' (Ricoeur, 1981, p.190). Such a view of appropriation, he suggests, leads to two errors, one being the notion that one can recover the ‘genius of the author’ and the other being that one can identify oneself with the original audience. The outcome of this line of thought is that interpretation is confined by the limitations of the understanding of the current reader. As has already been indicated Ricoeur understood appropriation to be something much more than that, in that it is ‘the process by which the revelation of new modes of being gives the subject new capacities for knowing himself’ (Ricoeur, 1981, p.192). This knowing one-self is the emerging of a new self, compared to the old self that existed prior to the encounter with the text, and it is the power of the text that mediates this unveiling of the new self or the manifestation of another world.

This implies a hermeneutics of *I am* rather than *I think* (Ricoeur, 1974) and also that in philosophy there is no absolute knowledge. The implications of this for the current study are two fold. In the first instance it leaves reason to hope that the participants of the family meeting, to the extent that they appropriate their experience of the meeting, come to know themselves in a new way and hence are able to be, to some extent, ‘new’ in their relationships with each other in the future. The only evidence of this one way or the other, however, is what can be gleaned from their expression of their experience and what it meant for them, as that is interpreted by the researcher. The other important implication is that the researcher, in appropriating both their own experience of the family meeting and the new world of possibilities that is created in the coming together of their own pre-understandings and the meanings conveyed by the participants through the text, also becomes someone new with the potential to relate and act in new ways.

This brings us to the point of being able to outline an overview of what Ricoeur describes as a paradigm of text interpretation.

## Explanation, Interpretation and Understanding

The concepts discussed so far, that is those of discourse as text, objectification of text (or distanciation), and appropriation, together form this paradigm of text interpretation. Most significantly it is a fresh approach to the relation between explanation and understanding, the unfolding of which involves the movement back and forth between the parts of the text and a view of the whole, during the process of interpretation

Ricoeur begins his discussion of this new theory of interpretation from the point of view that there are two ways of looking at text. The first of these he describes as considering only the internal nature of the text. From this perspective it has no context, no external world and there is no consideration of it having an author or an audience. What arises from it in this case is “explanation” based solely on an objective view of its structural characteristics.

> On the basis of this choice, the text has no outside, but only an inside; it has no transcendent aim (Ricour, 1991, p113).

Ricoeur explains that the four main features of the nature of text, (the text as a relation of speech to writing, the text as a structured work, text as the projection of a world and text as the mediation of self understanding), which have already been discussed in this chapter, constitute the objectivity of text and that it is this objectivity which gives rise to the possibility of ‘explaining’. This understanding is fairly superficial taking into account the meaning of the words as the reader understands those – which of course may not be the exact meaning intended by the writer, or in the case of interview transcripts, the interviewee. Unlike Dilthey, however, Ricoeur does not consider this way of looking at text to be borrowed from the natural sciences, but rather arises from the explanatory rules of language only.

The second way of looking at text proposed by Ricoeur, is to restore it to a living communication and in this case we begin to interpret it. In Ricoeur's view interpretation is the outcome of the coming together of the world of text with the world of the reader, to form something new. At first this interpretation, while adding to the interpreter's understanding, is still fairly superficial. However, as the reader continues to explore the text they begin to take into account a number of other factors. The first is what they know of the author, or in this case the interviewee as they are informed by the field notes and by what the interviewee reveals of themselves in the interview text. The interpreter is also informed, at this stage of analysis, by what field notes reveal about the context of the interview, for example the family situation, by their own life views as well as their experience and knowledge of the area of the content of the text. In this way a new level of meaning unfolds itself from the text. This suggests the beginning of the process of appropriation that we have already discussed and which Ricoeur describes as being at the end of the hermeneutic arc, "the brace of the bridge, the anchorage of the arc in the ground of lived experience" (Ricoeur, 1981, p.164).

Ricoeur summarizes the relationship between explaining and interpreting in the following words:

> To explain is to bring out the structure, that is, the internal relations of dependence which constitute the statics of the text; to interpret is to follow the path of thought opened up by the text, to place oneself *en route* towards the orient of the text (Ricoeur, 1981, p.161).

In some of his writings, for example, *The model of text: meaningful action considered as text,* first published in 1971 (Ricoeur, 1971), Ricoeur does, however, raise some contradictions within his theory of interpretation. He argues, for instance, that if objective understanding is something other than the subjective intentions of the author, then there needs to be a process for ascertaining the "right interpretation", from among a number of possible interpretations. In this context Ricoeur introduces the terms 'guess' and 'validation'.

The need for 'the art of guess", is explained in terms of the whole being made up of a series of parts. There may be no evidence to indicate the relative importance of individual parts in determining the nature of the whole and that differing decisions about the importance of the individual parts will result in a different understanding of the whole. This judgement of importance, Ricoeur claims, is a guess. He agrees with Hirsch in saying that the process by which we test or validate our guess is closer to a logic of probability than to a logic of empirical verification (Ricoeur, 1991, p.159). He concludes that although there is always more than one way to interpret a text, it is not true that all interpretations are equal.

> It is always possible to argue for or against an interpretation, to confront interpretations, to arbitrate between them, and to seek for an agreement, even if this agreement remains beyond our reach (Ricoeur, 1991, p.160).

Despite these contradictions, which will be examined in more detail below, overall this model of interpretation of text demonstrates that understanding has nothing to do with the immediate grasping of that which is foreign, nor does it involve some emotional identification with the mental intentions of the author. Rather the process of understanding is a dynamic relation between several layers of meaning in the same text, the outcome being mediated by each step of explanation and interpretation which leads to it. As Ricoeur puts it;

> Ultimately the correlation between explanation and understanding, between understanding and explanation is the *hermeneutic circle* (Ricoeur, 1981, p.221).

### Summary of Ricoeur’s Theory of Interpretation

The key tenets of Ricoeurs theory of interpretation are:

- that discourse is text and also that there is a relationship between metaphor and text and action and text,
- the concept of distanciation of text which he discusses in four parts; text in relation to speech, text as a work, text as a projection of a world and text as mediating self understanding,
- that this mediation of self understanding takes place through a process of appropriation
- that understanding (the finding of meaning) is the outcome of the interaction of explanation (what the text says) with interpretation (what the text talks about).

## The Problem of Guess and Validation

As satisfying as the above conclusion may be there remains, however, some inherent contradictions in Ricoeur’s theory, particularly relating to the issues of ‘guess’ and ‘validation’, that must be addressed before it can be applied with confidence to human sciences research.

Ricoueur’s suggestion that the only way to understand what is meant is to guess (Ricoeur, 1991, p.158), contradicts his concept of distanciation of text from the author’s intentions (Ricoeur, 1973) which allows the eventual appropriation of the meaning of the text by the reader. It also suggests that there is only one correct interpretation of the text which is contrary to interpretivist paradigm discussed at the beginning of this chapter and to Ricoeur’s own statement that there is no one right knowledge.

Geanellos (2000) in her discussion of these discontinuations in Ricoeur's theory suggests that methodologically attempting to guess the author's meaning raises three issues.  It disregards the fact that research interviews are a co-creation of data between the interviewed and the interviewee, which we have already discussed.  It also individualises experience at the expense of recognising that experience is relational and comes into being through engagement with others, a basic tenet of the theoretical perspective of interpetivism.  The third issue, that of giving prime importance to the experience of the author, forces the researcher into finding one static, unchanging knowledge and certainly contradicts Ricoeur's own statement that 'to understand is to follow text from sense to reference, from what it says to what it talks about' (Ricoeur, 1991, p.165).

By referring to Gadamer's (1989) concepts of prejudice, tradition and the fusion of horizons, which Riceour himself referred to in his elaboration of the concept of distanciation of text (Ricoeur, 1973, p.133), it is possible to bring some clarification to this issue.  Prejudice (or in Heideggarian terms – fore-understanding) develops out of the interpreters participation in 'tradition', those aspects of culture, language and location in the interpreter's life experience.  The unfolding of new understandings occurs when the horizon of the interpreter fuses with that of the text.  As Geanellos (2000, p.117) points out it is from this point of being that the interpreter accesses textual meanings. Fundamental to the Hermeneutical Circle, which Ricoeur himself claims is represented in his understanding of the relationship between explanation (what the text says) and understanding (what it talks about) (Ricoeur, 1991, p.167), is an acceptance that we enter the circle with pre-understandings, of which we need to be aware and acknowledge (Geanellos, 2000) and which form part of our horizon (our current view point) that is fused with that presented by the text and so a new understanding can unfold.

The second contradiction in Ricoeur's writing that needs to be addressed is the notion of validation. In this notion there is a contradiction between, on the one hand, the plurality of texts, which he discusses at length in terms of the polysemic (co-existence of multiple possible meanings) nature of words and sentences (Ricoeur, 1981) and the changing and incomplete nature of interpretation impacted on by pre-understanding. On the other hand, there is his desire to make judgements about which is the best interpretation. This certainly could be considered a reflection of positivist thought. Ricoeur does differentiate between validation and verification (Ricoeur, 1991), verification being an inappropriate way of judging hermeneutical text he claims. However, as Geanellos (2000, p.118) also points out such a notion does appear to negate the possibility that more than one interpretation may faithfully represent the text.

Methodologically, interpretive textual analysis is orientated towards faithfully representing a text by providing that text with every opportunity to reveal its truths. Even so, researchers need to appreciate that no single interpretation ever exhausts the meaning of a text (Geanellos, 2000, p.118). This conclusion is actually totally consistent with Ricoeur's own claim that distancification of text from author's intention, author's situation and the original audience, opens it to the ongoing unfolding of possible worlds, as the horizon of the author (what it says) interacts with the horizon of each new reader or even each new reading by the same reader (what it talks about).

In spite of these apparent contradictions, the firm foundation upon which Ricoeur's theory of interpretation has been developed makes it a very useful model for the analysis and interpretation of text in a manner that enables rigorous outcomes. This is a view that is supported by the work of Geanello (2000).

> ..his theory takes account of the relationship between ontology (interpreter) and epistemology (interpretation) and acknowledges the plural, changing and incomplete nature of interpretation.  Further, Ricoeur's concepts of explanation and understanding highlight the way interpretation proceeds through multiple stages of understanding where the interpreter seeks to understand that which is expressed and unexpressed within the text.  …as a method of textual analysis, Ricoeur's theory has much to offer hermeneutic researchers (p.118).

## Summary

In this chapter the epistemology (constructionism) and the theoretical perspective (interpretivism) which inform the methodology of choice, hermeneutic phenomenology, were identified and their main tenets explained.  A brief outline of the development of hermeneutic phenomenology and especially the influences having an impact on the development of Ricoeur's theory of interpretation were discussed.

The main concepts of Ricoeur's theory and some of the arguments by which he substantiated them were outlined.  Of special note is his concept of distanciation of text and the possibility of objective explanation that arises from it in the early stages of data analysis. The other crucial aspect of his theory is the concept of appropriation which, through levels of interpretation leads through the mediating power of the text, to a new understanding.   The contradictions within this theory, in particular his notions of guess and validation were noted and explored and it was established that when informed by that work of Gadamer, with which Ricoeur himself had clearly concurred, these contradictions did not detract from the usefulness of this theory in the interpretation of text.

The methodology of hermeneutic phenomenology, incorporating Ricoeur's theory of interpretation, is not only applicable to this particular study but also deserves consideration by other human sciences researchers as a useful foundation on which to base their methods of choice.  The next chapters will describe the specific methods which were informed by this methodology and utilised in this study.

# CHAPTER FOUR – METHODS 1

# PREPARING THE WAY

## Introduction

The process of investigating the essence of the experience of palliative patients, and their family members, who participated in a family meeting designed as an instrument of spiritual care, involved three major processes. These were recruiting and the implementation of the family meeting, collecting the data through interviews and analysing the data to develop an understanding of the participants' experience.

In this chapter the processes undertaken to prepare the way for the implementation of the family meeting model being investigated in this study, the subsequent data collection (Chapter 5) and data analysis (Chapter 6) will be described. These processes included, attention to rigour, ethical considerations and Human Research Ethics Committee approval, informing staff of participating services about the study, recruiting patients and their family members and the recruiting of staff involved in the care of these patients.

The outcomes of the recruiting process including demographic data of participants, geno grams and profiles of the participating families will also be presented.

## Rigour

Rice and Ezzy (1999) have described five main areas of consideration to ensure the rigour of qualitative studies. These standards for rigour will be outlined below and as the specific methods of this study are presented reference will be made to how they meet the described standards of rigour.

## Theoretical Rigour

As Rice and Ezzy (1999) explain, theoretical rigour is an outcome of sound reasoning and the choice of methods that are appropriate to the research questions. In the case of this study, it would not have been consistent with theoretical rigour, having adopted the theoretical perspective of interpretivism, (Chapter 3) to then choose to collect data using a measurement scaling questionnaire, in order to understand the participants' experience of the family meeting. Theoretical rigour, as it relates to the choice of theoretical perspective and methodology as applied in this study, has been achieved in the explanation of and justification of the choices made presented in Chapter 3.

Another aspect of theoretical rigour, as explained by Rice and Ezzy (1999) is achieved by ensuring that points of argument and discussion follow one another clearly and are supported by evidence either from literature (in which case it must be appropriately referenced) or by the data collected during the study.

The appropriate choice of samples, so that they provide the information being sought, is also an important aspect of theoretical rigour (Rice and Ezzy, 1999). In this study, the best information about the patient's experience of the family meeting is collected by in-depth interviewing of the participating patients. While the staff involved in their care (but not present at the family meeting) are able to make observations about the changes in the patients that may be associated with their experience of the family meeting, they (the staff) would not be the best source of information about the patients' experience of the meeting.

## Procedural Rigour

Procedural rigour is achieved through the careful documentation of how all decisions are reached (Rice & Ezzy, 1999). This involves the establishment of an audit trail that includes all processes of the study from the initial proposal to the drawing of final conclusions.

In this study procedural rigour has included the documentation not only of how all decisions were made (see also Chapters 5 and 6) but an account of how access to the participants was obtained, how the researcher presented herself and developed rapport, how mistakes and surprises were dealt with and an account of those patients who were referred but were excluded, or declined to participate. These matters will be detailed later in this chapter.

Other documentation that is important in maintaining procedural rigour are accounts of how the data is collected and recorded (for example how were the interviews conducted and the data processed and checked – see Chapter 5) and the methods of data analysis and all decisions relating to this. For examples of decisions about the creation of sub-themes, categories and sub-categories and any decision about the subsequent merging of some of these, see Chapter 6.

## Interpretive Rigour

Rice and Ezzy (1999) define interpretive rigour as follows:

> An account has interpretive rigour if it accurately represents the understandings of events and actions within the framework and world view of the people engaged in them (p.36).

The significant question here is ‘on what grounds can a particular interpretation be considered accurate?’ As Rice and Ezzy have pointed out, some theoretical perspectives such as postmodernism would claim that there are no final grounds for accepting an interpretation as accurate. Supporters of Riceour's Theory of Interpretation, as explained in chapter three, would also have to accept that because of the interaction between the world of the text and the world of the interpreter, each interpreter's account of the same text is likely to be at least slightly different from the others and, in fact, an account made by the same interpreter at a later date may be a bit different to the first one, as that interpreter's world may have changed in the interim. From this perspective, inter-reliability claims (where several people analyse the same text and then compare outcomes) do not make it much more likely that a particular interpretation is accurate. This does not however mean that all possible interpretations are equal.

In this study interpretive rigour has been maintained through the use of many direct quotes from the data texts (see particularly Chapters 7-10) in order to enable readers of the research study to get as good an understanding as possible of what is being conveyed in the text and how interpretations have been made. Interpretive rigour is also reinforced by the documentation of all analysis decisions as described above in the section 'methodological rigour' and as applied in Chapter 6.

## Evaluative Rigour

Evaluative rigour includes giving proper consideration to both the ethical and political aspects of the qualitative study. Rice and Ezzy (1999) have quoted Punch (1986) in stressing the impact of political issues on research into sociological issues.

> To a greater or lesser extent 'politics' suffuses all sociological research (Rice & Ezzy,1999, p.38).

In this study the 'politics' of the provision of funding to health care services and the setting of priorities for that funding, are relevant to the interpretation of data relating to the suitability of this family meeting intervention for inclusion in the regular palliative care service – one of the questions being investigated in the study. The attainment of evaluative rigour has been assisted by setting out clearly the researcher's views about these matters (Chapter 1).

Ethical issues, such as ethics committee approval, confidentiality, informed consent, and maintaining the well-being of the participants as a primary focus throughout the study, are all relevant to the evaluative rigour of the study. The specific details of how these were maintained in this study are discussed below in the section entitled 'Ethical Considerations'.

## Rigorous Reflexivity

Rigorous qualitative research must take into account the role of the researcher in the research process (Rice & Ezzy, 1999). The philosophical underpinning on which this particular research study is founded, acknowledges that the researcher is a part of the environment of the study and that their impact needs to be constantly assessed and taken into account along with the other data.

> Rigorous qualitative research is honest about the role of the researcher in the project (Rice & Ezzy, 1999, p.41).

A more detailed account of the involvement of this researcher in approaching referred patients, facilitating the family meetings and conducting the subsequent interviews, will be given later in this chapter and in Chapter 5. This honest reflexivity also needs to include an awareness and openness on the part of the researcher about how their background, beliefs, life experience and political views impact on their involvement in the research. These have been declared in Chapter 1 and will be referred to as appropriate throughout the following chapters.

## Ethical Considerations

It is acknowledged that palliative patients and their families are a particularly vulnerable population and the appropriateness of the methods chosen for this study will be discussed in more detail later in this chapter. The welfare of the participants, especially the patients, was however, the paramount consideration at all times. It was made clear for example, that if at any time during the family meeting or the interview the patient felt that they were too tired or wished to stop for whatever reason, that this would be respected immediately.

A number of other steps were taken to ensure that ethical standards were maintained in the conduct of this study. These include:

- The obtaining of informed, written consent from all participants, (Appendix II .1-3) including consent for interviews to be taped. It should be noted that one patient and their spouse while agreeing to be interviewed did not agree to these interviews being recorded. They were happy however to have the interviewer make some notes during the interview.
- Included on the participant information sheets (Appendix III. 1-3) was a list of appropriate independent professionals whom participants could contact should they experience any distress during the family meeting or interview, or wish to work further with any of the issues that arose for them during their involvement in this study.
- Confidentiality and security of data were ensured as follows:
    - Only the named researchers and a specified transciber had access to the data. The transcriber signed a confidentiality document prior to accessing the digital recordings.
    - Digital recordings, interview transcripts and demographic questionnaires (which do not include participant’s name) were numbered in a manner that does not identify the interviewee.

- Only the primary researcher had access to a list that connects interview data with demographic data. This was kept in a different locked cabinet to other data.
- When transcripts had been checked for accuracy, the digital recordings of the interviews were destroyed.
- Although direct quotes from the data have been used in reporting this study care has been taken that they do not identify the interviewee

This study was approved by the following Human Research Ethics Committees.
Research Ethics Committee – Royal Adelaide Hospital
Ethics Committee – Calvary Health Care Adelaide
Ethics of Human Research Committee – The Queen Elizabeth Hospital
The Human Research Ethics Committee, University of Adelaide – notification of approval by Royal Adelaide Hospital Human Research Ethics Committee only required. Notification given 27/8/05
Please see Appendix IV (1-3) for copies of these approval notices.

## Recruiting

Initially it was proposed to recruit from among those patients registered with one metropolitan palliative care service (Service 1). Patients admitted to the large public hospital with which this service is associated, the hospice incorporated within a private hospital which services the palliative care service region involved and also home care patients registered with this service were to be included. As the study progressed the rate of recruiting became a concern and it was decided to expand the intake area by including a second metropolitan palliative care service (Service 2). Following the appropriate ethics approval, participants were also recruited from Service 2. Patients registered with the second palliative care service also had access to a large public hospital, a hospice which is part of a private institution and home care provided by the outreach team.

In preparation for recruiting the researcher was invited to attend multi-disciplinary team meetings in order to explain the study to staff members and to discuss the selection criteria that had been laid down in the study proposal and approved by ethics committees. Staff members were also provided with information sheets about the study which included a list of inclusion/exclusion criteria (Appendix V). In each area of care a system for informing the researcher about potential participants was established.

As the study progressed it became apparent that there were inconsistencies both between the two services and within one of them. These related to whether or not the patient was aware that they had been referred to the study, before the researcher approached them. The following practices occurred:

- Service 1: Some staff referred patients from their list and did not speak to them about the study at all considering that this would be best done by the researcher. In this group two staff members referred largely on the basis of the official selection criteria while others very clearly were influenced by their own biases. Other staff members referred patients only after they had spoken to them about the study. It was apparent that these staff members were very selective indeed about which patients they approached. Clearly in this case the type and amount of information given to the patient about the study, prior to the researcher approaching them, would have varied and was dependent on the referring staff member’s understanding of the study and its purposes.
- Service 2: The researcher was invited to attend the weekly team meeting at which patients were discussed and considered for referral. With the exception of the key staff member from

the hospice it was apparent that referring staff were being influenced by factors outside the set study selection criteria. For every referral from this service the researcher was personally introduced to the patient by the referring staff member and then, if the patient was willing, the researcher explained the study to him/her. For patients admitted to either hospital or hospice the staff member usually continued with other duties and left the researcher to explain the study.

## Selection Criteria

Three categories of participants were recruited.

- Category A: Patient – defined as a person with a non-curable illness who is registered with the palliative care service.
- Patients considered able, physically and mentally, by the attending medical staff, to be present at and participate in the family meeting.
- Patients aware of the terminal nature of their illness and whose prognosis for life was less than six months.
- Patients able to converse and give informed consent in English
- Patients over 18 years of age.

Category B: Family member – defined as a person whom the patient considers to be important in his/her life, regards as “family”, and who they want to invite to the family meeting.  This person may be related to the patient biologically, related by marriage/contract or not related in these ways.

- Family members whom the patient would like to have present at the family meeting and who consent to be involved
- Family members able to converse in English and give informed consent in English
- Family members over the age of sixteen.

### Category C: Staff member – a person involved in the care of palliative patients referred to the study.

- Staff members from a range of disciplines e.g. medical staff, nursing staff, volunteers, chaplains/pastoral care workers and allied health staff such as social workers, occupational workers and physiotherapists, who have had some role in the care of the participating patients and families.
- Staff members who had been active in referring patients or encouraging other staff to do so.
- Staff members over the age of eighteen and have given informed consent.

### Exclusion Criteria – Patient:

- Patients considered unable, physically and/or mentally, by the attending medical staff, to be present at and participate in the family meeting.
- Patients unaware of or unwilling to acknowledge the terminal nature of their illness and whose prognosis for life is less than six months.
- Patients unable to converse and give informed consent in English
- Patients under 18 years of age.

This type of selection process is described by Rice and Ezzy (1999) as “criterion sampling” designed to recruit those participants most likely to provide rich data relevant to the research questions being investigated in this study. In this case the criteria were selected with the intention of involving as broad a cross-section as possible of the palliative care patient population, along with their family members, in the experience of the family meeting as described in this model.

No upper limits for the number of participants were set prior to commencing the study, the focus being on quality in-depth, rich data rather than on quantity of data (Rice & Ezzy, 1999). Data collection was terminated when it was perceived that sufficient rich and detailed data had been collected to provide a significant insight into the experience of a family meeting, of the type being investigated, from the perspective of patients, family members and staff.

## Patients and Family Members

The researcher was aware that from the first contact, whether by phone or personally, the development of rapport was very important, both to the well-being of the participants and for successful recruiting. Developing rapport included using a warm, friendly and relaxed manner, showing interest in participants and their surroundings, and an empathetic approach to answering their questions and concerns.

In the case of patients who had been admitted to either hospital or hospice, who were not aware that they had been referred until approached by the researcher, the following process took place at the initial meeting:

- The researcher introduced themselves and explained that they were involved in a study to which the patient had been referred by (name of referring staff member).
- The patient's permission was sought to explain the nature of the study.

If the patient, unaware that they had been referred, was a home care patient the following process took place:

- A phone call was made by the researcher to introduce them selves and explain that the patient had been referred by (name of referring staff member).
- Permission was then sought to make an appointment for the researcher to come to their home to explain the study.

- Any questions the patient had immediately were answered although it was found to be preferable to explain the whole study in person to the patient if possible.

Following an explanation of the study by the researcher any questions were answered. The patient was then asked if he/she would be willing to think further about it and discuss it with their family members. If they agreed information sheets were left with them and a time arranged (within 3 days) for the researcher to return and answer any more questions and to hear their decision about further involvement. At this second meeting, if the patient agreed to take part in the study a suitable time and place was arranged for the family meeting to take place.

At the appointed time, before the meeting began, the researcher explained the consent form (Appendix II. 1-2) to those present and invited them to sign it, after clarifying any points about which they were unsure. A brief demographic questionnaire was also distributed to each person present and they were invited to complete this (Appendix VI.1-2). Each consent form and corresponding demographic questionnaire was labelled with an identifying code which was subsequently used instead of the name of the participant.

### Staff

Recruitment of staff did not begin until the latter part of the data collection phase of the study in order to allow time for staff members to observe outcomes for patients who participated and to assess the possible benefits of including this type of family meeting into the regular palliative care service.

All staff members who had been actively involved in referring patients, or encouraging other staff to do so, regardless of their particular discipline of work, were provided with an information sheet (see Appendix III.3) and were invited to participate in a one on one semi-structured interview. If they agreed to participate an appointment was made for the interview. Before the interview began the consent form (Appendix II.3) was explained and the staff member was invited to sign it. They were also invited to complete a demographic questionnaire (Appendix IV.3).

## Recruiting Outcomes - Patients and Family Members

A summary of the overall recruiting outcomes for patients is shown below in Figure 2 - Overall Recruiting Outcomes.

***Figure 1: Overall Recruiting Outcomes***

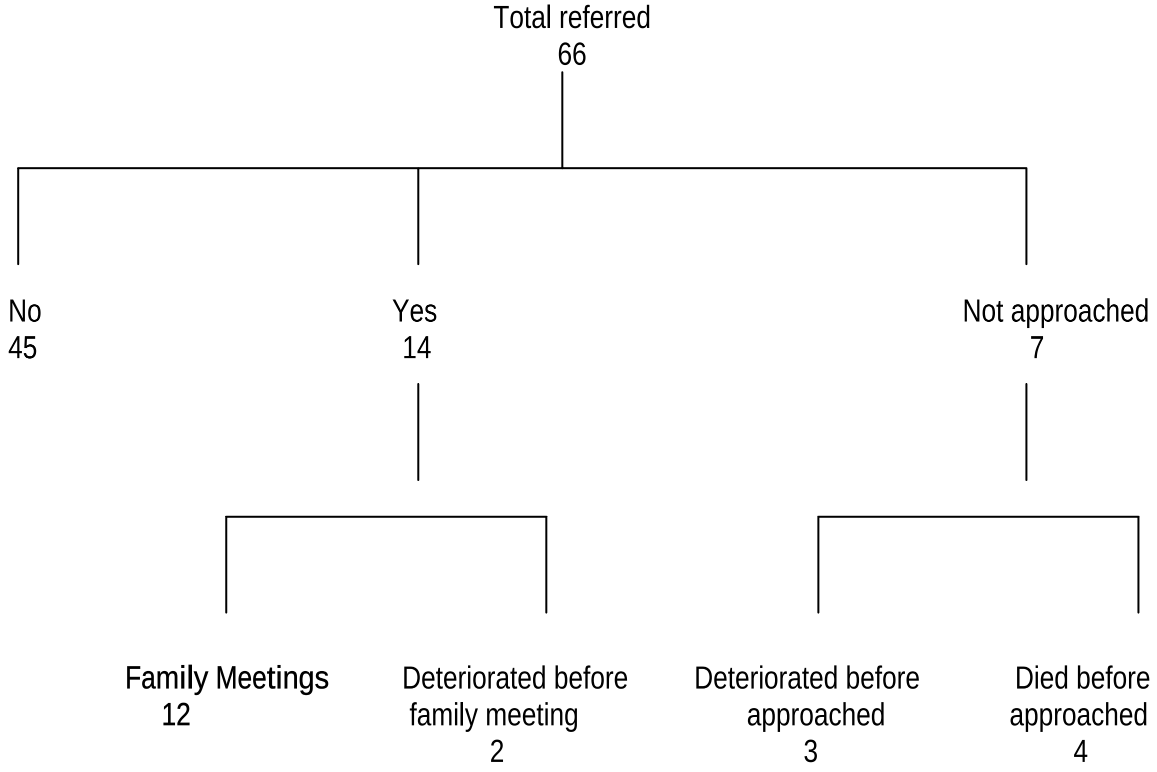


Table 4 below compares the recruitment rate for the two different services involved in the study and for the different places of care for the patient at the time of the family meeting.

***Table 4:Comparative Recruitment Rates***

| Item | Numbers 'Yes' | Percentage 'Yes' |
|---|---|---|
| Overall 'yes' rate | 14 from 59 approached | 23.7% |
| Home Care overall 'yes' rate | 7 from 24 approached | 29.2% |
| Hospital Care overall 'yes' rate | 1 from 10 approached | 10.0% |
| Hospice Care overall 'yes' rate | 4 from 25 approached | 16.0% |
| Service 1 overall 'yes' rate | 7 from 43 approached | 16.3% |
| Service 2 overall 'yes' rate | 5 from 16 approached | 31.3% |

The 'yes' rate for Service 2 was approximately twice that of Service 1. Some factors which may have impacted on this outcome are

- There was a stronger culture of participation in research in Service 2
- In Service 2 the researcher was more openly included as part of the team by:
    - Asking the researcher to attend all team meetings at which patients were discussed and decisions made about referral.
    - A staff member personally introducing the researcher to the referred patients.

Further recruiting issues in relation to recruiting, as raised by staff members in their interviews, are presented in Chapter 10 and the possible impact of these issues on the study outcomes are discussed in Chapter 11.

## Those Referred but Excluded

As shown on Figure 2 (p.75) two patients agreed to participate in the study but the family meeting did not take place due to rapid deterioration in their condition. Another 7 were referred but not approached also due to their deterioration.   All nine of these referred patients, although apparently meeting the selection criteria at the time of referral became ineligible and were excluded from the study.

The demographic data, as known for these patients is presented in Table 5 – Those Referred But Excluded below.

***Table 5: Those Referred But Excluded***

| Referral Number | Gender | Age * | Diagnosis | Comment |
|---|---|---|---|---|
| 63 | F | 57 | Widespread CA** | Said yes but died before family meeting |
| 65 | F | 80+ | Brain CA | Said yes but died before family meeting |
| 19 | M | 60+ | Widespread CA | Died between referral and first contact |
| 25 | F | 64 | CA Lung | Died between referral and first contact |
| 26 | F | 89 | CA | Died between referral and first contact |
| 37 | M | 60+ | CA | Died between referral and first contact |
| 20 | F | 75 | CA | Deteriorated rapidly between referral and first contact |
| 28 | F | 50+ | CA | Transferred out of zone before contact |
| 46 | M | 70+ | Lung CA | Deteriorated rapidly between referral and first contact |

* Age is approximate as this information was not always supplied with the referral

** CA - carcinoma

The religious affiliation, if any, of these excluded patients was not known.

## Participating Patient and Family Member Demographic Data

As indicated, before the beginning of the family meeting the patient and family members present were asked to complete a simple demographic questionnaire (See Appendix VI.1- 2). Patient demographic data have been collated in Table 6 (p.79).

Of the twelve participating patients, 7 (58.3%) were female and 5 (41.7%) were male. Their ages ranged from 59 to 82 years, the mean age being 68.7 years. Eleven of the twelve patients had been diagnosed with cancer in some form. Nine of the patients listed their religion as Christian. It was evident in subsequent conversations that only four of these considered themselves to be a part of a church community.

***Table 6:Patient Demographic Data***

| Code | Referral No | Age | Gender | Diagnosis | Religion | The one to whom they felt the Closest | No.* Close | Place of Care |
|---|---|---|---|---|---|---|---|---|
| P1 | 1 | 60 | M | Liver Cancer | Christian/Lutheran | spouse | 10 | Home |
| P2 | 3 | 61 | F | Cervical Cancer | Christian | Spouse/2nd daughter | 3 | Home |
| P3 | 17 | 76 | M | Muscular Dystrophy | Christian/ Congregational | spouse | 5 | Home |
| P4 | 23 | 59 | F | Wide spread cancer | Christian | spouse | 2 | Home |
| P5 | 32 | 63 | M | Pancreatic Cancer | Christian | sister | 10 | Home |
| P6 | 43 | 76 | F | Wide spread cancer | Christian | husband | 10 | Hospice |
| P7 | 52 | 60 | F | Brain Tumour | none | husband | 8 | Hospice |
| P8 | 56 | 59 | F | Cancer (lung & bone mets.) | none | husband | 4 | Hospice |
| P9 | 59 | 82 | F | Intra-peritoneal CA | Christian | Son | 10 | Hospice |
| P10 | 60 | 73 | M | Prostate Cancer | Christian/ Lutheran | wife | 10+ | Hospital |
| P11 | 62 | 82 | F | Breast Cancer | Christian /Uniting Church | husband | 10+ | Home |
| P12 | 66 | 73 | M | Multiple Myeloma | none | wife | 4 | Home |

* number of family members that they regard as being close to them

Of the 39 family members who attended the family meetings, 36 of these were interviewed. Member F5J, who was present at the meeting in the company of both her parents, wanted to complete the consent form and the demographic questionnaire but was not invited to have an interview being under the age criteria set for the study. Members 5FC and 5FD did not wish to be interviewed. 24 females (66.7%) and 12 males (33.3%) were interviewed. Three minors, aged 16, 11 and 8 (grandchildren of the patient) attended the family meeting in the company of both their parents but did not complete demographic questionnaires. The 16 year old wanted to attend the meeting but did not want to be involved in any data gathering including the interview. The age range of family members interviewed was 21-84 years and their mean age was 50.5 years. Full demographic data is presented below in Table 7 – Family Member Demographic Data which continues onto page 81.

***Table 7:Family Member Demographic Data***

| Code | Age | Gender | Religion | Relationship | Close to Patient | No. Close?* |
|---|---|---|---|---|---|---|
| F1A | 56 | F | Christian | Spouse | Yes | 4 |
| F1B | 29 | F | Christian | Daughter | Yes | 4 |
| F1C | 26 | M | Christian | Son | Yes | 4 |
| F1D | 26 | F | None | Other Relative - daughter in law | Yes | 6 |
| F2A | 72 | M | Christian | Spouse | Yes | 3 |
| F2B | 34 | F | None | Daughter | Yes | 7 |
| F2C | 32 | F | None | Daughter | Yes | 1 |
| F3A | 76 | F | Christian | Spouse | Yes | 10 |
| F3B | 41 | F | Christian | Daughter | Yes | 5 |
| F4A | 58 | M | Christian | spouse | Yes | 2 |
| F5A | 62 | F | Christian | sibling | Yes | 20+ |
| F5B | 52 | M | None | Other Relative - brother in law | Yes | 20+ |
| F5C | 60 | M | Christian | Sibling<br>(no interview) | No | 4 |
| F5D | 61 | F | None | Other Relative – sister in law<br>(no interview) | Yes | 3 |
| F5E | 43 | F | None | Other Relative - niece | Yes | 7 |
| F5F | 36 | M | Christian | Other Relative niece | yes | 7 |
| Code | Age | Gender | Religion | Relationship | Close to Patient | No. Close?* |
| F5G | 41 | M | None | Other Relative - nephew | Yes | 10 |

| | | | | | | |
|---|---|---|---|---|---|---|
| F5H | 36 | F | Other | Other Relative - nephew | Yes | 20+ |
| F5I | 21 | F | None | Other Relative great niece | Yes | 20+ |
| F5J | 14 | F | None | Other Relative great niece (no interview) | Yes | 20+ |
| F6A | 76 | M | Christian | husband | Yes | 10 |
| F6B | 47 | F | Christian | Other Relative - Daughter in law | Yes | 10 |
| F7A | 62 | M | None | spouse | Yes | 8 |
| F8A | 33 | F | None | daughter | yes | 7 |
| F8B | 30 | F | None | daughter | yes | 6 |
| F9A | 57 | M | None | son | yes | 25 |
| F9B | 49 | F | Christian | Other Relative - Daughter in law | yes | 25 |
| F9C | 50 | M | None | son | yes | 25 |
| F10A | 64 | F | Christian | spouse | yes | 10+ |
| F11A | 84 | M | Christian | spouse | yes | 10+ |
| F11B | 62 | F | Christian | niece | yes | !0+ |
| F11C | 53 | F | Christian | daughter | yes | 10+ |
| F11D | 74 | F | Christian | sister | yes | 2 |
| F11E | 81 | M | Christian | Other Relative - Brother in law | yes | 10+ |
| F11F | 55 | F | Christian | niece | yes | 6 |
| F11G | 62 | F | Christian | friend | yes | 2 |
| F12A | 66 | F | None | wife | yes | 4 |
| F12B | 40 | F | None | daughter | yes | 3 |
| F12C | 35 | F | None | daughter | yes | 4 |

* - number of family members that they regard as being close to them

Of the 39 family member participants 26 were female and 13 male. They ranged in age from 14-81 years (mean age 50.2 years). Twenty one claimed Christian affiliation, 1 was affiliated with an unspecified other religion, while 17 considered that they had no religion.

## Family Profiles

In order to create a picture of participating families a geno gram (Appendix VII. 1-12), was drawn up for each family which included each member present at the family meeting and other family members who were mentioned either during the meeting or in subsequent interviews.

As discussed in Chapter 7, data arising from the interviews that described how family members related to each other, their communication habits, emotional expression, values, impacting history and socio-economic status were summarised to form a brief profile of each participating family (Appendix VIII.1-12).

## Those Patients Who Said No

Because of the fairly high “no” rate in this study (68%) it was considered relevant to understand as far as possible why they said ‘no’, bearing in mind that ethically it was not possible to quiz these people about their reasons for declining to be involved. It was found that everyone gave some indication of the reason. These could not be explored further with them for the reason already indicated. Table 8 – Demographic Details for “NO” was complied from details contained on referral sheets. In some cases the age was not recorded on the referral sheet and if the researcher made personal contact with the patient an estimate only is given.

*Table 8:Demographic Details for 'NO' Responses*

| Ref No. | Gender | Approx. Age | Religion | Diagnosis | Location |
|---|---|---|---|---|---|
| 2 | F | 83 | unknown | Extensive CA | Hospital |
| 4 | F | 72 | unknown | Motor neurons | Home |
| 5 | F | 70's | unknown | extensive | Home |
| 6 | F | 71 | Uniting Church | Lung cancer | Hospice |
| 7 | F | 70+ | Lutheran | unclear | Home |
| 8 | F | 63 | unknown | Emphysema | Hospice |
| 9 | F | 51 | unknown | Rectal CA | Hospice |
| 10 | F | 77 | unknown | MND | Hospice |
| 11 | F | 66 | unknown | Colorectal CA | Hospice |
| 12 | M | 74 | Lutheran | Prostate CA | Hospice |
| 13 | M | 79 | unknown | Pancreatic CA | Hospice |
| 14 | F | 70+ | Catholic | CA lung | Hospice |
| 15 | F | 50+ | none | cancer | Hospital |
| 16 | M | 60+ | unknown | Brain tumour | Home |
| 18 | M | 70+ | Catholic | Rectal CA | Hospice |
| 21 | F | 70+ | non religious | CA | Home |
| 22 | F | 70+ | unknown | CA | Hospital |
| 24 | F | 70+ | unknown | Heart disease | Hospital |
| 27 | F | 47 | unknown | NSCLC | Hospital |
| 29 | M | 82 | Catholic | CA | Hospital |
| 30 | M | 78 | unknown | CA | Hospital |
| 31 | F | 59 | unknown | Ovarian | Hospital |
| 33 | F | 47 | unknown | Wide spread Ca | Hospital |
| 34 | M | 70+ | unknown | Lung & brain | Home |
| 35 | F | 70+ | unknown | Lung cancer | Home |
| 36 | M | 52 | unknown | Wide spread CA | Home |
| 38 | F | 74 | unknown | CA | Home |
| 39 | F | 70+ | unknown | CA | Home |
| 40 | F | 47 | unknown | CA | Home |
| 41 | F | 33 | Catholic | CA | Hospice |
| 42 | F | 57 | No religion | CA | Hospice |
| 44 | F | 47 | unknown | CA | Hospice |
| 45 | F | 70+ | unknown | CA | Home |
| 47 | M | 79 | unknown | CA | Hospice |
| 48 | F | 49 | unknown | Breast cancer | Hospice |
| 49 | F | 72 | unknown | NHL | Hospice |
| 50 | F | 72 | Catholic | Ovarian cancer | Hospice |
| 51 | M | 83 | unknown | CA prostate | Hospice |
| 53 | M | 80+ | unknown | CA | Hospice |
| 54 | F | 70+ | unknown | Motor neurons | Hospice |
| 55 | F | 50+ | unknown | Deg. brain disorder | Hospice |
| 57 | F | 53 | unknown | Breast cancer | Hospice |
| 58 | F | 80+ | unknown | Breast cancer | Hospice |
| 61 | M | 60+ | unknown | CA | Nursing home |
| 64 | F | 70+ | unknown | Stroke | Hospice |

Thirty three female and 12 male patients who were approached declined to participate. Ages ranged from 47 to at least 83 but it was not possible to calculate the mean age and in many cases their exact age was not available. Most had been diagnosed with cancer. Their location at the time they were approached was as follows: hospice 23, hospital 9, home 12 and nursing home 1. All contacts and attempted contacts with referred patients and their family members were recorded, along with notes about the exchange, in the researcher's field notes. These data were used to compile Table 9 - Reasons for Saying "NO"

***Table 9:Reasons for Saying 'NO'***

| | Patient Wanted to Participate but Family Didn't | Family Wanted to Participate Patient didn't | Spoke with Patient Only Who Said No | Spoke with Family Member Only Who Said No |
|---|---|---|---|---|
| Patient Considered too ill | nil | nil | 6 | 5 |
| Talking in a Group too Threatening | 6 | 2 | nil | nil |
| Too Much on Now | 5 | nil | 2 | nil |
| Wouldn't Benefit | 5 | nil | 2 | nil |
| Don't Need it | nil | nil | 2 | 1 |
| Other | 3<br>Too religious, cultural, bad exp. with social worker | 1<br>Doesn't talk about feelings | 5<br>No close family, family interstate, in other study, no interest in topic, big family problems | nil |

## Recruiting Outcomes – Staff

A total of sixteen staff members across the two participating services were approached to participate in semi-structured interviews. Fourteen of these, seven from each of the services, agreed to participate. One of those (a medical consultant) who declined felt that they had not been sufficiently involved to make a useful contribution. The other (a medical resident) agreed but cancelled the appointment due to unexpected circumstances. They were then absent on leave until the end of data collection period.

Demographic details of participating staff members are presented on Table 8 – Staff Demographic Data below. It will be noted that they comprised 8 females and 6 males. The total included 5 medical specialists, 7 nurses, 1 counsellor and 1 social worker. Nine of the participants considered that in their normal working life they were involved in the spiritual care of patients and family members in some way.

***Table 10:Staff Demographic Data***

| ID | Age | M/F | Religion | Role | Importance of Spiritual Care | Involved in providing spiritual care? |
|---|---|---|---|---|---|---|
| S1 | 37 | F | None | Nurse | Important | Yes |
| S2 | 52 | F | Buddhist | Nurse | Very Important | No |
| S3 | 38 | M | Christian | Medical | Very important | No |
| S4 | 46 | M | Buddhist | Medical | Very important | No |
| S5 | 36 | F | None | Counsellor | Very important | Yes |
| S6 | 49 | F | Christian | Nurse | Very important | Yes |
| S7 | 61 | F | Christian | Medical | Very important | Yes |
| S8 | 58 | F | Christian | Nurse | Very important | Yes |
| S9 | 51 | M | Buddhist | Social worker | Very Important | Yes |
| S10 | 52 | M | None | Medical | Very important | Yes |
| S11 | 50 | F | Christian | Nurse | Important | Yes |
| S12 | 64 | M | Christian | Medical | Very important | Yes |
| S13 | 34 | M | Christian | Nurse | Important | Yes |
| S14 | 39 | F | Christian | Nurse | Very important | Yes |

## Summary

In this chapter the processes needed to prepare the way for the implementation of the family meeting model being investigated in this study, and the collection of data, have been discussed. These included matters of rigour, ethical considerations, preparation for recruiting, recruiting of patients, family members and staff. The outcomes of this recruiting were also presented.

In the next chapter the methods of implementing the family meeting and data collection will be described

# CHAPTER FIVE - METHODS 2

# IMPLEMENTATION OF THE FAMILY MEETING AND INTERVIEWING THE PARTICIPANTS

## Introduction

This chapter will outline the nature of the family meeting as described by Murphy (1999) and will discuss the process of meeting facilitation in this study. The details of how the interviews, both those with patients and family members and those with staff participants, were conducted will be outlined.

Firstly however, the role of the researcher as both facilitator of the family meetings and interviewer will be discussed

## The Researcher as both Meeting Facilitator and Interviewer

In this study the researcher was both the family meeting facilitator and the interviewer. This potentially raises issues of rigour which need to be addressed. The reasons this decision was made and why it has minimal impact on the rigour of the study will be now discussed.

Hermeneutic analysis is, as Ezzy (2002) describes it, ‘like a dance in which the interpretations of the observer and the observed are interwoven until a more sophisticated understanding is developed’ (p.25). This description is very consistent with the level of in-depth interpretation described by Ricoeur in his Theory of Interpretation (Chapter 3). In this type of research the investigator can never be just a totally objective observer. As already described in Chapter 3, it is only at the first level of interpretation “what does the text say” that the interpretation is confined to the semantics (the meaning of the word or phrase) of the text. At the deeper levels of interpretation the position and background of the researcher and what is known of the background and views of the participants is all taken into account in determining ‘what the text is talking about’. It therefore follows that the more exposure the researcher, as the interviewer, has to the context and background of each family meeting, the richer the data and the fuller the eventual understanding of the participants’ experiences of the family meeting is likely to be.

Consideration was given to the possibility of the key researcher being present at the family meetings as an observer while someone else facilitated the meetings. Apart from the practical issues of the availability of a suitably qualified person, who had been trained in working with family meeting model of the type utilized in this study, and the lack of funds to pay them to do it, it was realised that the presence of the researcher as an observer would still impact on the participants of the meeting and would in fact result in two “strangers” rather than one impacting on the family system. A decision was made not to record the family meetings as it was considered this would be likely to be an additional inhibitor for some families who would already find this process to be quite different to their normal ways of relating to each other. If the data is to come from the constructionism perspective, that is, that knowledge is constructed though the interaction of individuals with their environment (see Chapter 3), then it was necessary for the researcher to be present at both the family meetings and the interviews. Repeated exposure to the same researcher at introductory meetings, family meeting and interviews is also significant in the development of trust and rapport with the participants.

The assessment of rigour in qualitative research in general cannot be based on whether the investigator followed particular objective criteria, as might be the case in a quantitative study. Ezzy (2002) outlines an interpretive model of rigour, appropriate for studies informed by interpretivist philosophy, as this study is (Chapter 3). His summary of this model, as presented in Ezzy (2000, p.54) is shown in Table 11 below.

***Table 11:Interpretive Model of Rigour in Qualitative Research***

NOTE:
This figure is included on page 109
of the print copy of the thesis held in
the University of Adelaide Library.

It was considered that rigour, when considered in the light of this model, had been achieved in this study.

## The Family Meeting

A detailed account of the nature of the family meeting as described by Murphy (1999) and its facilitation in this study will now be presented. The importance of storytelling in the process of meaning making has already been discussed in the literature review (Chapter 2). Telling the story of the illness, of life together, of the joys and the sorrows along the way – is fundamental to Murphy's family meeting model and so a short description of how this underpins the model, as he advocates it, will now be given.

## Storytelling

> Storytelling is the expression of the warmth and darkness of relationships and connections, both intimate and more remote, in the world and beyond. The substance of these connections is our stories, which might be thought of as soul food (Murphy, 1999, p.24).

Murphy (1999) expresses very strongly that our stories need to be told before witnesses and that in families where the stories are not told, these hidden stories emit a sense of darkness and foreboding as death approaches for one of their members. It is his experience that it is the families that cannot or will not tell the stories that feel heavy and doomed in the face of death, while those that can tell, even the most horrendous stories, can be free of the terror at the end. He illustrates the power of telling the story, and of reframing it, in the example below quoted from his book (Murphy, 1999).

> Michael was a man in his mid-seventies who was referred to the hospice about one month before he died. He lived alone in a run down apartment devoid of most creature comforts, and had little to say except that he had recently been in the hospital and was diagnosed with lung cancer. Initially no family were present; all that the visiting hospice nurse saw was a quiet, withered little man who had been an alcoholic and obviously had a short time to live. Four of his five living children agreed to meet in Michael's apartment, and during the next month there unfolded a story that curdled the imagination for the breathtaking suffering incurred by each one in the family.
>
> Michael had been an alcoholic for as long as each child could remember. He was extremely violent when drunk, and their mother, who had died three years before, had been repeatedly admitted to hospital with bruises and broken bones. Arrests and evictions were common place. One evening while drunk Michael had fallen on his infant daughter causing brain damage still evident in her physical disability 30 years later. Both she and the two youngest sons had been sexually abused for years by family members and all five of the living children were alcoholics. One child was in jail, and a sixth had died in a motor accident

that was probably both induced by alcohol and suicide-related. The younger boys, both now sober, said that the only feelings they could ever remember in association with the growing up were shame and rage.

It became very difficult to manage Michael at home in the last few days of his life, especially because his home was devoid of anything of comfort, so he agreed to go to the hospice Inn. The children spent many hours at their father's bedside and were visibly closer as they told more of their family story. Very little was known of Michael's early life other than that he was abused as a small child, abandoned by his mother at age four and spent his childhood in a series of foster homes. As we talked around his bed we reframed his story, developing the image of a frightened little child at age four putting on a ferocious Halloween costume with which to scare everyone. The costume would stay on until the following Halloween, when the little boy would exchange it for another. Year by year, each costume grew more fearsome than the last, and Michael lived his life frightening everyone and attacking anyone who might try to come close, until at this time, with his life almost spent, the costumes fell away and the vulnerable little child was once more exposed. This story resonated with Michael's children in a place beyond hatred and shame, and with the exception of the oldest son, who was unable to acknowledge either his own alcoholism or his connection with his father, Michael's children were able to tap a well of compassion that is often obscured in much less traumatised families. The jailed son was present both at a family meeting when Michael was conscious and at the time of Michael's death.

The death itself was quiet and peaceful in stark contrast to the death of Michael's wife in a hospital three years before. Michael's children told me that at the time of their mother's death, they were all frightened and upset, enraged at Michael and quite unable to be present with their mother as she died. The daughter, who best exemplified the neglect abuse and self hatred in the family, ran screaming through the hospital after her mother died; she drank

> heavily and was quite depressed for many months thereafter; requiring a six weeks stay in a psychiatric ward. At their mother's death the family was overwhelmed with the chaos, fear and loneliness of the whole family, all of which lay so close to the surface but was not to be voiced until shortly before Michael's death. The family story had never been told before; this time the fearful gaps in their family life were named and witnessed. In the telling, the black hole of shame, rage and abuse, which had continually drained the life out of each family member, lost some of its force (Murphy, 1999, p.26-28).

The reframing of stories, or the seeing them in a different light, context or focus, allows them to become 'unglued from the wall of the soul', as Murphy (1999, p.94), describes it and so to be relinquished. As Murphy acknowledges, the question could be asked as to whether this process is heroic, impossible or untrue. He claims that it is heroic in that it is a difficult thing that needs to be done and the doing is therefore heroic and is an affirmation of life – possibly a happier more fulfilling one than so far lived. It is very difficult but not impossible and requires a great degree of generosity. He also affirms however that the letting go and the healing cannot take place without it. To reframe a story, as occurred in the example above, is not untrue. It is, Murphy claims, a truthful version of the story in that moment and is as true as any other version of it, and one that is much more likely to be helpful allowing the possibility, not only of a peaceful death for the one dying, but sometimes even more importantly, the breaking of the terrible cycle of pain, abuse and unfinished business for those that must continue to live.

As Murphy (1999) points out, it is easily understandable that people would rather avoid telling their stories, even those that are a lot less painful and traumatic than the example quoted above. Frequently these stories when they are told are not treated with respect, the hearer attempting to avoid the hearing by interrupting or correcting the story to something they are more comfortable with.

Murphy (1999, p.28) points out that the storyteller can never reach the point of reframing their story until it has been heard in full by a witness who is able to give it their full, non-judgemental attention.

For practical reasons people suffering from dementia and those under the age of sixteen were not included in this study. However, Murphy strongly believes that members of the family who fall into either of these categories should ideally be included as they can also benefit from the experience. In two cases in this study, Family 2 and Family 5, children under sixteen did come to the meeting, unannounced in the presence of both their parents. After the parents had confirmed that they wished them to be present they were permitted to stay but were not interviewed as this would not have been consistent with ethics approval granted for this study (see p.71).

Another important consideration in planning the family meeting is setting the right atmosphere.

> Storytelling is a sacred event that speaks of spirit and soul, and while sacred events are beyond time and space, there are some settings that inspire us to open up while others seem unsafe, causing us to withdraw. (Murphy, 1999, p.32)

The place chosen for the family meeting needs to be one in which the participants can feel as comfortable, relaxed and safe as possible. For many this will be their own home and in this study, if the patient was in home care, most chose to have the meeting in their home. In some cases it was necessary to have it in the hospice or the hospital, but in this setting a private place where others could not hear was chosen and some of the patient’s possessions were brought to the room, if it wasn’t their own room. Flowers were found if there weren’t some already in the room.

Some quite subtle things can be easily overlooked and at least one example of this occurred in this study. One of the participants of this study indicated in her interview that, although her mother – the primary carer – had arranged the meeting in the lounge (her custom when the family had guests – in this case the facilitator), the family would have felt more relaxed in the kitchen where most other family discussions took place. The facilitator had not picked up on this at the time of the meeting.

Equally important in considering atmosphere is space after the meeting to make sure that people are in a state that is safe to drive if that is what they need to do. In this study it was suggested that a cup of tea or even a meal be arranged for the family after the meeting to give this space. In most cases this occurred. The facilitator was usually invited to join this. If there was evidence that some of the participants were unduly stressed the facilitator definitely accepted the invitation so as to provide the opportunity for some members to speak privately with her if they wished.

The main features of the family meeting as Murphy (1999) has described it are as follows:

- It is a time for making peace, discharging old resentments, giving thanks.
- It may be the opportunity to say goodbye.
- It is an opportunity for all to speak rather than the meeting being dominated by those in the family who traditionally dominate or control.
- It is potentially a time in which things that are never talked about but have festered away in the family can come to light and be put to rest.
- It is potentially a time of enormous emotional healing. Things need to be said and done now. There is no time later.
- It is not a time for judgement or an occasion to try and explain an unhappy past although it may be an opportunity to see that past in a different light.
- It is an opportunity for family members to listen to each others' stories and to allow themselves to let go of resentments and betrayals.

The successful family meeting needs to take place in an atmosphere in which those present feel comfortable and as relaxed as possible.

## The Three Roles in the Family Meeting

Murphy (1999) describes three main roles in the functioning of the family meeting. These roles are those of the storyteller, the witness(es) and the guide. These roles will now be described.

### The Storyteller

The storyteller is the one who speaks of their joys and sorrows, pains and losses, their roots and their secrets. In the context of this type of family meeting the first storyteller is usually the one who is dying. They will be followed in turn by other members of the family. It is a fundamental condition of a successful family meeting that only the nominated storyteller may speak at any given time. Every person present is given their chance to be the storyteller. It is then that they may tell how it was for them – to tell the story from their perspective, understanding and experience, as they perceive it in that moment of time.

In this study the patient was always invited to be the first storyteller. There were two main reasons for this choice, apart from the fact that this is what Murphy suggests. The first is that their illness is the centre of, the trigger of the meeting. Most of the patients were very ill and they tired easily, so having told their story they could sit back and relax more as they listened to others as they spoke.

### The Witness(es)

The perfect witness is one who listens and absorbs but is neither judge nor interpreter. The witness listens with ego suspended. The witness has no need to say or do anything. This is the art of a human, being, rather than a human, doing. The task of the witness is to really hear what the story-teller is trying to convey. A witness may not interrupt, correct, judge or say anything else. (Murphy, 1999, pp.34-37)

In practice of course few of us make perfect witnesses, especially in circumstances where we are intimately and perhaps very painfully involved in the story. In the implementation of the family meetings which are a part of this study there were very few difficulties with ‘witnesses’ interrupting. In all but one case this was handled by the facilitator noting the interruption and returning the role of storyteller to the nominated person as soon as the interrupter stopped speaking. In these cases there was no repeat offence. In one instance, a person who was clearly used to dominating the airwaves at family gatherings needed something less subtle. The facilitator gave this person a gentle reminder that others needed their opportunity to speak.

## The Guide (or Facilitator)

The guide or facilitator is not present as a therapist although it is important that they have skill in working with family groups. The facilitator is a trusted one who is able to nudge the story along when it becomes stuck. They give permission for the storyteller to speak and invite another member to take on that role when the previous person has finished their story. The facilitator keeps order, supports and strengthens, encourages but does not demand greater depth. The facilitator may use a few ‘probe’ questions from time to time to encourage the story-teller. Some examples of probe questions used in this study are shown in Table 12 (p.97).

Very important facilitator skills, apart from the ability to work with family groups, is the ability to quickly establish rapport and trust with a wide range of individuals, to have refined listening skills and to be able to encourage people to speak at greater depth. The self-awareness of the guide or facilitator is also an important quality in the success of the family meeting. It is very difficult to be effectively involved in relationship-centred care of the dying and their families unless one is aware of and comfortable with ones own grief and attitudes to loss, death and dying. With this in mind Murphy

(1999) promotes training programs such as the one he currently runs in Ireland and Europe (Murphy, 2005) . The researcher attended two such programs during the course of this study.

***Table 12: Sample Prompt Questions: Family Meeting***

- What has this illness been like for you?
- Would you like to say a bit more about that?
- What are your concerns?
- What would you like to say to….?
- What have been some of the best/worse times for you?
- What has been most important to you these last few weeks (months, years)?

## The Five Part Process of the Family Meeting

Murphy (1999) has developed a five-part paradigm to guide families through the process of the family meeting. In describing these five parts of the process the names used by Murphy have been included, however, in the implementation of the family meeting in this study and in the production of information sheets it was decided that some of the language needed to be changed so that it would be more easily understood by the likely participants of this study, within the general Australian cultural context.

### The Story of the Wound

The story of the 'wound' almost always begins with a story about the journey of the illness, initially as it has been experienced by the one who is ill and then later as the others speak, the story of how it has been for other members of the family. Sometimes this leads to the story of other wounds such as those of abuse or alcoholism or neglect. In this study the word 'wound' was not used but rather participants were invited to speak about their journey or simply to speak about what it has been like for them these last few months (years). This decision was made because the participants of this study would be more likely to relate to this latter terminology.

## Worries and Fears

It is important that participants of the family meeting, beginning with the one who is ill, have the opportunity to speak of their worries and fears. Sometimes in this study the word ‘concerns’ was used. The worries and fears expressed are sometimes quite predictable and can include things such as concern for a spouse or children, financial concerns and fear of being a burden. At other times the fears and concerns that are expressed surprise the witnesses who may not have realised that their family was worried about those things or even cared enough to worry about them.

## Speaking of Roots

Murphy considers that speaking of family roots or history, both recent and not so recent is an important part of the family meeting process. This involves, as Murphy describes it, ‘bringing these memories and images from the shadow into living consciousness’ (p.88). This allows those stories to be told and the pain and the loss to be witnessed (in the sense of witness described above) and then mourned.

> Wounds unwitnessed, unmourned and unspoken, leave a paralysis of the soul that is passed on from generation to generation. (Murphy, 1999, p.88)

This is illustrated by the experience of one of the families participating in this study. They had a long history (at least three generations) of death from pancreatic cancer, hidden and never spoken of, and this was brought to light by the patient who was determined to bring change in the family as a result of his death. This was tentative at first, and then more freely spoken about by others. Many tears were shed – many of them expressions of grief over the loss of those long gone whose death had never really been mourned.

Murphy (1999) asserts that these openings don't always come as easily and that one meeting is not always enough to bring all these stories of the roots to the light of day. This is illustrated by the experience of another family participating in this study. It became quite evident that there was 'history' that was not being spoken about. Various family members present (and perhaps even more significant were the ones not there) would speak but go only so far, resisting any attempts by the facilitator to encourage the next step of opening up. For others, as described in the last chapter, the possibility (or perhaps the certainty) that a painful past would come to light was too much and they declined to participate.

## The Family Speaks

As already indicated each member of the family who is present is invited to speak. They are encouraged first of all to tell their story – how it has been for them – rather than to respond directly to what others may have already said. Of course what others have said may well become an important part of their story. For example the statement 'I didn't know you felt that way' indicates that the context of this person's story has already shifted to some degree.

## The Blessing

Murphy uses the term blessing as a way of describing the closing aspect of the meeting stating that these meetings end with a ritual or a blessing. For this study the term 'blessing' was not used as it was considered to have too strong a religious connotation to be inclusive of the general palliative care population. The phrase 'bringing the meeting to a close' was used instead.

The form this ending takes depends upon the family, their beliefs and habits. A family that is overtly religious may wish to include religious rituals or prayers. Non-religious families, will also however, usually find value in a closing a ritual. This needs to be custom designed to fit the needs and beliefs of each family. Candles and flowers used in various ways may be acceptable. Sometimes it might be just words or even one word that each person chooses, to express something of the life of the one who is dying or something about them that they have valued most. This can be seen as a blessing even if not accompanied by the traditional laying on of hands or anointing.

Immediately after leaving the family meeting the facilitator recorded in their field notes journal an outline of the issues raised, process for that family, notes on facilitation and significant interactions that had taken place during the meeting. These notes also formed part of the data.

## The Twelve Family Meetings

Each family meeting was unique as would be expected as each family is different, having different micro cultures, different expectations, different needs and different things to say. The meetings were held at a location most suitable for the patient. Seven were conducted in the patient's home, four in a hospice room and the other in a hospital room. The length of the meetings varied from one to two hours, the duration being dependent on factors such as the number of people present and how much talking they wanted to do. While every meeting followed the five part paradigm described above the details of conversation varied enormously as would be expected. Some families were pretty relaxed from the beginning while others were more tense. In some cases this was a result of underlying family tensions while for others it was caused by unfamiliarity with this way of communicating with each other. There were no fights or shouting, possibly because those most likely to engage in this behaviour declined to be involved. In every case there were tears and often laughter as memories were shared. The reality of impending death was always very palpable. Some times this was met with loving acceptance and expressed gratitude for a life shared. For some there was fear and anguish about the inevitable nature of their loss. By the end of every meeting there was a general sense (which may not have applied to every individual), of having done something which may have been difficult but was precious, leaving them with the memories of something given and shared that perhaps would not otherwise have been.

## The Interviews

All the patients and family members who were present at a family meeting were invited to take part in a one on one in-depth interview. As indicated in Chapter 4, a total of 11 patients and 37 family members were interviewed. Fourteen staff members were also recruited and interviewed. Details of the type of interviews and the process of conducting them will now be described.

### Patient and Family Member Interviews

Following the completion of each family meeting all the participants were approached to make an appointment for an interview. Apart from those present who were under the age of 16 mentioned above, only two people who attended the family meetings declined to be interviewed. These were both members of Family 5. Patient 2 was not interviewed because her health deteriorated rapidly the day following the family meeting and an interview was not appropriate. Patient 12 also deteriorated and was admitted to the hospice between the time of the family meeting and the planned interview appointment. He was however, most insistent that the interview go ahead. The interviewer limited the time of this interview to ten minutes as this seemed to be as much as he could manage.

On arrival at each interview appointment the interviewer first confirmed that the patient or family member were still willing to participate in the interview. A second consent form, giving consent to the interview and to its audio recording, was then signed by the participant. One patient (P7) and their spouse (F7A) were willing to be interviewed but did not want it audio recorded. They agreed however to the interviewer making hand written notes. In the case of Family 4 the recorder was found to be not working and hand written notes were also made during the interviews of P4 and F4A.

In depth interviews, which draw on an interpretive framework, as discussed in Chapter 3, were considered to be most appropriate for this study. This method of data collection was chosen not only because it provides rich data (a requirement of the methodology arising from the theoretical underpinning of this study), but because a number of researchers (Kellehear, 1989; McCracken, 1988; Silverman, 2000; K. E. Steinhauser et al., 2000) have concluded that not only is this method not excessively stressful for palliative patients, but may in fact be therapeutic as it provides them with an opportunity to tell their story in their own way and at a pace they choose.

In-depth interviews were conducted with patient and family member participants. Rice and Ezzy (1999) describe the in-depth interview as a negotiation of meaning between the interviewer and the interviewee and therefore stress that the relationship between the storyteller and the listener is as important as the content, and hence the very strong emphasis on the development of rapport as discussed in the first section of this chapter. These authors also discuss the advantages and limitations of in-depth interviews and these are summarised below in Table 13 – Advantages & Limitations of In-depth Interviews.

***Table 13:Advantages and Limitations of In-depth Interviews.***

NOTE:
This figure is included on page 123
of the print copy of the thesis held in
the University of Adelaide Library.

The art of asking appropriate questions is crucial to the success of in-depth interviewing. Every interview began with the statement “I’d like to hear about your experience of the family meeting we held on ____.” As appropriate, probe questions were used to encourage more depth and clarity to the information given. Rubin and Rubin (1995, p.150) , describe six types of probe questions:

Elaboration probes that ask for more detail

Continuation probes that encourage the participant to keep talking

Clarification probes that attempt to resolve ambiguities

Probes that confirm that the interviewer is paying attention

Completion probes that encourage the following through of a particular line of thought.

Evidence probes designed to find out how sure that person is about what they said (to be used with caution).

In this study this range of probe types were considered in determining the probe questions used during the interviews. Rice and Ezzy (1999, p.58) also point out that questions need to be phrased using vocabulary understood by each individual interviewee and that questions as far as possible need to arise from the content of the interview. Some examples of the probe questions used in this study are shown in Table 14 below.

***Table 14:Sample Probe Questions: Patient and Family Member Interview***

- Would you like to tell me more about that?
- What did you think about that?
- I'm really interested to hear that.
- What do you think will be the outcome of that?
- In what other ways was the family meeting helpful/not helpful to you?
- Are there other things that you wish had been included/talked about?
- Are there other things that you wish had not been included/talked about?
- Are there other ways in which you feel better/worse as a result of the family meeting?
- If I understand you correctly you are saying……..
- Can I just check that I have understood you correctly?
- Do you think your view of that will change later?

Throughout each interview, the interviewer was very aware of the well being of the interviewee, especially so in the case of patients. On several occasions when the patient appeared to be tiring the interviewer offered them the opportunity to stop the interview at that point. None of them agreed to do this and were keen to complete the interview. The average length of the patient and family member interviews was thirty minutes.

Care was always taken to ensure that the interviewee understood that their efforts and involvement were valuable and appreciated. A thank you note was sent to each participant after the interviews for that particular family meeting had been completed.

As soon as the interviewer had left the scene of the interview field notes were recorded in their journal. These notes which also formed part of the data, included insights on their interviewing style and how that may have impacted on that particular interview, emerging ideas arising from the data and non-verbal communication that was noticed during the interview which would not have been recorded on the audio recorder.

## Staff Interviews

Before the interview began with any staff member, as indicated in Chapter 4, they were asked to sign a consent form which included permission to record the interview, and also to complete a brief demographic questionnaire. In one case (S7) the recorder was found not to be working and notes were the sole source of data for the interview.

The interviews with staff were also designed to collect rich in-depth data and were conducted in a very similar manner to the in-depth interviews with patients and family members, with the exception that the content focus of the interviews with staff was narrower and more clearly defined. At the beginning of each interview the interviewee was told that the focus of the interview would be on three main areas:

- The process by which they decided which patients to refer to the study
- Their observations of the impact of the family meeting on patients who participated and on their family members
- Their observations about whether this type of family meeting intervention could or should be offered as part of regular palliative care service

Probe questions were also utilized in these interviews and some examples of those used are shown in Table 15 below.

***Table 15"Sample Probe Questions Staff Interviews***

- Would you like to tell me more about that?
- What did you think about that?
- I'm really interested to hear that.
- What do you think will be the outcome of that?
- Are there other ways in which you perceived the family meeting to have been helpful/not helpful for the patients and family members with whom you are/have been working?
- Are you aware of any other benefits/disadvantages of the family meeting for patients, family members or staff
- Would there be other benefits/ drawbacks to offering this type of family meeting as part of the regular service?
- What other factors do you think are important when deciding to refer a patient to a study such as this one?
- Do you think that process/outcome would be different if this had been offered as part of the regular service rather than as part of a study?

### Transcribing of Data

All digital audio recordings were transcribed by a professional transcriber who, prior to commencement of work, signed a confidentiality agreement. When each transcript was returned to the researcher it was checked against the original digital recording for accuracy of transcription. The checked transcripts were then stored as document files in NVivo 2 software (QSR International, 2002, Melbourne), in preparation for data analysis which will be discussed in the next chapter.

## Summary

In this chapter the role of the researcher as both facilitator of the family meetings and interviewer of the participants was discussed and the steps taken to enhance rigour were presented. The nature and process of the family meeting model utilised in this study was described in detail. The type and process of the interviews carried out in the study were also outlined including examples of probe questions utilized. As part of maintaining rigour in the study the checking process for transcribed data, in preparation for analysis, was also outlined. The next chapter will describe the processes of data analysis utilised in this study.

# CHAPTER SIX – METHODS 3

# ANALYSING THE DATA

## Introduction

Data were collected from two sources, patients and their family members (participants of the family meetings) as well as from staff who were involved in their care, as has been described in the previous chapter. Coding of the interview transcripts was assisted using the computer software package QSR International NVivo 2.0 (2002).

The interpretation of coded data was carried out according to Paul Ricoeur's theory of interpretation, the philosophical underpinning of which has been discussed in Chapter 3. The practical application of this theory involves three levels of analysis which will be outlined in detail in this chapter. A brief summary of the outcomes of this analysis will also be presented in tabulated form.

## Patient and Family Member Data

### Level One Analysis – Explanation

The first level of textual analysis, as explained in the discussion of Ricoeur's Theory of Interpretation in Chapter 3, is that of considering only the internal nature of the text. In this process the text is seen as having no context and no author or audience. What arises from this is an 'explanation' based solely on a literal consideration of what the text says.

The patient and family member interview transcripts, as well as the researcher's journal notes made during the interviews in the cases already indicated and immediately after all initial meetings with the participants, all family meetings and all interviews, were imported as document files into NVivo software. The transcripts were analysed in family blocks each transcript being individually coded to free nodes (unorganised or emergent ideas), using in-vivo coding. This involved highlighting and then coding any word, phrase, sentence or group of sentences that said anything at all about the individual's or family's experience of the process of recruiting, being a part of the family meeting or being interviewed following the meeting. Any information about the individual's or family's history, culture, ways of relating or past experiences which might conceivably have any relevance to their experiences in being involved in this study were also coded to free nodes. This included extra information that they raised, or matters of concern which had not been mentioned during the family meeting, or at any other contact between the researcher and the participant prior to the interview. It was considered possible that this reflected on an outcome of the meeting or on a need which had not been met by the meeting. Following the completion of this process for all documents relating to families one to five (in all 21 interview transcripts plus the relevant researcher journal notes transcripts) a total of 730 free nodes had been identified.

A large amount of data was collected in this study and it seemed that a point close to theoretical saturation had already been reached with the analysis of data from the first five families. It was decided, following consultation with the supervisor, a person experienced in the use of NVivo software in the qualitative data analysis process, that to continue to analyse the rest of the data at this level would be very unwieldy and that any new ideas, not already accounted for in the 730 existing free nodes could be added as the remaining documents were analysed in the level two phase of data analysis.

Before proceeding to level two of the analysis those documents that had already been coded to free nodes (Families 1-5) were re-read, to check the accuracy of this coding process.

## Level Two Analysis – Naïve Understanding

According to Ricoeur’s Theory of Interpretation, level two analysis begins the process of understanding what the text is talking about rather than just what it literally says. This moves the analysis into the area of interpretation, as opposed to explanation, and its outcome is what Ricoeur describes as a naïve understanding of the text.

The first stage of this process in this study involved examining the 730 free nodes which had been coded in level one analysis and coming to an understanding about which ones were talking about the same thing. With the assistance of the NVivo software those free nodes which were talking about the same or closely connected ideas were grouped into themes (tree-nodes in NVivo terminology) and sub-themes. Each of these was given a description identifying the theme of the data coded to it. For example, the sub-theme entitled ‘Outcomes for the speaker’ was described as including anything that gives information about the outcomes of the meeting for the speaker – things that have continued on from the meeting or anything that is new for them since the meeting, that they connect to their experience of the meeting.

If it was initially unclear where a particular free node would rightfully be located, within the emerging hierarchical coding system, this was clarified by either referring to the original text to give a broader context to the coded section, or by listening to the original sound recording of the interview. A total of three themes and twelve sub-themes were created in this process.

Each sub-theme was then examined individually to identify how the free nodes coded to it could be grouped into categories, each category speaking of some aspect of the sub-theme. Each category was also given a description. For example, one of the categories identified as giving information about one aspect of the sub-theme entitled ‘The speakers’ experience of the family meeting’ was called ‘How they felt’ and was described as including all free nodes that gave information about ‘how the speaker felt during the family meeting or as a direct result of it.’

The next step of level two analysis was to code the documents relating to families six to twelve. These were coded in-vivo to the sub-themes and their categories that had already been identified when coding documents for families one to five. During this process a further sixty-two free nodes identifying passages which were not considered identical to already existing free nodes, were found. However these additional free nodes could be coded to already existing sub-themes. All documents relating to families six to twelve were then re-read so that the coding could be checked and confirmed.

The twelve identified sub-themes were found to have between three and six categories each. Between one and ninety two free nodes were coded to each category. The details are shown of Table 16 (p.111) and Table 17 (p.112). An examination of the twelve sub-themes also identified that eight talked about the participants experiences of the family meeting while the remaining four spoke of background information about the families and individuals in them that may have impacted on their experience of being involved in the study. Tables 16 (p.111) and Table 17 (p.112) provide a summary of the outcomes of data analysis at this level. As was described in Chapter 6, further analysis of these data resulted in some of the categories being merged or relocated to a different sub-theme. These changes can be identified on examination of the flow charts Figures 3-5 (p.116-118).

*Table 16: The Participants Experiences of the Family Meeting*

| Sub-theme | Category | Number of passages coded |
|---|---|---|
| (1.1) Speakers experience of the meeting | (1.1.1) Experience of speaking | 92 |
| | (1.1.2) How they felt | 71 |
| | (1.1.3) New understandings | 53 |
| | (1.1.4) Negative aspects | 26 |
| | (1.1.5) General positives | 66 |
| | (1.1.6) Making a contribution | 24 |
| (1.2) Outcomes for the speaker | (1.2.1) Freedom to speak | 24 |
| | (1.2.2) Understanding others | 12 |
| | (1.2.3) Negative outcomes | 1 |
| | (1.2.4) Feelings remaining | 29 |
| | (1.2.5) Neutral outcomes | 5 |
| | (1.2.6) Personal changes | 5 |
| (1.3) Observations of others' experience of the family meeting | (1.3.1) Observed benefits patient | 45 |
| | (1.3.2) Observed difficulties patient | 11 |
| | (1.3.4) Observed difficulties family members | 23 |
| | (1.3.4.3) Observed benefits family members | 37 |
| (1.4) Meeting Facilitation | (1.4.1) Well facilitated | 17 |
| | (1.4.2) Stranger/Outsider as facilitator | 9 |
| | (1.4.3) Specific qualities of facilitator | 28 |
| (1.5) Another Meeting ? | (1.5.1) Would agree to another meeting | 22 |
| | (1.5.2) hesitant/qualified yes | 12 |
| | (1.5.3) Would not agree to another meeting | 2 |
| | (1.5.4) In theory yes | 8 |
| (1.6) How the meeting could have been different | (1.6.1) Rest of the family present | 11 |
| | (1.6.2) Less people present | 4 |
| | (1.6.3) Children | 6 |
| | (1.6.4) Management of individuals | 4 |
| | (1.6.5) specific rituals/actions | 16 |
| | (1.6.6) Timing | 6 |
| (1.11) General Applicability | (1.11.1) Generally a good idea | 57 |
| | (1.11.2) Potential problems | 25 |
| | (1.11.3) Specific targets | 10 |
| (1.12) Observations about family outcomes | (1.12.1) speaking about illness & death | 21 |
| | (1.12.2) Relationships in the family | 41 |
| | (1.12.3) Impact on feelings | 7 |
| | (1.12.4) Impact on the grief process | 8 |
| | (1.12.5) Other general impacts of meeting | 7 |

Note that the bracketed numbers refer to coding reports generated by NVivo software.

*Table 17:Family Background Information that may Impact on Experience*

| Sub-theme | Category | Number of Passages Coded |
|---|---|---|
| (1.7) Family Relationships | (1.7.1) Negative influences | 18 |
| | (1.7.2) Degree of closeness | 20 |
| | (1.7.3) Significant individual issues | 13 |
| (1.8) Family History | (1.8.1) Positive impact of | 6 |
| | (1.8.2) Negative impact of | 32 |
| | (1.8.3) Impact not clear | 4 |
| (1.9) Family Culture | (1.9.1) Ways of being together | 38 |
| | (1.9.2) Acceptable topics of discussion | 16 |
| | (1.9.3) Uncomfortable topics | 15 |
| | (1.9.4) Emotional expression | 38 |
| | (1.9.5) Support base | 32 |
| (1.10) Family Communication | (1.10.1) Good family communication | 36 |
| | (1.10.2) Poor/limited communication | 61 |
| | (1.10.3) Individual's communication impacting on the family | 13 |

## Level Three Analysis – In Depth Understanding

The outcome of level three analyses of data, according to Ricoeur's Theory of Interpretation, is an appropriation, or making your own an in-depth understanding of what the text is talking about. This is a process of moving back and forth between explanation and understanding. The acts of interpretation that are a part of this process are informed by the knowledge, experience and beliefs that the researcher brings to the task (as outlined in Chapter 1), and the researchers' knowledge and experience of the families taking part in the study, as outlined in the field journal notes and as expressed by the family members themselves in interview transcripts. As explained in Chapter 3, in Ricoeur's terminology, this is the extremity of the hermeneutical arc which anchors it in the ground of lived experience (Ricoeur, 1981).

Because the researchers' knowledge and experience of the participating families does inevitably impact on the process of interpretation, it was considered important to begin this level of analysis by further working with the data coded to sub-themes, identified in level two analysis, as talking about the family culture, history, relationships and communication habits. In this way the researcher could be more conscious about precisely what views and understandings of the families were impacting on the interpretive process. The sub-themes to which these data were coded and the categories which further inform them are detailed on Table 17 (p.112).

These data were further examined by referring again to the context of the original text and in some cases by listening again to the original sound recordings of the interviews. As already indicated interpretation at this level was also informed by the researchers' experience of working with families and individuals in a palliative care setting, particularly in relation to psychosocial and spiritual issues. Further analysis found that these data could be arranged into six main areas of interest:

- How the family relates to each other
- Communication in the family
- Emotional expression
- Culture/Values
- Impacting history
- Socio-economic situation

These formed the basis for a family profile for each of the participating families (Appendix VIII.1-12).

Attention was then given to the data coded to the sub-themes which spoke about the speakers' experience of the family meeting and anything that had arisen for them as a result of this meeting. These sub-themes and their categories are detailed in Table 16. As for the data coded to the sub-themes shown on Table 17, these data were further examined by referring again to the context of the original text and in some cases by listening again to the original sound recordings of the interviews. As before, interpretation was also informed by the researchers' experience, knowledge and beliefs as well as by the now clarified understanding of the families and their mode of functioning as outlined in the developed family profiles.

The coding reports for the sub-themes identified on Table 16, and their categories, were read to gain a clearer overview of these data. It was apparent that three main themes emerged which were identified as:

- Theme 1 - The individual: Their experience of the family meeting and personal outcomes.
- Theme 2 – The speaker's observations of the experience of other family members and the outcomes for them and for the family unit.
- Theme 3 – The implementation and applicability of the family meeting

As the data were sorted into these three main themes it was found that the primary sources of data for each theme were the following sub-themes and relevant categories identified with coding reports as numbered below and shown on Tables 16 and 17:

- Theme 1 – coding reports 1.1 and 1.2
- Theme 2 – coding reports 1.3 and 1.12
- Theme 3 – coding reports 1.4, 1.5, 1.6 and 1.11

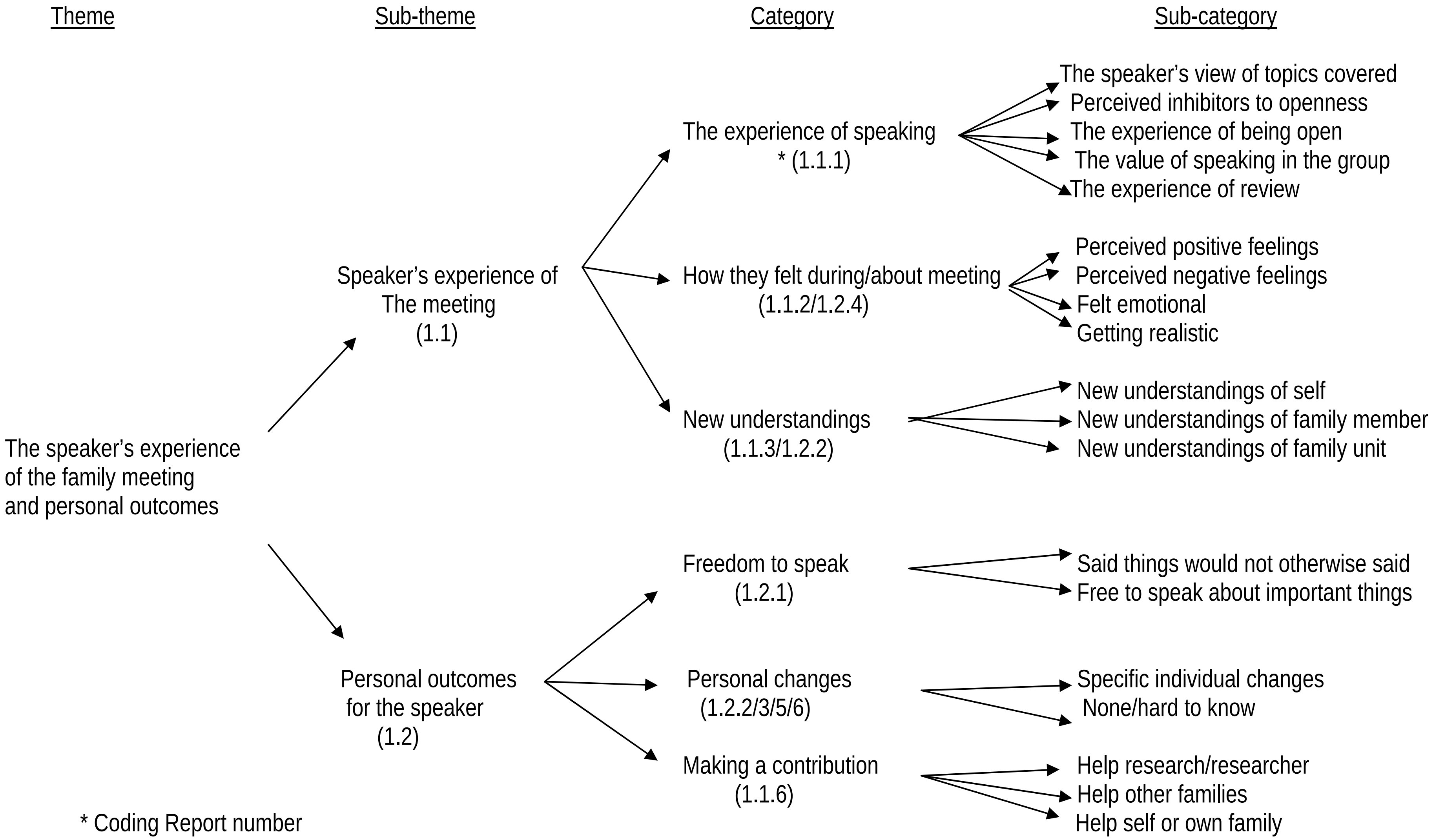
Each theme was then individually examined and categories and sub-categories within each sub-theme were identified.

During the process of analysing data relating to each individual theme, it was found that some coded items would be better related to either another sub-theme within that particular theme or, as in some cases they also provided data relevant to another theme. Decisions were made to merge categories and sub-categories that had been created. All these changes were recorded in the researchers' journal as well as on hard copies of the coding reports. Some examples of these changes are:

- It was decided that sub-theme 5 Level 2 Analysis/Another meeting and sub-theme 6 level 2 Analysis/Could have been different, could be merged to form a new sub-theme 5/6 entitled ‘What if anything would have made it better?’
- The decision to merge coding report 1.1.4 Level 2 Analysis/speakers experience of Family Meeting/Negative aspects, with coding report 1.1.2 Level 2 Analysis/speakers experience of Family Meeting/How they felt, was made because all the examples of negative aspects of the experience of the family meeting related to feelings.
- On closer examination of coding report 1.1.5 Level 2 Analysis/Speakers’ experience of FM/General Positives, it was found that data coded from document 5 passage 3 (*‘I think it came at the right time’ P3 para.103)* more appropriately belonged to theme three and was re-located to sub-theme 5/6 ‘What, if anything, would have made the meeting better’, category (c) ‘the timing of the meeting’.
- During the detailed interpretation of theme 1 (The speaker’s experience of the family meeting) three categories were identified which each had sub-categories. Data within the category “New understandings’ was at first divided into four sub-categories - ‘of self’, ‘of immediate relative’, ‘of other family member’, and ‘of the family unit’. However, on further reflection it was decided that two of these, ‘of immediate relative’ and ‘of other family member’, would be more appropriately merged to form one category entitled ‘new understandings of other family members’.

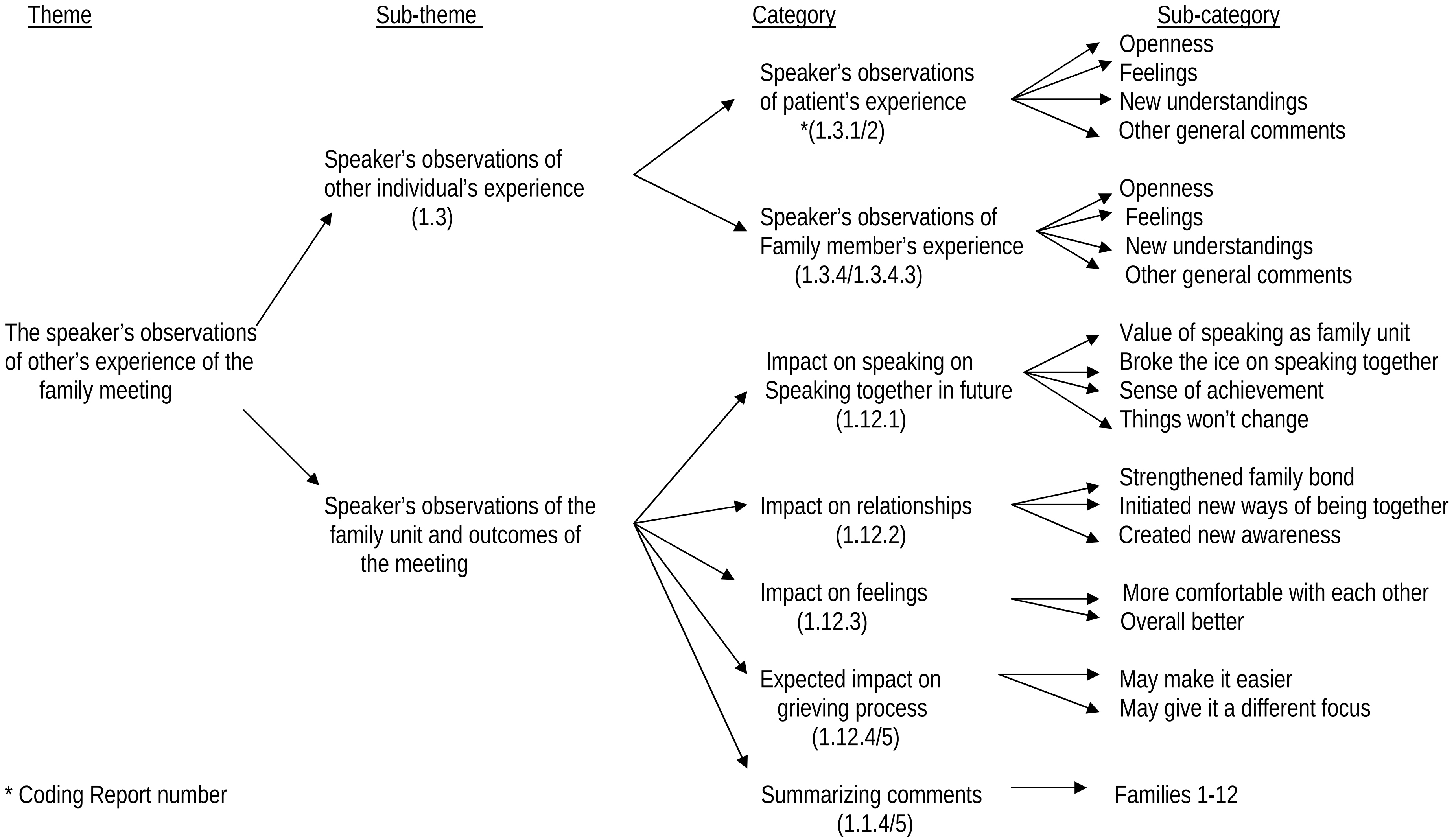
As each theme developed, a flow chart (p.116-118) was drawn up which depicted the sub-themes, categories and sub-categories that informed the theme. This chart also records the major coding reports created in level two analyses, which were incorporated into the theme. During the development of each theme some changes were made to these flow charts.

Figure 3 - Flow Chart Theme 1: The Speaker's Experience of the Family Meeting and personal Outcomes



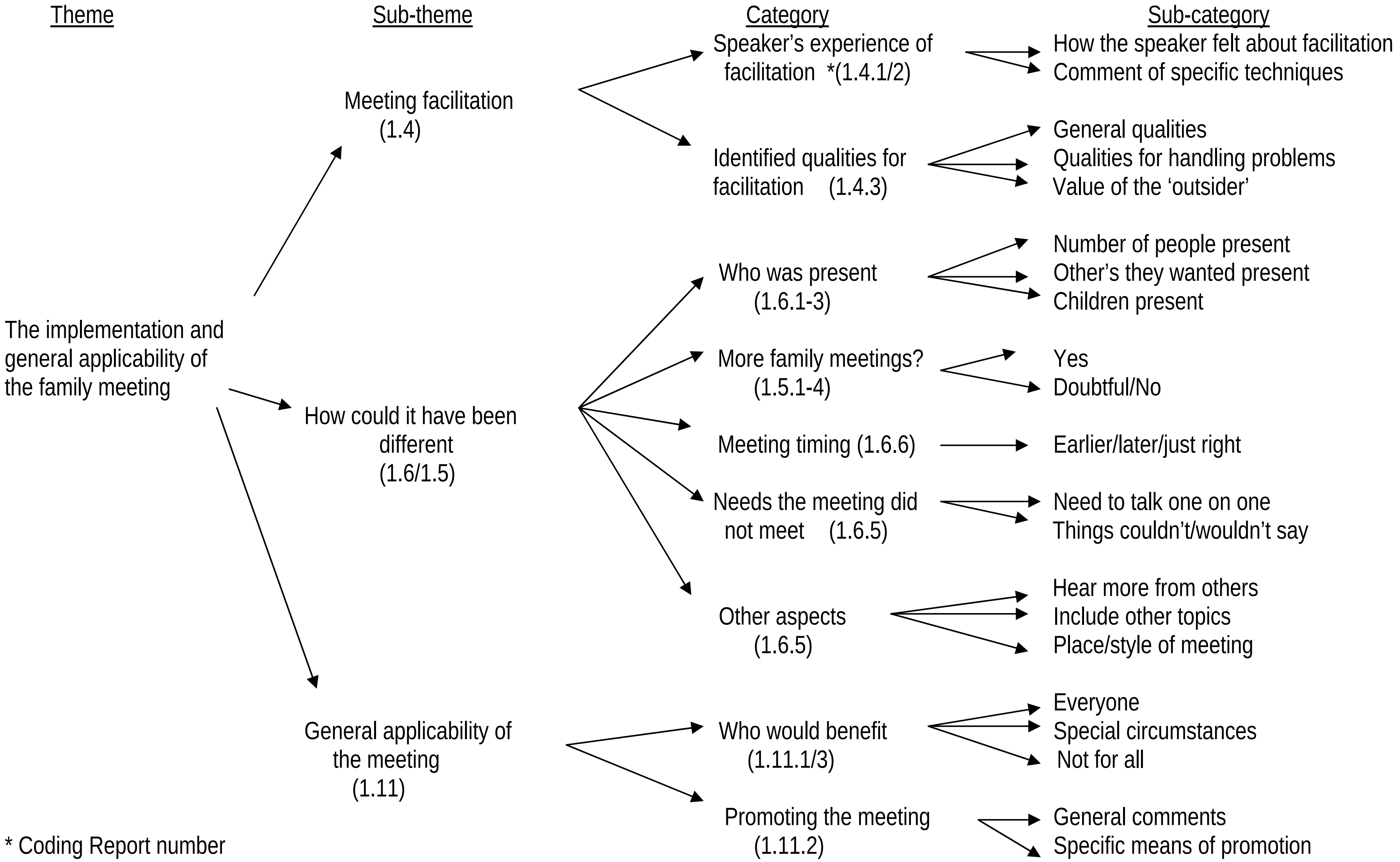
* Coding Report number

Figure 4 – Flow Chart Theme 2: The Speaker's Observations of Other's Experience of the Family Meeting



* Coding Report number

Figure 5 – Flow Chart Theme 3: The Implementation and General Applicability of the Family Meeting



* Coding Report number

During the development of each theme a table (Appendix IX.1-3) was drawn up for each one. These mirrored the flow charts in identifying sub-themes, categories and sub-categories within each theme, but also identified the main ideas within each sub-category as well as indicating the coding report to which they are coded and the interview code identifying the speaker. There are several important features of these tables:

- They were used as a basis from which the results chapter for each theme was written.
- The coding report references provide a route to the exact paragraph within the transcript texts from which the particular idea was sourced. For example: Coding report reference 1.1.1 refers to sub-theme address 1.1.1 and doc 17(2) refers to coded document 17, passage 2 within this coding report. On referring to this point of the coding report it will be found that the speaker was F11G and that the passage was from paragraph 6 of the original transcript text.
- Coded passages which were not from the principle coding report informing the sub-category being described are identified by their coding report reference. For example: On the table for theme 1 (Appendix IX.1), sub-theme 1, category (a), sub-category (1) it will be seen that the source coding report for all of the ideas contained within this sub-category, except one, is coding report 1.1.1. The exception to this is taken from coding report 1.1.4 doc 3(1-2). This is an example of a coded passage that was found to fit more appropriately into a category or sub-category other than the one to which it was originally coded, or to contain information relevant to more than one category or sub-category.

Following the completion of the above tables for each theme, consideration was given to the distribution of coded sections within each sub-category, across the participating families. Tables: “Frequency and Distribution of Comment” can be seen in Appendix X.1-4) In this manner it was possible to ascertain if particular experiences in relation to the family meetings were common to most participating families or pertinent to only one or two. It was considered that in the latter situation, it may be possible to identify possible connections between particular experience of the family meeting and certain family characteristics.

Another relevant matter for consideration in the interpretation of data at this level is the handling and resolution of apparent contradictions in the data presented by the same individual. When faced with an obvious contradiction the researcher re-read the context of the apparently contradictory statements and also listened again to the original voice recording of the interview. The data relating to the speakers’ family as well as any information that was known, either from the speaker themselves or from other family members about the speakers’ situation, personality and ideas about family were reviewed. It was also another opportunity for the researcher to review her own beliefs and ideas about the matter under consideration in order to be very conscious of how this may be impacting on the interpretation of the apparently contradictory data.

A detailed account of the steps taken in dealing with an apparent contradiction in the data presented by participant P1 will illustrate this process. The sections of text concerned are as follows:

> I didn't see it as being anything that was going to make my situation change for the better or anything like that. I did not think that by and large our family has got (telephone rings) - I don't think it will make any changes. (P1 para.5)

> But what I did find that was really quite interesting was that F1D (name removed), who was previously outside of our family and is now inside had so much courage to open up, particularly because her family situation has not been the best, and I was very, very pleased that she was able to be as comfortable with it as she was. (P1 para.5 – two sentences after the above)
>
> She was here yesterday and whenever she comes in now the first - as soon as she sees me she comes up and gives me a big hug. 'Hello, Big Fella. How are you getting on today?' and so on and I just love that from somebody who was I guess, now they were building a relationship, they have been together nearly two years now, and for the first year I didn't see a great deal of them, but to see her now and the way in which she responds to not only just me, because I've got this illness, but to other members of the family I think it's just wonderful. (P1 para.9)

In summary these passages seem to be saying the following:

- First coded section: There will be no changes in the family as a result of the meeting.
- Second coded section: Hasn't changed his mind about outcomes from the meeting but acknowledges that there were some surprises in a family member's behaviour during the meeting.
- Third coded section: He describes a big change in the behaviour of this family member since the family meeting one which he thinks 'is just wonderful'.

The following steps were taken in investigating this apparent contradiction:

- The transcript was re-read and the researcher listened again to this section of the recorded interview being conscious of intonations that would not be evident in the transcript. It was noted that the speaker was some what clinical in his initial summation (serious business like tones) but became more animated and enthusiastic in his expression in the third excerpt quoted above.

- Evidence relating to the speakers' situation, personality and ideas about family, was reviewed. The following were key factors: thinks the family has got it all together (P1 para.5); females show their emotions outwardly – that's expected (P1 para.5); Germanic Lutheran background – definitely head of the family (Int. notes –preliminary meeting); 'they know what I feel, I don't need to say it' (Int. notes – FM); 'a little bit military in his precision' (F1D para.13); perception may be impaired by pain relief (F1B para.49); only once seen him get emotional or tearful (F1B para.49); likes to be in control and not leave anything in a mess (Int. notes – FM); strict with children (Int. notes – FM).
- Any comments made in interviews by other members of the family about the response of F1D to the meeting were reviewed and the following evidence noted: she is now part of the family (F1A para.48; felt a bit apart before (F1C para.7); hope she feels more included now (F1C para.12); she hasn't been a member of the family as such compared to the rest (F1B para.46); good to hear her views (F1B para.44).
- Comments made by F1D herself, if any, about her response to the meeting in relation to being part of the family were searched. Her experience is summed up best in the following quote:

  Firstly, I think at least I know where I stand now with the family. That's something that I was struggling with for quite a while. They are quite an open sort of loving family but at the same time that's within their family and they are very, very nice lovely people but I sort of never sort of quite felt am I part of the family? Am I not part of the family? Do they want me to do this? Do they not want you to do this? When all I really wanted to do was help as much as I could, so now it's a little bit more clarified for me and I think it's great. I've been able to relax a little bit more and I don't have to sit there and think should I do it or should I not do it before I do it. I can just either do it or not do it now. It's a lot better. It's fantastic. (F1D para.5)

It is quite evident that for this person one outcome of the family meeting is that they now feel very much clearer about belonging and about their role in the family.

- The researcher reviewed her own experience and beliefs to consider if they were impacting on the interpretation of this apparent contradiction. She was aware of the following in this regard: although their own family background is not Germanic Lutheran it was however, strict, male dominated and lacking more than minimal abilities to express feelings and verbalise intimate thoughts. Having grown away from that point of view significantly, they are possibly likely to respond somewhat negatively to those who practice it. They have also learnt, painfully at times, that most of the time people don’t know what someone else thinks and feels unless an attempt is made to verbalise it. Again the researcher may well be inclined to take a negative stance towards those who insist on taking the view expressed by this patient.
- All of the above relevant information was reviewed in order to come to a conclusion about what P1 really meant.

It was concluded that there were significant changes in F1D’s relationship with the family unit, as a result of the family meeting. This is supported not only by P1’s later statement but by the views of other members of the family and most of all by F1D herself. It was also decided that the reason for P1’s change of view between paragraph 5 and paragraph 9 of the interview transcript may have been influenced by the following factors: he started the interview feeling a bit apprehensive about the unfamiliar process being a person who likes to be in control, especially of his family, and is used to a somewhat dominant role in relation to females rather than being interviewed by them. Possibly to admit that there had been a change as a result of the meeting would be to admit that his family was perhaps not as quite together as he would like to believe. As the interview proceeded, however, he realised that the interviewer was not too threatening and he relaxed and was able to acknowledge and express to some degree his delight about the change that had occurred in F1D.

Level three analyses of the data have provided an in depth understanding of the experience of patients and family members in relation to the family meeting, both as individuals and as family units. The data is summarised in the form of flow charts and tables and will be discussed in detail in the following chapters.

## Staff Data

The data arising from the semi-structured interviews conducted with staff participants informed the fourth major theme within the entire study data. This fourth theme is entitled ‘Staff Perspectives’. Due to the semi-structured nature of these interviews with staff members, three sub-themes were determined by the nature of the questions. As discussed in Chapter 5 the interviews were designed to learn about the staff members’ perspectives in relation to the three areas of:

- the recruiting process
- the impact of the family meeting on patients and their family members who participated in a family meeting
- suitability of this family meeting intervention for offering in the regular palliative care service.

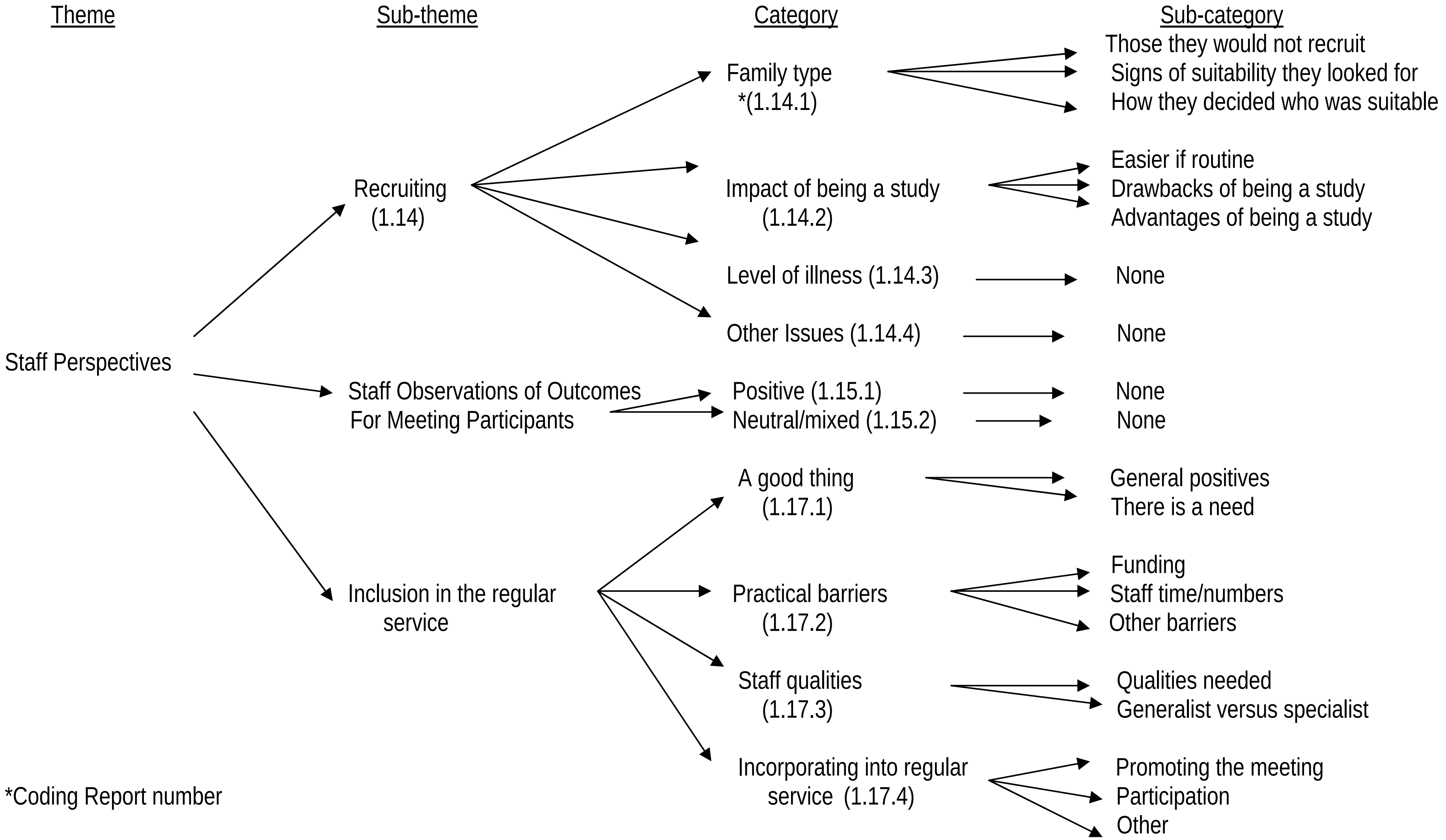
The analysis of data arising from the interviews with participating staff proceeded in a similar manner to that already described in this chapter for the analysis of patient and family member participant interviews. The same checking and double checking processes already described were also utilised in the analysis of staff member interviews. Level 1 analysis (what does it say) involved the coding of free nodes within each of the identified sub-themes named above. This means that each item for coding was identified as saying something about recruiting (coding report 1.14), the impact of the family meeting on participants (coding report 1.15) or about the interviewee's opinion about the possible inclusion of this intervention into regular palliative care services (coding report 1.17).

During level 2 analysis each of the above three sub-themes were examined independently to determine which of the coded items within a sub–theme are talking about the same thing. In this process categories were created within each sub-theme. For example, within the sub-theme 'recruiting' four categories were identified. These were entitled: 'family type', impact of being a study', level of illness' and 'other issues'.

Level 3 analyses were undertaken in the same manner as already described for the analysis of patient and family member interviews. Subcategories were identified within most of the categories named above. For example the category 'family type' was found to have three sub-categories which were entitled: 'those they would not recruit', 'signs of suitability they looked for' and 'how they came to conclusions about suitability'. A flow chart outlining the sub-themes, categories and sub-categories of this fourth theme 'Staff perspectives' was prepared (Figure 6).

As for themes 1-3 both a theme table (Appendix IX.4), and a 'Frequency and Distribution of Comment' (Appendix X.4) were drawn up for theme 4.

Figure 6 – Flow Chart: Theme 4: Staff Perspectives



*Coding Report number

## Issues of Rigour

The issue of interpretive rigour is particularly relevant to the process of data analysis in any qualitative study. Rice and Ezzy (1999) claim that, ‘an account has interpretive rigour if it accurately represents the understanding of events and actions within the framework and world view of the people engaged in them’ (p.36).

One way to achieve interpretive rigour is to ensure that it is very clear how the interpretation was arrived at. This includes a clear audit trail that outlines interpretive decisions, the reasons for them and the evidence from the data which supports them. In this study audit trails have been established as has been described above and conclusions are supported by the use of clearly traceable direct quotes from the data transcripts.

Some researchers, for example Daly, McDonald and Willis (1992) argue the value of the technique known as inter-rater reliability in which other researchers view the data and grade them on an agreed set of categories. The authors then report on the degree of statistical inter-observer agreement. This of course assumes that interpretations generated by so called interdependent observers will somehow be more accurate. This assumption however is based on the idea that there is somehow a ‘right’ or ‘true’ interpretation, a concept which is not consistent with the philosophical underpinning in this study as discussed in Chapter 3. In order to ensure that the interpretation of data in this study did accurately represent the understanding of those involved in the study, in the context of their experience and beliefs, each process of coding was repeated at least once as has been described above. In situations where there was doubt, or appeared to be contradictory evidence an extensive process of reviewing all evidence that could conceivably relate to the issue in question was undertaken, as has been described.

Rigorous reflexivity, the continual examination by the researcher of their own position, experience, beliefs and world view in relation to their impact on the study, is of vital importance throughout the study but is of special significance in the process of interpretation. In this study the researchers' position is clearly stated at the beginning of Chapter 1 and was regularly reviewed at each stage of the project. Particular emphasis was put on this process when the data were ambiguous or seemingly contradictory.

## Summary

This chapter has described in detail the process of data analysis, including how Ricoeur's three levels of analysis were applied to the data collected for this study, details of how decision were made and how a trail was created which made clear the analysis process. Summaries of the outcomes of this analysis are presented within the chapter in the form of flow charts and in the appendices. The following four chapters will present the results for each theme in detail beginning in Chapter 7 with an account of the results for Theme 1: The speakers' Experience of the Family Meeting and Personal Outcomes.

# CHAPTER SEVEN – RESULTS THEME 1

# PATIENTS AND FAMILY MEMBERS SPEAK: THE SPEAKERS' EXPERIENCE OF THE FAMILY MEETING AND ITS PERSONAL OUTCOMES

## Introduction

The first of three major themes arising from the analysis of patient and family member interviews, as discussed in the previous chapter, is 'The speaker's  experience of the meeting and its personal outcomes'. As seen in the flow chart, Figure 3 (p.116), two of the sub-themes developed in level 2 data analysis, 'The speaker's experience of the meeting' and 'Personal outcomes for the speaker', inform this theme.  Each of these sub-themes has a number of categories and sub-categories which are also depicted in Figure 3.  The ideas and concepts coded into each sub-category, and the coding reference identifying the source transcript document, are shown in Appendix IX.1.  The number of coded items for each sub-category, the number of families that spoke of each issue and the families for which it was a particularly important matter have been identified in Appendix X.1.

This chapter will give a detailed account of the ideas and concepts embodied within the sub-themes, categories and sub-categories that inform the theme 'The individuals' experience of the meeting and its personal outcomes.'

## The Speakers' Experience of the Meeting

The sub-theme entitled 'The speakers' Experience of the Meeting' was defined as any data which speaks of the individual's experience of the family meeting, either patient or family member. This sub-theme embodies three categories: 'the experience of speaking', 'how the speaker felt during the meeting' and 'new understandings'. Each of these will be discussed using their respective sub-categories as key points for the discussion which will be illustrated with quotes from the interview transcripts texts.

### The Experience of Speaking

The category 'the experience of speaking' included all data that described the speakers' (patient or family member who had been present at the family meeting) experience of speaking at the family meeting. Five sub-categories were identified: 'the speakers' view of the topics covered', 'inhibitors to openness in discussion', 'their experience of being open', 'their perception of the value of speaking in a group' and 'their experience of reviewing past events during the meeting'.

#### The Speakers' View of Topics Covered

The sub-category entitled 'the speakers' view of topics covered' included all data relating to the content of the meeting discussion - whether they considered it important, relevant, appropriate or not. Most participants expressed the opinion that the matters they considered important and had wanted to discuss, had been covered to their satisfaction during the family meeting. The following examples from the texts illustrate this point.

> I think there was enough opportunity to bring up what ever you wanted to (F8B para.21).
>
> I think it has more or less been all talked about, yeah. No I don't think there's any issues that are sort of hanging over anybody's head, no (F6B para.35).

It was also recognised by a patient participant who considered himself a realist, that the topics were totally appropriate to his situation.

> Nothing inappropriate. I'm a realist (P12 para.16).

For one patient participant in particular, however, it had been very important that she felt able to avoid, or at least decline to discuss, topics they found too sensitive or painful. As recorded in the field notes for family meeting four (para.4), this participant was very emotional and was unable or unwilling to tell her husband what she had valued most about their relationship.

Three of the speakers, one a patient and two family members were disappointed, for differing reasons, with the topics discussed in the meeting. The patient concerned believed that nothing, that he and his wife had not already discussed, had been raised at the meeting.

> Participant: I think it was helpful. It was more like a preliminary meeting and not really any specifics came out of it.
>
> Interviewer: No. So the things that were talked about were things you sort of knew anyway and had talked about together before, you are saying?
>
> Participant: Yes (P10 paras.6-8).

One family member who expressed disappointment had apparently been unclear about the purpose of the meeting from the beginning and had been expecting it to be a discussion of medical issues.

> There was minimal information (F9A para.14).
>
> I don't think anything major came out (F9A para26).

The third disappointed participant considered that ‘nice things’ were said but that some issues, important to her were not raised and she did not feel free to raise them as it may have resulted in volatile reactions from others present.

| | |
|---|---|
| Interviewer: | So the things that weren't talked about were not things that you felt you could bring up. |
| Participant: | No. |
| Interviewer: | Even though you would have liked them to have come up or - - - |
| Participant: | Not specifically - I didn't - I certainly know my parents well enough to know that certain things will never be spoken about (F3B paras.10-13). |

It was evident that the majority of those who chose to comment on the content of the discussion during the meeting were either satisfied with it or were able to control it to meet their needs. It is likely that the needs of those who expressed disappointment could have been met by either clearer communication to all family members about the purpose of the meeting (an issue discussed in relation to recruiting challenges) or by a second meeting that offered the opportunity for deeper exploration of matters as yet unaired. The matter of whether a second (or more) meeting is appropriate for some families will be discussed in chapter nine.

## Perceived Inhibitors to Openness

Coded within the sub-category ‘perceived inhibitors to openness’ were all data which identified any factors which the speaker found had hindered his/her ability to speak openly about the issues of importance to them during the meeting. Those participants, who spoke about things that they had experienced as inhibitors to their openness during the family meeting, raised three main issues.

The first of these was a family culture that lacked openness in relation to sensitive issues, especially talking about matters related to death.

> I think he (*the patient)* is just fantastic and just to blurt out things like that *(about death)*, I don't know, I didn't think it was sort of appropriate at the time (F5F para.48).

This family culture of reticence was also exacerbated in one case by a difficult personal relationship with all of the rest of the family, except for the patient,

> ..I guess the dynamics in our family are a bit different, in terms of me personally anyway, being completely open I guess about things - it was probably not the right environment for me to do that - just a personal thing from my perspective (F2B para.4).

and in other instances by personal reluctance to speak in any group.

> I was ok with it but you know like X (name removed) I don't really say a lot when I'm in a crowd; especially people I don't know, even people I do know. I find it hard to speak in front of groups of people (F11G para.6).

For two families, it was evident that the rest of the family was being guided in the 'appropriate' degree of openness by the patient.

> I thought it was actually really good that you had Mum speak first so that we could find out what she was hoping to get from the session and a bit how she was going to approach it because if she was going to go into it and not say much at all it makes it difficult for us then to open up as well (F8B para.23).

One member of Family 11 commented on how he perceived that the patient and her husband had controlled the content of the discussion and for him this had been limiting.

> I think we went to the gate and didn't go through the gate (F11E para.8).

The third factor that appeared to inhibit openness for some participants was a lack of clear understanding of the purpose of the meeting and so a reluctance to speak up on more sensitive issues.

> The more time you spend with someone the easier it gets and I think once you realise too the way it is going to go, because it was an unknown…. We didn't know what you wanted from us (P8 paras.25 & 28).

Aside from long history of personal reticence to openness, the factors most likely to be inhibiting were, lack of familiarity with openness in the family context and uncertainty about what was expected in this unfamiliar situation.

## The Experience of Being Open

All data pertaining to the speakers' experience of being open in their conversation during the meeting were coded to the sub-category 'the experience of being open'. It was apparent that for a number of the participants, speaking in a family group about matters of this nature was quite a new experience.

> I've never been in that particular situation before where there were people around that were talking openly. And I found it a comfort actually (F11B para.27).

For some, being more open than usual was not an easy experience, even if they could not immediately acknowledge this.

> Interviewer: So what was it like to talk about these things in the presence of your wife and your daughter?
>
> Participant: No problem (then later)
>
> Participant: It's certainly a different experience and not as easy as one might think (P3 para.22-23 & 27).

It was evident that the second statement was a more truthful reflection of his experience and perhaps, as he became more relaxed with the interviewer, he was more able to acknowledge his real experience. Other participants indicated that being open and having that respected and valued by others present had been a very good experience for them.

> To have it all in one place and in front of everyone so that everyone could hear, I thought that was really positive, to sort of bring it all together like that. So yes I thought it was really positive in that respect (F1C para.5).

The other major area discussed by participants, in relation to their experience of being open, were the things that they saw as encouraging openness for them. Among these was the style of the meeting that had enabled them to feel relaxed. Also, in at least one case, the desire to help and cooperate with the patient, who had really wanted the meeting, had encouraged more openness than usual for this person.

> I thought everyone spoke fairly well and were fairly happy to talk and I - that's primarily due to the fact of who *the patient* (name removed) is. Everyone has a vested interest in *her* so we always think we'll do what we can – not for *her*, because it is not for her as such, but in a way it is (F11G para.6).

Another factor that was seen as aiding openness was that the meeting brought a focus to the experience of the illness and the impending death, which gave permission to speak about things that otherwise might have either been taboo, or which would have been very awkward to raise.

> Probably that your discussion (in the meeting) is focused so you actually talk about things that relate to the illness and about the person and about how we'll go on because otherwise you have conversation in passing and one conversation will be that Dad really wants us to get the carport finished for Mum and then another conversation might be 'well we've got to

> get the finances in order but you don’t actually sit down and talk about that in a holistic way (F12B para.10).

One participant found the experience of being encouraged but not pressured to openness, very important.

Although, in general, participants did not find the process of being open about matters discussed in the family meetings an easy task, the factors that assisted the individual to greater openness were the style and the setting of the meeting, that gave permission for these topics to be discussed, and their experience of being valued and respected in their attempts to openness.

## The Value of Speaking in the Group

Data which indicated that the speaker had identified value in speaking together in a group were coded into the sub-category ‘the value of speaking in the group’. Almost all of the participants who chose to comment on this, as opposed to having one on one conversation only, came from one of two families. For members of Family 1 the focus was on the value of having everyone together to hear the things that each of them had probably said to most of the other family members in individual conversations.

> I thought it was really, really good to have a family sort of discussion and hear people’s views and their feelings. We have that from time to time but we don’t necessarily all – we’re not necessarily all there at one time type thing. It may be something that is discussed with one member or another at different times so it was good to have that group session type thing and to have everyone express their views and be a party to that (F1A para.4).

For the members of Family 5 the focus was on the perception that being together as a group provided value because it gave an opportunity for things to occur that would never have normally taken place for this family. They believed that this was because being together in the group gave people courage to be more open than normal and in particular to ask difficult questions that they would not have otherwise asked for fear of causing offence.

> I was very happy with what happened because I think *the patient* (name removed) and I talk, and I'll ask questions. And he answers them honestly. And I'm not afraid to ask questions. But a lot of people are (F5A para.116).
>
> I got the awkward questions answered that I wanted to which was good (F5E para.8). But I wouldn't have brought it up if we hadn't have had that meeting and I didn't even want to ask him where he was going and whether he had thought about a hospice and all that (F5E para.52).

It is significant that the two families that commented most on the value of speaking in the group probably represent the opposite ends of the spectrum, among the participating group of families, in relation to family communication on issues of illness and death. Family 1 considered them selves very open and claimed it was their custom that no topic at all was taboo or an inappropriate focus of conversation amongst them. There was evidence in some of the individual interviews that communication was not in fact as clear and open as some, particularly the patient and his wife, would like to believe. For instance:

> I think this was a very relaxed environment for Dad to speak about his emotions because he doesn't really vocalise what he is feeling a lot so I think it benefited him in that respect (F1D para.6).

Family 5 on the other hand was very clear about their lack of communication, especially on issues of illness and death from cancer, which had been a repeating experience for the family in the past and one which had never been talked about openly. The patient in this family expressed his view of the value of meeting when he said:

> If we had something like this, if it's not mandatory, but it is easy to access, meetings like this to everyone, I think you will find that people will be with me and I'll die feeling better (P5 para.197).

The other two comments relating to the value of speaking in a group, as opposed to one on one, came from a most unusual family in the context of this study. Family 11 practiced a very broad idea of family which included close friends and some of the patients many past foster children. Some of the individuals at the meeting did not, in normal circumstances, see very much of some of the others invited.

The experience of these families suggests that there is value in having the family meeting regardless of whether family communication is usually very good or very bad. It would be interesting to know why the members of the other nine families, whose level of communication ranged at various points between that of families one and five, did not comment one way or the other directly on the experience of speaking together as a group.

## The Experience of Review

Whether they related only to the journey of the illness, or to a broader span of their life experience, the speakers' comments on their experience of reviewing the past, were coded to sub-category 'the experience of review'. It was agreed by those who spoke about their experience of reviewing the past, either the journey of the illness or other specific events of the past, that it was a beneficial process. Three different benefits were articulated. Several participants spoke of the joy, comfort and pleasure of remembering the good times.

> I think reminiscing is a great comfort at this stage, a great comfort (P6 para.19).
>
> She really liked talking about her family and showing me her photos (Int. Notes P7 para.14)

The process of reviewing the past was also identified as an opportunity for releasing the past and moving forward to what is to come.

> A few months later looking back on it, it is always quite interesting to just call back on your perceptions at that time and communicate it to others and to release it in a way I guess. So it was beneficial (F1B para.12).

One participant particularly valued the process of reviewing the past as an opportunity to reassess some things that he had done and to perhaps make amends while there was still the opportunity.

> Because we went back many years and recounted a lot of experiences, I think it brings back many experiences of early married life and even before. It was a situation where one perhaps did a bit of examination of what one's – the way one had handled the years - whether one was sufficiently attentive. I know I spent a lot of time overseas and interstate when we were first married. And *the patient* (name removed), she handled that pretty well. But you don't think about these sought of things until you have a session like that. I think it was good for all of us (F6A para.15).

For these participants the experience of reviewing past events was a source of comfort and pleasure, an opportunity to release some things and to reconsider performance while there was still time to make a positive response.

## How the Speaker Felt During/About the Meeting

The second category identified within the sub-theme 'the individual's experience of the meeting and its personal outcomes', was 'how the speaker felt during the meeting'. All data identifying the feelings of the speaker, as they pertained to their experience of the meeting, were coded to this category. Five sub categories: ‘perceived positive feelings’, ‘perceived negative feelings’, ‘emotional’, ‘impact of the meeting’, and ‘getting realistic’, were identified within this category.

## Perceived Positive Feelings

Data coded to the sub-category ‘perceived positive feelings’ included a wide range of feelings that were considered positive by the speaker. Fairly general expressions of feeling such as happy, positive, good and pleased were quite widely used.

> So I needed to remind myself that what my father was saying was very unusual for him in that meeting and I’m pleased to have heard it (F3B para.23).
>
> It’s been a good experience for me (F6A para.77).

Other participants were able to be more specific in the description of their feelings using words such as warm, cared for, supported, comforting, meaningful and powerful, comfortable and relaxed.

> I felt extremely comfortable with it (P1 para.13).
>
> I felt that it was very warm, caring and rewarding in a certain sense (F11B para.25).
>
> We felt relaxed (P6 para.11).
>
> It felt as though it was a - like it had an impact on me. I didn't feel that it was something that sort of happened and I didn't feel that it was not meaningful or anything like that. It felt that it was - it felt very meaningful and very powerful (F1B para.12).

Three participants indicated that they felt easier or more comfortable with the imminent death of their relative, both during the meeting and as an outcome of the meeting.

> I felt a lot easier in myself you know – just to sort of help ease the pain a bit (F2A para.8).
>
> I’m a bit more comfortable with it. I don’t talk a lot about it either. When he starts talking I do, but I’m just a bit more comfortable with it (F5G para.29).

> It makes death easier. That sounds sick, but, you know (F5B para.17).

Another participant expressed something similar in saying they now felt freer in relation to expectations of the patient that they had been holding onto.

> In fact there was something quite freeing about that – a sense of this really was my last chance I think to hear what my parents are prepared to – what my parents can say; what they won't say. I don't feel like I've left any stones unturned so I have felt quite free in some ways since then (F3B para.35).

Two participants from family three, a family in which both the patient and their spouse considered that communication within the family was open, said that they felt very grateful for the opportunity to meet together in the manner offered.

> I'm just grateful that we had it (*the meeting*) (F3A para.66).

> What you did for us was provide an arena to speak in that would not have been available to the family in any other way. So that was really important and I am actually really grateful for that (F3B para.25).

Some participants expressed feelings that related to some unexpected aspect of the family meeting. In Family 11 for instance, where the definition of family was very broad indeed and included a close family friend and a number of ex-foster children (who are now adults), one person felt honoured to have been included in the meeting. In two other families people also expressed surprise and enjoyment at being together in a much more open way than was usual.

> I was surprised too at how much my father said (F3B para.31).

Two other participants indicated that the meeting had triggered a reflective mood in them, both in relation to what is important in life and to how they had handled some aspects of their life in the past.

> It makes you think about things (FM2 notes P2 para.6).

Several participants felt positive in the sense that something they would have considered negative, such as intrusive, threatening, emotional or angry did not occur. For example the following comments:

> I thought it was quite good actually because any of those sort of programmed things like that, like just a sudden different thing can be quite threatening (F11G para.10).
>
> I felt ok with it. There was nothing that was threatening to me – yes, nothing really invasive because it is just the way things are (P8 para.15).

A similar feeling was expressed by a patient when he said:

> It was pretty well balanced all the way round. I felt extremely comfortable with it (P1 para.13).

This patient was known by his family for his 'military precision', his lack of emotional expression and his obvious discomfort with others displaying more than fairly minimal degrees of emotion. He was comfortable, in part at least, because no one, in his view, got out of control emotionally during the meeting.

For others an awareness of positive feelings in response to the meeting took some time. For example the stirring up of past painful memories of much unresolved grief, left a participant feeling drained for a while but as they reflected on it they became more and more aware of what were for them, positive aspects of the meeting.

> Initially I thought, I don't know if it is a good idea because it just brought up too many painful memories and painful experiences. I was wondering if in a week's time I would change my opinion again and feel more positive. Even today I feel a little more positive again (F5E para.83).

> I went home and I had to take a moment just sort of sitting with the things that I had raised and how that had made me feel but I wouldn't say that was negative (F1B para.12).

The majority of the participants expressed some form of positive feeling in relation to their experience of the family meeting. For some this was expressed in general terms such as 'happy' and 'pleased'. Others were more articulate and specific in expressing both the nature of their positive feeling and the source they considered to be the biggest contributor to how they felt.

## Perceived Negative Feelings

Not all feelings arising from the experience of the meeting were perceived as positive by the participants. The sub-category 'perceived negative feelings' contains all data relating to feelings arising during the meeting, or about the meeting, which have been seen as negative or as mixed by the speaker. Some of these mixed feelings arose from temporary nervousness, from lack of self confidence in groups, from an experience of 'heavy heartedness' which was accepted as part of the process, or from a fleeting moment of tension between two participants that reflected some issue of family history.

> I didn't like the first five minutes. It was probably the most nerve-wracking (F1D para.10).

> I think there was a situation there with Dad and I that was a bit awkward and maybe I answered the question the wrong way and, yes that was a bit funny (F2B para.63).

Others were much less specific about their mixed feelings. For example:

> I wouldn't really say – I don't think I could say anything negative about the experience (F2B para.74).

> I don't think there was anything difficult or bad about it or anything like that (F1D para.10).

For another participant it was clear that the use of the word ‘traumatic’ did not actually indicate an overall negative feeling about the meeting.

> It was personally really traumatic for me, for whatever reason. I said on Saturday I just really didn’t want to do it Saturday and I don’t know what it was, but afterwards I felt better (F12B para.6).

Other words used, that did not necessarily indicate an overall negative view of the meeting and its outcomes, were ‘exhausted’, ‘stressful’, ‘more gruelling than expected’ ‘angry’, and ‘ a bit over whelming’. The first three of these terms were used by different members of Family 5 which had a very strong history of unresolved grief from earlier deaths of family members from the same form of cancer as that suffered by the current patient. They acknowledged that their feelings were largely due to the stirring up of past painful memories that hadn’t as yet been adequately processed, these matters not being a topic of discussion within the family at all in normal circumstances.

> I thought it was a lot more gruelling than I thought it would be. I thought it would be a bit emotional but not as emotional as it was. It took me a few days to recover actually. …. It just brought up too many painful memories and painful experiences (F5E para.6).

The very strong culture in this particular family, of avoiding any talk of death, even when it is blatantly imminent, was further emphasised by another member of the family when they spoke of feeling sad.

> I feel immense sorrow for *the patient* (name removed) that he has had to come to that point of admitting to himself and the rest of the family that he may die soon and you know that’s an incredibly courageous thing to do. It’s just so sad (F5F para.22).

The people who had described themselves as feeling angry or a bit overwhelmed also indicated that they saw this as a normal part of the process of coming to grips with the imminent death of a parent rather than as negative feelings about the meeting as such.

> Last night I was angry. I've never been angry (*about father's illness*) before. That was interesting. That was a reaction to yesterday (*the meeting)*. …that was just my next step (F12C para.4).

Some participants felt very uncomfortable with at least some of the content of discussion. For instance, for one person, discussion about different types of coffins was being too open about death, and another couldn't see any positive side to talking about what people were thinking and feeling about a person's impending death.

> It was good beside the fact everyone got to sort of vent their own issues. I can't really see the positive side of talking about it personally (F5I para.30).

Most of the so called negative feelings that were expressed in relation to the participants' experience of the family meeting, were acknowledged as arising either as a normal part of their process of dealing with the approaching death of someone they love, or as being the outcome of past unresolved grief and of facing something they would prefer to pretend did not exist.

## Felt Emotional

A number of the participants commented on the degree of emotion they experienced during the meeting and how that compared with their expectations or 'normal' experience in the family. All data relating to this matter were coded to the sub-category 'felt emotional'.

There was a range of levels of emotion experienced including: less than expected, comfortable levels of emotion, more than expected and very emotional. One participant considered the experience had been less emotional than she expected because she had heard most of things discussed at the meeting before. For another participant, levels of emotional expression that they found comfortable were considered an important part of the overall success of the meeting.

> It didn’t get to an emotional level where no one coped. It was generally really informative and very comfortable and I think that was probably the reason why it went so well (F1D para.10).

One participant felt they needed time to recover from the experience because it had been more emotional than they had expected.

> I thought it would be emotional but not as emotional as it was and it took me a few days to recover actually (F5E para.6).

It is likely in this case that the unexpected emotional impact of the meeting is related to large amounts of unresolved grief being carried by members of this particular family. It is also significant that the patient in this family, who was very keen to have the meeting in order to assist the family to deal with his approaching death and who was extremely positive about the outcome of the meeting, verbalised the family culture about crying in the following exchange:

> Interviewer: How did you find their expression of grief? I mean the fact that most of those people you have just mentioned were crying at one point or another. How did you find that? Was that alright for you?
>
> Participant: Yes I didn’t mind
>
> Interviewer: You didn’t see it as unreasonable?
>
> Participant: No, because I still think that crying is actually – it’s self pity about something (P5 para.88-91).

This family norm, in relation to crying, was also confirmed by another member of the family, who incidentally was also very positive about the meeting.

> It was self pity. I’m sorry that’s my opinion (F5A para.38).

A number of participants described the experience as a moderately or very emotional experience.

> I found it quite an emotional process, an emotional meeting, just reflecting on the course of events that had happened over the last six months or so (F1B para.4).

One participant, in describing his experience of the meeting made a connection between ‘emotional’ and ‘sincere’. His experience of finding the meeting emotional was a sign for him that the deep and important things had been touched on, something he doesn’t often experience.

> But this was more of an emotional, sincere discussion we had with you; as it should have been. And I don’t think you, no you don’t do that under normal circumstances; I don’t think so (F6A para.30).

Participants of the family meetings felt and expressed varying degrees of emotion. This was influenced by family culture in relation to emotional expression, whether the participant heard something that was new or surprising to them and whether the meeting stirred up past unresolved grief issues. There was not necessarily any relationship between the level of emotion experienced and either positive or negative outcomes of the meeting for the speaker.

### Getting Realistic

One impact of the meeting, for some of the interviewed participants, was on the degree to which they were facing the reality of the approaching death of their loved one. All data pertaining to this issue was coded to the sub-category ‘getting realistic’.

For one participant, being faced with the reality of her uncle's approaching death was a particularly difficult and unwelcome experience. She just wanted everything to be normal and now felt that she could no longer pretend that it was.

> I think it will be harder for me, but some people think it will be easier for them (F5I para.8).
>
> I feel uncomfortable around him *(because the reality of his approaching death is now out in the open)* and I feel guilty for that (F5I para.36).
>
> I just feel so helpless (F5I para.136).

Other participants, while acknowledging that it is hard to come to terms with the fact that someone you love is going to die soon, experienced the meeting as helping them to do this, in some cases to start the process. They acknowledged that facing the reality of the impending death was a necessary part of the process for them.

> Well put it this way, you come to terms with it, you know, and that's what I've started in the last week or so, coming to terms (F2A para.4).
>
> And I know last week with the boys (*adult sons of the patient)*, you know, it was all 'Come on Mum, eat up, you're not going to die, you're not going to die.' And she's saying 'How ridiculous, of course I am.' But I think that's a very hard switch for people too, and we've been lucky to have this week, and maybe a bit longer, to all adjust ourselves to that, and say the few things we want to say (F6B para.18).
>
> The family meeting kind of brings it back up, so you are more conscious again that it is in our face and it is something that we've got to deal with, however we're doing it (F12B para.66).

Three of the participants who commented on the realistic nature of meeting discussion were patients. One of these had recently (about six weeks before) been diagnosed with wide spread cancer and although she found the meeting difficult in many respects, felt that it had been an important part of her process of coming to grips with the diagnosis. Two others, for whom the process of acceptance was much further progressed, were quite philosophical about the realistic nature of the discussion.

> I felt ok with it. …. It's just the way things are (P8 para.15).

While only one of the forty eight patient and family member participants of this study indicated distress at feeling confronted by the reality of death when attending the family meeting, this possibility is certainly a relevant consideration. This is particularly true in relation to patients, although in this study the twelve patients had all come to terms with their approaching death or had begun the process of doing so. It is relevant to note, as mentioned in Chapter 4, that at least a few of those patients who declined to participate in the study (or were persuaded to by unwilling family members to do so) were not yet ready to face the reality of approaching death. Most participants, who commented on this issue, indicated however, that while it was a painful experience, it was one they needed to face, and that the family meeting situation had provided a safe and supportive environment in which to do this.

## New Understandings

It was apparent that many of the participants of this study believed that new understandings had arisen for them as an outcome of being involved in the family meeting. Data coded to the category 'new understandings' was further assigned to three sub-categories. These are entitled: 'new understanding of self', 'new understanding of another individual family member' and 'new understanding of the family unit.'

## New Understanding of Self

For some participants, the process of the meeting and hearing what others said, opened up new understandings of themselves. Data relating to these observations were coded to the sub-category ‘new understanding of self’. There were found to be four main ideas or types of new understanding of self which arose from these data.

Two patients had a particularly strong experience of realising for the first time how much they were valued and appreciated by their family. One was a bachelor brother and uncle who had lived a fairly independent life. He was amazed that they cared about him and were as interested in what he thought and wanted, as they had demonstrated during the meeting.

> I didn’t think they were so caring; the family was so caring (P5 para.9).

Another patient had apparently never before heard her family verbalise their love and respect for her. One of her daughters described her response as follows;

> I thought she looked very pleased with what everybody said. It was sort of like her face lit up at that time I thought (F2C para.46).

For others the experience had been a reflective one leading to a clear understanding of what was important, such as letting go of expectations they had of others and a new perspective on some of their own past actions.

> Moments of reflection - maybe a bit of self examination (F6A para.20).

For another participant the experience of the family meeting had led to the realisation that if he was ever diagnosed with a terminal illness he would like to have such a meeting with his loved ones.

> I imagine that I would like that kind of thing if I was ill. I think I’d probably talk about my illness much more than my mum and sister did (F5E para.8).

One of the participating patients found himself very reassured that he had in fact done something of value with his life even though it was about to end somewhat prematurely. He expressed this in the following dialogue.

> Participant: I was very surprised that they – the things that I took naturally that they appreciated so much. That's something that's really (long pause).
>
> Interviewer: That was really a bonus for you?
>
> Participant: Yes. I thought 'Oh well I've done something in my life and, (pause) yes (P5 paras.245-247).

The other very significant break through in self understanding occurred for a partner of one of the sons of the patient in Family 1. This family considered itself very close but despite being allegedly a part of the family for two years ('we do consider our children's partners part of the family – a very close part of the family' F1A para.48) she felt that only after being included in the family meeting did she really know where she stood with the family.

> Firstly, I think at least I know where I stand now with the family. That's something that I was struggling with for quite a while. So now it is a bit more clarified for me and I think that's great (F1D para.5).

New understandings of self are of course likely to be very individual experiences. It is very likely also that some participants would not be willing to verbalise such experiences to a stranger. It is difficult to place a value on realising that you have done something worthwhile with your life or on finding your place in the scheme of things within the family group of which you are a part, or on the other hand to predict the outcome, if any, for a person confronted with an unfamiliar moment of self reflection.

### New Understanding of Other Family Members

At least one member of nine of the twelve participating families came to a new understanding of at least one other member of their family, as a consequence of participating in the family meeting. The nature of the new understanding varied but all data that spoke of learning something new about another family member were coded to the sub-category ‘new understanding of other family member’.

Some of the new understandings came from specific things that were said during the meeting. These included new understandings about parents, particularly it seems of fathers who were patients.  For instance:

> He (*father)* just skims across the top and keeps it all calm to keep everyone else happy but I think that – I don’t know whether it helped you or not but it certainly gave me an insight into what he’s – because I’ve been dealing with it from my perspective and it gave me an insight into how he’s dealt with it (F12C para.10).
>
> For Dad that was a major revelation which I've really sort of had to chew over (F3B para.23).

Two of the patients were surprised by what others said.  They hadn’t been aware that their daughters felt the way they did or that other family members were worried about particular things such as, where he wanted to spend his last days, and whether or not he would be willing to take pain relief drugs before the pain was too bad.

> Participant: I reckon it was great and I found out things that worried them and I didn't - -
>
> Interviewer: You hadn’t realised?
>
> Participant: No, I hadn’t realised anything like that, you know, especially X (name removed), which is my number one niece (P5 para.5-7).

A greater understanding of the nature of her parents-in-law’s relationship was an outcome for another participant.

> I feel more was said yesterday that hasn't been said before, especially when we touched on *patients' and husbands'* (names removed) relationship (F6B para.7).

Other new understandings were expressed more as general perceptions arising from the meeting as a whole, than from specific things that were said. This included a better understanding of relations with family members such as a grandson, sister and sister-in-law.

> I thought it was good to look at it through *sister-in-law's* (name removed) eyes (F1B para.48).

One son very much surprised his mother by taking the day off work to come to the meeting even though he wasn't keen on the idea of being involved. One patient surprised his sister with a demonstration of courage of which she hadn't considered him capable.

> I think *he* (name removed) is very brave; he's very courageous with what he did. I admire him for that meeting, I really do (F5A para.71).

The family meeting, in the form it was presented in this study, was very unfamiliar territory for most of the families involved and so it seemed to provide opportunities for different things to be said and for loved ones to be observed in a different setting. In these cases it has provided opportunities for new understandings of and insights into other family members.

### New Understandings of the Family Unit

Data relating to the speakers' new understandings or perceptions of the family as a unit were coded to the sub-category 'new understandings of the family unit'. Some of these data were particular to the way in which the family was able to speak together as a group. Some families were able to listen to each other better than they normally do and were able to tackle the subjects of discussion in a much more holistic manner than usual, opening the way for a fuller picture of the situation.

> You don't actually sit down and talk about that in a holistic way and say 'Well, okay, I understand now that's an issue for you. Leave it with me. I'll go away and do it.' …. When you have the conversations in passing one of the things that I noticed is that when we try to reassure Dad and we're saying 'It doesn't matter, don't worry about the carport. We'll fix it.' It took us a little while to realise that it wasn't important to us because we could fix it but for Dad it was really important and for Dad it couldn't wait and I think you get some of that insistence, or perhaps you get the sense because you're maybe focusing on it, maybe listen better to some of what he's saying. I don't know (F12B para.10).

For other participants the experience of the family meeting didn’t so much give them a new understanding of the family unit, although some heard about things that had happened for the first time, but rather confirmed things they thought they knew but which had never really been verbalised before.

> I thought that getting together with others and talking about it all together was probably a good thing because we all knew what was going on but no one had sort of said anything to the other about it (F11D para.23).

> It was interesting some of the things that had happened along the line that you hadn’t realised what’s happened (F11F para.38).

Some participants were strongly drawn to hear what others thought, in spite of in one case, having a strong aversion to speaking about illness and death.

> I was just sitting there just because I was so intrigued about – I really wanted to listen to what everyone was saying (F1D parap.16).

Other new understandings about the family unit related more to the possibilities for the family in the future. For instance they could now see the possibility that their family could understand each other better while recognising that they weren't all the same, that they were capable of being more inclusive and of talking together about deep and important issues even though they hadn't done this much, if at all, in the past.

> I think we'd understand each other better if more of this sort of thing was happening (P3 para.81).

New understandings whether they are of self, of other family members or of how the family functions as a unit, always have the potential to bring change for the individuals concerned. This change may be short lived or it may have long term potential for how the family manages challenging situations in the future. Again it is very difficult to quantify the value of a change of understanding that enables a person to die feeling they have done something worthwhile in their life, or gives a young mother the determination to break with the family culture of secrets and silence, in the way she now works with her two year old daughter around the death of a loved uncle. This leads us to consider the expressed personal outcomes for the patients and family members participating in this study.

## Personal Outcomes for the Speaker

The second sub-theme that relates to the individual's experience of the family meeting is entitled 'personal outcomes for the speaker.' Three main categories were identified within the data coded to this sub-theme. The first of these related to the impact of having the freedom to speak in the meeting and included data coded to two sub-categories: 'I said things I would not have otherwise have said', and 'having the freedom to speak in the future about such matters.' Data were coded to a second category, within the sub-theme 'personal outcomes for the speaker', which was entitled ‘personal changes’.  This included data coded to two sub-categories, one relating to specific personal changes discussed by the participants and the other containing data indicating no awareness of change resulting from the meeting.  A third category was named ‘having a sense of making a contribution’.  Data coded to this category spoke of contribution in a number of areas including: helping research, helping other families, helping their own family and helping themselves. These areas will now be discussed in more detail.

## Freedom to Speak

As already indicated, the category ‘the freedom to speak’ contained data relating to the outcomes for the speaker of the experience of having the freedom to speak during the family meeting.  Two main areas of comment were revealed and coded to the sub-categories: ‘I said things I have would never have otherwise have said’ and ‘I feel free to speak in future about such matters.

### I Said Things I Would Never Have Otherwise Said

A variety of insights were offered by participants into their experience of saying things in the meeting that they had been putting off, or would just never have said in their normal circumstances.  All data relating to this issue were coded to the sub-category ‘I said things I would not have otherwise said. The data coded to this sub-category were of two main types – those which simply indicated that these things would never have been said if the meeting had not occurred and those which gave some insight into what it was about the meeting that allowed these things to be said then, but not in any other situation in that particular family’s experience.

A couple of reasons were offered by speakers who indicated that they would never have said the things they said in ‘normal’ circumstances. These included: it was just too hard to say those things normally and they would just not think of saying them, which in some cases at least was due to entrenched family culture of not verbalising ‘emotional or sincere’ things like that.

> I think you, no you don’t do that under normal circumstances (F6A para.30).
>
> I think it brings out a lot of little things that people don’t say. Don’t think to say sometimes (F12A para.6).

One patient explained that the important thing for him in telling his wife what he had valued most in their relationship, something he found just too hard to do normally, was that now, if she died in the next day or two he would always know that he had told her.

Some participants were able to articulate what it was about the meeting situation that had allowed them to speak of things that they would not have otherwise expressed.  One family member indicated that their family would never have got together to talk about these matters as a group.

> What you did was provide us with an arena to speak in that wouldn’t have been available to the family any other way (F3B para.25).

This same person also said that because the purpose of the meeting was to speak about matters relating to the illness and death of the patient it was also much more natural to raise some issues in this setting.

> I felt like it gave me an opportunity to say some things to him that would have been more manufactured maybe if I’d had to try and squeeze them in somewhere (F3B para.23).

Another participant suggested that when the family got together, at the meeting,  and started to speak about these matters, some members who wouldn’t normally have done so got the courage to speak up because others were doing it also.

> *(There was)* a lot more free speech. I probably wouldn't have the same things to say, or you wouldn't have the same things to say, one on one. …. But because everyone else is having a go like, it makes it a lot more easier to really say what you really feel and mean, than just to come out and tell someone, it's not that hard (F5G para.86).

A different perspective offered was that the meeting made an appropriate time to say things for which the time seemed otherwise never to be right.

> …you think that well there are things she needs to know or things that I should say before it is too late but it's never the right time… (F8B para.7).

It is significant that at least one member of eight of the twelve participating families believed that they were able, for a variety of reasons, to say things that they think they would never have said, had they not had the opportunity to be a part of the family meeting.

### Free in Future to Speak About Important Things

All data that indicated that a participant would feel more free in the future to talk to other family members about issues of illness and death or other sensitive issues such as depression, were coded to the sub-category entitled 'free in future to speak about important things.'

Some participants spoke generally about it now being easier to speak about these things. A variety of reasons for this greater ease were offered such as; they now realised that talking about illness and death would not cause offence as they had feared it might or that they now realised that others were also interested in hearing about these things.

> This has opened the door now for conversations later on, so yes, I think it was definitely a good thing for us, a good thing for me (F8B para.7).

> I think it will make it easier for me…. I will be more open with them. I think that might be the way to go (P5 para.133).

Other participants who were interviewed made it quite clear that they saw themselves now being much more open with some members of the family but not with others.

> You know the two girls – I think I would be comfortable in talking about *the patient* (name removed) and maybe their grieving process more openly with them – maybe not *my brother-in-law* (name removed). I really like *him* (name removed) and we get on well but he's not a very openly emotional person and quite a macho kind of guy and I don't feel comfortable talking to him about any emotional sort of stuff, so probably not *him* (name removed). Probably *my sister in law* (name removed) – I would talk about it with her and *my other uncle and aunt* (names removed) (F5F para.42).

The family meeting gave one family member, who had taken on the role of executor of the patient's will, permission to speak further with him about his experience and wishes.

> I just thought it did open an avenue for me to ask Uncle (name removed) more things (F5E para.83).

One very interesting aspect of this notion that the family meeting assisted people to feel more free to speak in the future to at least some members of their family about illness and death, is that every comment made about this except one, came from Family 5. Five of the eight family members interviewed expressed this feeling of greater freedom to speak. Considering this family has a very strong history of deaths from the same kind of cancer, a very strong family culture of silence and secretiveness about these experiences and much unresolved grief, it is reasonable to hope that some sort of critical momentum for change in this area may have been achieved. Obviously further follow up would be required to establish if change did in fact occur in the longer term.

## Personal Changes

A small number of participants made comments on whether or not they saw their experience of the family meeting resulting in any personal changes for them. These data were coded to the category 'personal changes'. Those who believed they would be making changes were quite specific about these and data relating to these changes were coded to sub-category 'specific individual changes'. Where participants specifically commented that they did not see any changes resulting the data were coded to sub-category 'none/hard to know'.

### Specific Individual Changes

Two patients made reference to the role of the family meeting in re-orientating their thinking to a higher power, one they felt they had had a connection with in earlier life but had lost conscious touch within the context of busy lives.

> Interviewer: Would you like to tell me a little bit more about why it was useful - what particularly was useful for you?
>
> Participant: It was useful to - - -
>
> Interviewer: - - - a tissue?
>
> Participant: Thank you - useful to get things orientated to Father in Heaven and that might be enough said (P3 para.10-13).

Another patient who had rigorously avoided contact with any family beyond her husband (including her three children of a previous marriage), following the family meeting, decided to make contact with a granddaughter. In another case a small, but in the family context, significant decision was made by one family member participant about how she would handle the anticipated death of her uncle in relation to her two year old daughter who regarded the patient as a stand in grandfather.

> I can remember my mother saying ‘funerals are not for children’ and she didn't believe in crying in front of people even and then I thought - well I wasn’t going to when the time happened, I wasn’t going to take *my two year old daughter* (name removed) and then I thought well maybe I will. I’ll tell her what has happened of course to *the patient* (name removed) because she understands everything and I think people underestimate children (F5E para.57).

## None/Hard to Know

Only two participants chose to specify that they either didn’t think any changes would result or that they found it hard to know if any would and one of these later changed his mind.

> I didn’t see it as anything that was going to make my situation change for the better or anything like that. I don’t think it will make any changes (P1 para.5).

As most of the interviews were done within a few days of the family meeting it is not very surprising that few of the participants commented one way or the other on possible personal changes that may result from their experience of the family meeting. A longitudinal study of the remaining family members would need to be undertaken in order to have a clearer understanding of the outcomes of the meeting in terms of personal changes.

## Making a Contribution

Quite a strong category emerging from the data was entitled ‘having a sense of making a contribution’. More than half the participants expressed this in various ways including a desire to help research in general, to help other families, to help their own family and to help themselves or the patient. Data relating to these expressions were coded to three sub-categories. These are discussed below.

### Help Research/Researcher

Some participants seemed to have quite a high belief in the value of research in general and were keen to make a contribution, to the point of expressing gratitude for being offered the opportunity to be involved.

> I felt very privileged yesterday that you were interested enough in us *to do this* (P6 para.23).

One patient who had deteriorated significantly in the few days since the family meeting carried this determination to help to the point of insisting on going through with the interview even though he found it difficult to do so. Others having had relatives involved in PhD studies understood some of the challenges and wanted to help.

> Let’s face it, most of us have had kids or relatives doing their PhDs and you think, oh well anything we’d do to help (F11G para.24).

Others apparently liked the interviewers’ ‘quiet and gentle’ approach (P6 para.91-93) and ‘friendly open manner’ (F12A para.62) and decided on those grounds to participate.

## Help Other Families

Some patients and their family members were strongly motivated by the possibility of helping other families and this led to the sense of having made a contribution.  Some expressed this as feeling that something good had come out of their traumatic experience if they could help at least one other family.

> I think it was interesting for my part and it does sort of give you a feeling of having some sort of contribution to what is a very traumatic time and having some sort of thought that you might be making things better or easier or different for someone else going through the same experience so I think that's a positive (F2B para.74).

One family member, even though he seemed quite uncertain about the purpose of the meeting was willing to be involved on the chance that it might do something useful for someone.

> He didn't really get its (*the family meeting)* purpose although he was very willing to help (Interviewer notes F9 para.22).

The desire to help others was not, however, a passive thing for some participants who were very keen to understand just how this research might help others.  Could it become part of the regular palliative care offering, for example?

> This patient had been told quite a bit about the study by palliative care staff and had read the information sheet.  He was very taken with the idea of doing something for others and it was of vital importance to him to be clear about how this might happen (Information meeting notes P5 para.3).

In one family at least, the possibility that it might help some other family was the deciding factor in choosing to be involved.

> I think the added element of being of use to someone else, to your PhD study, was - it gave them an excuse to go that extra bit and say 'We need this and it would be useful' I think. I suspect it probably wouldn't have happened (*otherwise)* (F3B para.70).

The desire to feel that at least something good might come out of a bad experience was a strong motivator for participation.

## Help Self or own Family

The possibility that being involved in the family meeting might help either themselves or their family members was also a strong motivation for some participants and led to a sense of achievement for some. For the patient in Family 5 there was a strong desire to change the way the family experienced the death of its members, to change the culture of secretiveness and suppression of expressions of grief. This was not only expressed by the patient but also recognized by other members of the family.

> He thinks it is his duty almost to talk about it and to prepare the family (F5F para.24).

Others who were not so keen to be involved personally agreed to attend because they wanted to support the patient who was very keen to have the meeting.

> Mum and Dad were really keen so I did it for them and I'm quite happy to have done it now (F12C para.53).

> I just wanted *the patient* (name removed) to feel comfortable and get his story across; I really did (F5A para.68).

Of all the participants, the one who probably found the process of the family meeting the most difficult and painful felt that it was all worth it if it could help her dying uncle.

> Almost I feel there is nothing I can do. Nothing I can do (F5I para.144).

> If it helps somebody, it's worth it (F5I para.188).

It was interesting to note that the degree of closeness and openness of the family was not necessarily an indicator of their willingness to be involved if they thought it would help one of their own.

## Summary

Most of the participants came to the conclusion that for them as individuals the family meeting was overall an emotional but positive experience. It was recognised by some participants that any negative feelings they had about the experience were a part of the inevitable grief process which they were experiencing. Being assisted in some way in the process of coming to terms with the reality of the approaching death of a loved one was a painful experience but, one that they regarded as ultimately helpful.

There was wide agreement that the family meeting had provided participants with an opportunity to speak about important matters that in many cases would not otherwise have been raised, or at best discussed in individual conversations with some of the family members. Some participants believed their new experience of openness in the family context would be likely to lead to longer term changes in the way they dealt with such difficult matters. The main inhibitors to openness during the meetings were seen as factors relating to family culture, history and relationships, and the fact that for many, openness in such a setting was quite a new experience. It is possible though, that more inhibitors that are external to the family culture may be identified in theme 3 (Chapter 9) which will more specifically discuss data relating to the structure and style of the meeting. A particular point of interest is that those most vocal about the value of meeting as a group to discuss issues of illness and death, were from two widely differing families, in relation their usual habits in this regard.

Another significant feature arising from the data coded to theme one was the new understandings participants found they had acquired about themselves, about other family members and about how they operate as a family unit.  One can speculate about the possible longer term benefits to both individuals and family groups that might arise from these new understandings. Of course longitudinal studies would certainly be needed to assess this further. A few personal changes, arising from the experience of the family meeting, were identified but again an understanding of the longer term impact of these would require further investigation.

As more than half of the participants found motivation and a sense of achievement in doing something that may help someone else, whether they are a member of their own family or other families going through similar traumatic events, the importance of this factor in undertaking studies with this population should not be underestimated.

A detailed discussion of the second major theme arising from the data collected from the patients and family member participants, of the family meetings, will now be discussed in the following chapter.

# CHAPTER EIGHT - RESULTS THEME 2

## PATIENTS AND FAMILY MEMBERS SPEAK: THE SPEAKERS OBSERVATIONS OF OTHERS EXPERIENCE AND OUTCOMES OF THE FAMILY MEETING

## Introduction

The second major theme arising from the analysis of patient and family member interviews, as discussed in the previous chapter is, ‘The speakers’ observations of others’ experience and personal outcomes of the family meeting’. This chapter will give a detailed account of the ideas and concepts embodied within the sub-themes, categories and sub-categories that inform this theme.

The sub-themes, categories and sub-categories which inform this theme are summarized on Flow Chart (Fig.4, p.117). Two of the sub-themes developed in level 2 data analysis; ‘The speakers’ observations of other individuals’ experience’ (coding report 1.3), and ‘Speakers’ observations of family unit experience and outcomes of the meeting’ (coding report 1.12), as well as the category ‘General Positives’ – subsequently renamed ‘Summarizing Comments’ (coding report 1.1.5), inform this theme. Each of these sub-themes has a number of categories and sub-categories which are also depicted in Figure 4. The ideas and concepts coded into each sub-category, and the coding reference identifying the source transcript document, are shown in Appendix IX(2). The number of coded items for each sub-category, the number of families that spoke of each issue and the families for which it was a particularly important matter have been identified in Appendix X(2).

## The Speakers' Observations of the Patient's Experience

The sub-theme, identified in level two data analysis (coding reports 1.3) entitled 'The speakers' observations of other individuals' experience of the family meeting' was defined as any data which gave information about the speakers' observations of the experience of other individuals who attended the family meeting. This sub-theme was found to have two categories: 'the speakers' observations of the patient's experience of the family meeting and 'The speakers' observations of the experience of a family member other than the patient, of the family meeting'. Each of these will be discussed using their respective sub-categories as key points for the discussion. This discussion will be illustrated with quotes from the interview transcript texts.

### The Speaker's Observations of the Patient's Experience of the Family Meeting

The category 'The speakers' observations of the patient's experience of the family meeting' included all data that described the speakers' (family member other than the patient who had been present at the family meeting) observations of the patient's experience of the meeting. This category was found to have four sub-categories: 'openness', 'feelings', 'new understanding' and 'other general comments'. These four sub-categories will now be outlined in detail.

#### Openness

Data coded to the sub-category 'openness' included any section of non-patient family member interview text that referred to the observed degree of openness demonstrated by the patient during the family meeting.

A range of views were expressed, by members of four different families, about the patient's degree of openness during the family meeting. Members of Family 3, who were present at the meeting, both considered that the patient had been more open than expected, although one member would have liked the patient to have demonstrated even more openness.

> I was just impressed at his ability to talk to you and give you answers because a lot of his thinking is pretty woolly (F3A para.23).

> I was wondering because Dad is not entirely conscious any more – I was wondering if something might slip out – even a veiled acknowledgement of difficulties or something but that didn't happen (F3B para.13).

A member of Family 11 observed that the patient had maintained their usual very positive stance during the family meeting and their normal degree of openness, which however did not involve telling the whole story.

> *She* (name removed) described the melanomas and the operation - some of the operations she had - but she didn't go through to describe the absolute agony and trauma that she goes through and that's kept to herself and that's part of her strength I guess. She has dealt with that through hospitality, through a brave face, through Christian faith, through medical attention, through palliative care - and those sorts of things - so she didn't go into that area I thought or into the predicting or forecasting where the future is. She's dealt with where she's come to and has hope in the future but the other - the trauma of that word 'cancer' that's devastating (F11E para.8).

The relaxed atmosphere of the meeting was suggested as the reason for a greater than normal openness demonstrated by one patient.

> …I think that was a really good relaxed environment for Dad to speak about his emotions because he doesn't really vocalise what he is feeling a lot so I think it benefited him in that respect, that he was in an environment that he felt comfortable opening up in and it wasn't done like my brother *(who is a psychologist) would* have done it which would have been really analytical and quite a bit more clinical I guess (F1C para.7).

Another explanation offered for the increased openness of the patient, suggested that the meeting gave him an opportunity to raise issues which he had been unready to discuss with his family before.

> I felt *he* (name removed) joined in much better than he has been joining in conversations in recent months. Also it gave him an opportunity to express things that somehow I have found it difficult to approach because he seems to be to me to have negated the stage of life he's in, although I think he's beginning more to accept that (F3A para.5).

This statement implies that the timing of the meeting may well have had a significant impact on the patient's readiness to be more open about his illness and approaching death.

Two members of Family 5 reflected on the patient's possible motivations for being, in their experience, unusually open in the family meeting. It was suggested that his greater openness was motivated by a desire to help the family.

> I think that's what led to this really – is that people haven't spoken about it and that it has been so secretive. He thinks that it is duty almost to talk about it and to prepare the family (F5F para.24).

Another family member suggested that it was good for the patient to have the opportunity to speak in a more open manner than usual.

> The person who's in the trouble, I think, well I don't know, but I think it would be better for them to be a bit more open and more to talk about. Surely it would have to be not easier, but more relaxing (F5G para.17).

Generally those family members who commented on the degree of openness of the patient at the family meeting considered that they had been more open than usual.

## Feelings

The sub-category 'feelings' contains all data relating to family member observations of the feelings of the patient during the family meeting. Three areas of feelings were mentioned by members of seven of the twelve participating families. These were: feeling happy, feeling supported and expressing emotion.

Two of the participating patients were observed to have felt happy at some stage during the family meeting. This happiness, in both cases, was associated with joy and pride in children and grandchildren. For one, it was seeing the grandchildren, who had been brought to the meeting by their parents, for what turned out to be the last time before her death. This happiness was expressed through a beaming face and was commented on by all other family members who were interviewed.

> But then when she saw the grandkids there was like a huge smile on her face (F2C para.61).

The other patient was observed to express happiness during her experience of telling the researcher about her family – children and grandchildren – and sharing the photos she had of them.

> He wasn't able to articulate particular things that were good except that his wife (the patient) had really liked talking to me about the family and was very happy showing me the photos (Int. notes F7A para.10).

A feeling connected to happiness was expressed when one family member stated that she believed the patient had appreciated the experience of the family meeting.

Members of three families reported observing that the patient felt supported or reassured during, or as a result of the family meeting. In Family 2, the patient's husband believed that his wife had seen attendance at the meeting, by most of her children and grandchildren, as an affirmation of the family decision to look after her themselves as much as was possible, and as a sign they were now beginning to function together as a family unit – a new experience for this family.

> Participant: As she (the patient) said she's going to fight with me through this. We know it's not going to be a permanent cure but at least it's going to be maybe short term. I don't know.
>
> Interviewer: But you feel strongly that you want to be together?
>
> Participant: Oh, yeah.
>
> Interviewer: Whether it's short or long.
>
> Participant: Yes, and I mean *my daughter* (name removed) has agreed on that anyhow and she knows in herself that her Mum wants to be where I am until the end and I do think that we, if we work together, we can get her through this, you know. It *(*the coming together*)* made it a lot more painless for her (F2A paras.14-18).

In the other two families who perceived that the patient felt supported, the coming together for the meeting was not seen as indicative of the change of family culture that was expressed in Family 2, but was seen as important for the patient.

> I haven't had it (cancer) but even though they may feel like they are alone they're really not. Everyone is going through it. I think it's a good support for him (the patient) and it would be good for *him* (name removed) to know that everybody - - - *cares about him (*F5H para.94).
>
> *It was* a positive that she can meet other people that she feels close to (F11F para.12).

The third type of feeling that was observed was described as being sad, touched or unusually emotional.

> And I looked at *the patient* (name removed) when everyone was crying, and he looked very sad (F5A para.36).
>
> Dad was a bit teary which is unusual, very unusual (F3B para.68).

The family members observed a range of feelings expressed by the patient in their family. In the context of the individual family, it is apparent that in most cases the feelings that were commented on were somewhat unusual for that person, or were seen as unexpected in the context of the family meeting.

## New Understandings

Family members' perceptions of the new understandings (sub-category – new understandings) acquired by the patient as a result of being a part of the family meeting, were of two types - a new understanding of family members' thinking and attitudes and new understanding of their own situation. Members of more than half the families observed these new understandings.

Specific ways in which the patient was perceived to now have a new understanding of their family members included: her family values and what she has done for them, that the family are behind them and can be trusted and that new things about the family members have been revealed.

> I think it was just nice for her to hear about how valued she is and the ways that she was valued (F2B para.23).
>
> I can imagine it would have been quite eye-opening for him to hear of the rest of the family's perceptions and feeling on life over the last seven months. (F1B para.49)

> She knows we're here. She knows that we can discuss anything and let it go, and not take it any further if she doesn't want to (F11C para.116).

Two specific ways were mentioned in which the patient was perceived to have reached a new understanding of their own situation past or present, as a result of the family meeting.  Two patients had apparently been having difficulty coming to terms with the reality of their approaching death but were perceived to have been assisted with this process by the meeting.

> It makes her realise too that it's no good sweeping it under the cupboard. We know it's there and that's it, you know (F2A para.63).

Another patient was observed to find a new perspective on some of her past experiences through the process of reminiscing and sharing old photos.

> It seemed that she has lived a very hard life with disabled children and bringing up a grandchild and also another disabled grandchild in the family. She spoke a lot about all the love there had been in this (FM7 Notes para.4).

In addition to these new understandings that were observed in the patients, a number of other general comments were made about the experience of the patient during or as a result of the family meeting.

### Other General Comments

All data pertaining to a family members' observations of a patients' experience and outcomes of the meeting, which could not be included in the sub-categories already discussed, were coded to the sub-category 'other general comments'.  These data fell into two main areas: general comments that the meeting was a good/beneficial experience for the patient and general comments that questioned whether it was really a good experience for them.

In suggesting that the meeting was a good experience for the patient such phrases as: real benefit for him, he got what he wanted out of it and coped well, were used.

> I think he got what he wanted out of it (F5I para.28).
>
> *She* (name removed) stood up to it pretty well (F6A para.15).

Two family members, from different families, however expressed some doubt about whether the family meeting had actually been beneficial for the patient. The husband of the patient who had had a hard life which included looking after disabled children and grandchildren, quoted in the section ‘new understandings’ above, expressed concern that his wife’s tears may have been an indication that the meeting just made her sad. It was evident however, in her words, both at the family meeting and at the later interview that this was not really the case.

> She didn’t think that it was sad at all (Int. Notes P7 para.14 – interview not audio recorded).

Another family member in reflecting on the impact of the meeting on the patient acknowledged that his doubts were more a reflection on how he thought he might feel if he was the patient rather than based on any evidence that the patient found it to have a negative impact.

> I think it has been tremendous *for us* but I’m not sure whether if I think about myself in *his* (name removed) whether I would feel any better at all or whether I would feel actually worse (F5F para.8).

Family members who were interviewed following participation in a family meeting, made comments about their observations of the patient’s experience of the family meeting in areas including; their degree of openness, their apparent feelings, new understandings that they may now have about themselves or their other family members, as well as observations about the general benefits, or otherwise, of the patient's experience of the meeting.

Many participants also made observations about the experiences of family members, other than the patient, who had been present at the family meeting. These will be discussed in the next section.

## The Speaker's Observations of the Experience of Family Members Other Than the Patient

The data coded to the category entitled 'The speaker's observation of the experience of family members other than the patient', included any pertaining to the speaker's observations of the experience of a family member, other than the patient, who was present at the family meeting. These data were found to include four sub-categories: 'openness', 'feelings', 'new understanding' and 'other general comment'. These sub-categories will be discussed in detail below.

### Openness

Any data relating to the observed degree of openness at the family meeting , of a family member, or to any perceived outcome of being open, was coded to the sub-category 'openness'. An increased openness was observed in other family members in more than half of the participating families. Some participants spoke of family members being open during the meeting and comments included: showing a lot of courage in being open, saying what they thought, loosening up and being as open as they could be.

> People I think generally said what they thought (F5H para.64).

> Just the way people eventually started to open up, and not treat it like, oh, he's dying. Yeh, I like that. They sort of calmed down (F5B para.53).

> What I did find really quite interesting was that *she* (name removed), who was previously outside of our family and is now inside, had so much courage to open up (P1 para.5).

On the other hand some of the participants were observed to have difficulties with openness at the family meeting. This perspective was verbalised in statements such as: it touched a raw spot and so it was hard for her to express herself and, they were not as talkative as usual or as talkative as the speaker had hoped.

> I sort of felt as though perhaps she couldn't quite get out of it what she might be able to if she wasn't feeling that it was really touching a raw spot (F1B para.43).

> I would have liked to hear more about what the young girls were thinking because the one who didn't say anything is a talker and she couldn't get it out (P5 para.19)

One participant apparently had some regrets later about her degree of openness during the meeting.

> My sister had a few reservations over what she said yesterday. She's already talked to me today (P11 para.19).

It was observed that some participants had particularly benefited from the experience of being open and speaking during the family meeting. Some examples of these are:

> I think it was positive in the last element of kids being able to say what they love about their Nanna and what they're going to miss (F2B para.76).

> … she was very touched and it was very valuable to her. I don't know how she will chew around Dad's response that he doesn't expect to meet her again but I think she - I think it was really valuable for her to say what she said (F3B para.68).

Varying degrees of openness were observed in family members during the family meeting. This included responses considered normal for the person concerned as well as those that surprised, pleased or disappointed the observer. Some participants were perceived to have particularly benefited from the experience of speaking during the meeting.

## Feelings

Many observations were made that related to how other participants, other than the patient, felt during or as a result of the family meeting. These data were coded to the sub-category ‘feelings’. These expressions of observed feelings were found to broadly fall into four sub-categories: the expression of emotion, degrees of comfort, other feelings regarded as negative and others seen as positive.

In Family 5 the crying was seen as related to past unresolved grief experiences, although it was acknowledged that bringing out their feelings was good. One participant appreciated that others were able to loosen up a bit and speak.

> I thought, my impression of the purpose of the meeting is talk, bring it out. Bring out your feelings and you will feel better afterwards. That was my idea of the meeting. I thought they did (P5 para.43).

Other participants were described as being emotional, touched or a bit upset.

> I realise *she* (name removed) got a bit upset, but then I guess that’s okay (F3A para.51).

> I did notice my auntie got very emotional with it, so whether that brought to light what’s really happened – whether she’d been trying to cover up (F11F para.14).

A number of observations were made relating to other family members' degree of comfort with the meeting process and the topics of discussion. Some were seen to be quite comfortable although possibly surprised about at least one topic of conversation.

> I was very, very pleased that she was able to be as comfortable with it as she was (P1 para.5).
>
> I mean it just happened like we'd gone down to *a funeral parlour* (name removed) on Saturday and perhaps surprised someone there (at the family meeting) you know, talking about coffins (F11A para.51).

Some participants on the other hand were seen as feeling uncomfortable or embarrassed.

> I think it was very hard for her, very hard (F5I para.64).
>
> Perhaps *she* (name removed) was a little bit embarrassed (F11A para.17).

Negative feelings were also perceived in family members and commented upon. These included finding the meeting painful, stressful or scary.

> It was pretty stressful for my girls and of course as soon as they see me welling up, they'll start welling up and crying and visa versa and god – so it was a bit hard for them (F5H para.66).
>
> Scary and uncomfortable (for her sister). She just bawled the whole time (F5I para.64).

Others were seen as either being very slow to warm up or as being particularly sensitive to others' feelings.

> Participant: The reason I spoke up when I did to start with, and I really thought this, because they couldn't.
>
> Interviewer: No, it took a while for people to warm up, didn't it?

> Participant: Yes, so that's why I thought well I'll talk, because I'm the calmest one out of that group (F5A para.30-32).

More positive feelings that were observed in association with family members' experience of the family meeting were described as glad, focused on being happy, supported and trusted.

> So she was glad to have that opportunity to speak about those sorts of things (P3 para.44).

Observations about the feelings of other family members during their experience of the family meeting included comments about their expression of emotion, whether or not they appeared comfortable being a part of the meeting, some examples of more negative feelings, such as stressful, painful and scary, as well as others that were regarded more positively. These latter examples included being supported, trusted and feeling glad or happy.

## New Understanding

Some participants spoke about what they thought other individual members of the family had learnt as a result of the family meeting. These data were coded to the sub-category “new understanding'.

Some of these comments were general in nature, such as:

> He said that he'd learnt a lot from it (P11 para.71).
>
> I think they understand me now rather more fully than they would have before (P3 para.35).

Other remarks were more specific about the particular new understanding that had arisen for the observed family member. These included facing the reality of the patient's state of health, understanding parents' relationships better, having insight into the patient's perspective on life after death, realising they were not alone in dealing with the imminent death of their loved one, becoming aware that there is more than one way to deal with terminal illness and realising that now is a good time to patch up differences before it is too late. Some of these are illustrated in the following examples from the interview texts.

> It's still good that she know what's going on because when the inevitable happens then she's not really prepared, but she's got an idea of what to expect (F5H para.22).
>
> Participant: And now has suddenly realised (another family member) - I think it's a little bit more serious than I thought, well what do I do? How do I handle it?
>
> Interviewer: Time is running out maybe?
>
> Participant: Yeah, how can I fix it up? Time's running out, can I fix it up? Which is understanding and expected with some, but she has realised in quite a bit of time to spare I think. So she can patch up her differences long before time (F11C paras.56-58).

It was observed that participating in the family meeting had been instrumental in opening up new understandings for some of the participants.

## Other General Comments

As was the case in their observations of the experience of the patient, participants also made general observations about the experience of family members other than the patient, in relation to the family meeting. These data were coded to the sub-category 'other general comments'. As in the case of general observations relating to the patient, general comments relating to other family members' experience were of two broad types. These were general comments of a positive nature and general comments that questioned whether it had been a positive experience for the observed family member.

Observations of a positive nature included: they thought things went very well, they got definite benefit, it was a positive experience and although they were sceptical they found it good. These are illustrated by the following quotes from interview texts.

> There's a definite benefit to them, to the meetings, from what I saw sitting back there (F5B para.51).
>
> My daughter felt the same way about it – sceptical to start with (P12 para.8).
>
> Well I think two that were sitting on your side of the room, two a little bit older than me, weren't expecting very much at all. One had a lot more input than the other, but I think they got a lot more out of it, because they weren't intending to go, finished up feeling that they should, and then got a lot more out of it than they first thought (F11C para.8).

Comments that were interpreted as indicating the speaker had doubts about whether the observed family member found the family meeting to be a positive experience included: they found it hard, they looked as though they didn't like it and I don't think he saw much point in it. Again these are illustrated with quotes from interview texts.

> I think it was hard for my girls (F5H para.16).
>
> I know just looking at one person, he probably didn't like it much, but I'm sure he would have come away with some sort of positive out of it (F5A para.35).

Participants' observations of the experience of other family members, apart from the patient have been described in the four main areas coded to the sub-categories entitled 'openness', 'feelings', 'new understanding' and 'other general comments'. So far the presentation of results in this theme "The speakers' observations of the experience of other family members in the family meeting' have related only to the experience of the individual, either patient or other family member. Observations were also made about the impact of the family meeting on the family as a unit. These will now be presented.

## The speakers' Observations of the Family Unit Experience and Outcomes of the Family Meeting

The sub-theme (coding report 1.12) 'The speakers' observations of the family unit experience and outcomes of the family meeting' includes all data relating to the speakers' (any participant of a family meeting) observations about the impact of the meeting on the family unit as a whole. This sub-theme was found to have four categories which are entitled: 'impact on speaking together in future', 'impact on relationships in the family', 'impacts on feelings' and 'expected impact on the grieving processes. These are out lined in detail below.

### The Impact on Speaking Together in Future

The category 'The impact on speaking together in the future' included all data that made any reference to how the experience of the family meeting might have influence on how the family speaks, or does not speak, together in the future. This category was found to include four sub-categories which are entitled; 'reminded of/taught the value of speaking about these things as a family', 'broke the ice on speaking about these things together', 'a sense of achievement' and 'things won't change'. The data coded to each of these sub-categories is outlined below.

### Reminded of/Taught the Value of Speaking About These Things as a Family

The participants (members of six of the families) who commented on the value of speaking about the matters discussed in the family meeting came from broadly two perspectives: those that had been aware of the value of talking together as a family about important issues and had been freshly reminded of this and those for whom speaking together in this way was a new experience.

Some families were reminded of the value they derive from speaking about important issues together and were grateful to have this reinforced.

> (The family meeting was) an advantage in that it just sort of reinforced how good it is to have those discussions and to ensure that we continue to have them in various intervals (F1A para.16).

For some participants whose experience of speaking together as a family in this way was either non existent or minimal, there were some outcomes they found surprising. Some members of family five, where there was much evidence of unresolved grief from the past, concluded that although the meeting experience was painful it was still better than not talking about it at all and they wished that they had had this opportunity before.

> For *my brother* and *his wife* (names removed) I think it was good and the girls my nieces. I think it upset *my brother* (name removed). He doesn't often get to talk about the upsetting side of Mum and *my sister (*name removed). Didn't openly, but I think it was good. We talked about it after and they thought it was good to talk about it openly and perhaps it would have helped our family because our family kind of went all silly after Mum and *my sister* (name removed) died and it may not have happened (F5E para.36).

Some were surprised at how much was revealed during the meeting, even more than in the numerous individual conversations that were common in this family.

> I feel more was said yesterday that hasn’t been said before, especially when we touched on *my parents in law’s* (names removed) relationship (F6B para.7).

Another family, for whom the experience of speaking together in this way was quite new, were stimulated to consider having further meetings with family members who had not been invited to be a part of the family meeting for this study. The speaker thought it would be a useful way of helping them to come to grips with the reality of his impending death.

> So there are still three branches of the family not yet discussed and they would have - they might have trouble facing up to what's going to happen in the future (P3 para.111).

> We must consider that (using the family meeting as a way of introducing other family members to a realisation that time is very limited) (P3 para.119).

## Broke the Ice on Speaking About These Things Together

Any data identified as indicating that the experience of the family meeting would enable families to speak together more easily about matters such as terminal illness and death, were coded to the sub-category ‘broke the ice on speaking about these things’. These data included comments of a general nature indicating that it would now be easier for them to talk, some specific reasons as to why it would be easier, and two specific situations when they would be likely to talk together in the future

Some participants were definite that they would be able to talk more easily together in the future as an outcome of the family meeting. This is expressed in the following examples:

> ….this has opened the door now for conversations later on so, yes, I think it was definitely a good thing for us, a good thing for me (F8B para.7).

> It just makes it a bit easier for everyone I think (F5G para.9).

Other participants expressed it more as a hope for the future rather than a definite.

> Any rate so it’s gone and passed by and there may be more to come up in discussion (P3 para.49).

A few of the participants were able to give specific reasons as to why they thought it would be easier for their family to talk about issues such as terminal illness and death in the future. These reasons included; the topic was no longer taboo, they had overcome their fear of upsetting others by talking about it and that it had stimulated other things to talk about together. The following quotes from the transcript texts illustrate these points:

> You don’t want to offend that person, and you’re too frightened to ask (F5A para.116).
>
> When I got home, I started thinking of all these things I could have said; I never did. But I’ll get around to seeing him (name removed) again anyway (F5I para.178).

One member of Family 5, for whom speaking in the family group was a new experience, had identified particular times and styles of conversation that may take place among family members in the future. For example, during the family meeting a family excursion had been planned to assist the patient to meet an unmet need, and it was possible this may be an occasion when there could be further conversation between family members

> But on that excursion it will be time to talk about it (F5F para.72).

This participant also predicted that not only would they be able to talk about the death of the patient after he had died, something that did not happen in this family in the past, but that the focus of their conversation could be more of a celebration than a litany of regrets.

## A Sense of Achievement

It was apparent for some participants, the experience of speaking together as a family group had left them with a sense of achievement. These data were coded to the sub-category ‘a sense of achievement’. Several causes of this sense of achievement were identified. One of these was described as clearing the air.

> I think it just sort of clears the air a little bit too (F8A para.89).

Having said what they wanted to say before it was too late was a source of satisfaction for other participants. For other participants the opportunity to say things they would probably not have otherwise said, gave them good memories of the obvious pleasure this openness gave the patient.

> She was clearly fairly chuffed never the less that people had said these things (F9C para.26).

## Things Won’t Change

Two participants, from different families were quite clear that in their view the experience of speaking together as a family would not bring changes in the future, or at least not in particular areas they would like to see change.

> For me, from my perspective, no, I can't see that anything is going to come - nothing that we're going to talk about that we wouldn't talk about before or anything like that. She keeps you informed on the 'need to know' basis if she thinks you need to know she rings up and says 'This is what's happening' and if she doesn't think you need to know - so what I mean is she doesn't come running every time she thinks - but, yes, she lets you know when there's something - - - (F11F para.94).

> Certain things were unsaid which was disappointing (F3B para.7). I certainly know my parents well enough to know that certain things will never be spoken about (F3B para.13).

For some at least, well entrenched habits and protective devises would not be changed as a result of one family meeting

## The Impact on Relationships in the Family

Another important area identified by the speakers' observations of the impact of the experience of the family meeting on the family unit, and its possible outcomes for them, was in the area of relationships within the family. Data relating to this matter were coded to the category entitled "Impact on Relationships in the family'. Three sub-categories were identified within this category. They described outcomes in the following areas: 'strengthened family bonding', initiated new ways of being together' and 'created new awareness and understanding. These will now be presented in more detail.

### Strengthening Family Bonding

It was recognised by members of more than half the participating families that meeting together in this way was an important step for the family and that it increased their sense of togetherness. The question of whether or not this was a short or longer term effect was also raised. All data relating to these matters were coded to the sub-category 'strengthening family bonding.'

One participant indicated that the family meeting had been important for her family because, although they had them occasionally, this particular meeting marked a turning point in the depth of discussion and opened the way for more such meetings.

> Its' important for the family to be together I think - like you did the other day. I think it's important for the family as a group to get together and discuss that. I mean we've discussed it as a group at home before I started my hospital rounds and it was beneficial then but the girls would only go to a certain point and stop. Now whether further down the track they

> want to do that again that's fine with me and Richard and we will sit down and do it but after yesterday, or Saturday, we decided we're going to do it once a month (P8 para.96).

It was considered important that the family meeting had brought together and created a sense of bonding among those to whom the patient felt close and who cared about the patient. This was also seen as a means of mutual support for family members.

> I thought it was sort of quite really – like bonding – hopefully a bonding situation (F11D para.44).
>
> It's brought us closer together that yes, to talk about stuff (F5E para.40.)
>
> I guess this sort of helped again to support everybody else as well as trying to get through it yourself (F5I para.82).

At least one participant wondered if the sense of togetherness would be more than a temporary experience for his family.

> So I don't know. I would hope that it would bring them closer together, and I'd say it probably will for a short time. But after that I don't know (F9C para.172).

The experience of the family meeting generated a stronger sense of togetherness for many families, at least in the short term.

### Initiated New Ways of Being Together

The increased sense of togetherness generated by the family meeting, as discussed above, also had led to specific ways of being together that were new for the families concerned. These data were coded to the sub-category 'initiated new ways of being together'.

Members of three of the participating families expressed the view that an outcome of their family's involvement in the study had resulted in plans for new ways of being together as a family in the future. These included: starting a tradition of pulling together, planning a family excursion, and planning to have a family meeting once a month.

> We have a tradition in my family now where we make sure we all pull together (F2A para.80).

> But on that excursion it will be time to talk more about it and it would be good if we could all go at the same time as well, but you don't' know (F5F para.72).

There were also some developments that were perceived to have emerged from the experience of the family meeting, in the way some individuals within the family were relating to each other. It was expected that these would have an impact on the family unit in the future. In two different families the daughters of the patient had begun to get together in ways they had not before the meeting.

> Its been good though that the girls are keeping more in touch with each other which before they weren't doing so they've got something – a common theme type thing (P8 para.104).

It was perceived the family meeting may have prompted the sons of one patient to finally get together to discover their mother's wishes in relation to her jewellery.

> The boys all went down to try and get Mum to decide about her jewellery, as to who she might like to leave something to. So that may well have been prompted by that (F9B para.171).

In the case of one family in particular there was a new understanding of the degree to which the patient had kept the family together and the question was actually raised in the family meeting as to whom, if anyone would in future take on this role.

> *My niece* (name removed) says to me well 'When *the patient* (name removed) is not here are you're going to be the king pin?' I thought well I don't really know and also probably not

> because - I mean I've always been around and I get on well with most of my nieces and nephews but *she* (name removed) has been the one they've always sort of more or less turned to (F11D para.67).

The meeting was also seen as having raised the possibility for the patient to sort out some unfinished business with one of her sisters.

> The only thing I would like is for *my younger sister* (name removed) and *the patient* (name removed) to get together and sort out what the problem is (F11D para.142).

An important outcome of the meeting for one family, commented on by most of the members who had been present at the meeting, was that the partner of one of the patient's adult children had finally found her place in the family.

> To see her now and the way she responds to not only just me, because I've got this illness, but to other members of the family, I think it is just wonderful (P1 para.9).

In addition to new ways of being together and of enjoying each others company it was also perceived by a number of speakers that the family meeting had been responsible for a new awareness of and understanding of each other. These insights are outlined below.

### Created New Awareness and Understanding

The sub-category entitled 'created new awareness and understanding' is informed by data indicating new insights into other members of the family and how they think and feel in relation to the terminal illness and approaching death of the patient. Some of these comments were of a fairly general nature.

> I think the family meeting makes you perhaps more aware of other people. Even if you know where they are at it makes you more aware of where they are at. I know that we are all dealing with the same thing (F12B para.62).

It was also considered that this greater awareness of each other had made it less likely that they would step on each others toes in ignorance.

> That's probably the big part because you are probably less inclined just to tread on toes in ignorance and I think even with a close-knit family like ours I feel that's what's been happening at the moment. We're treading on each other's toes. Now partly that is because we're different people and *my sister (*name removed) and I have a relationship where I'm ultimately most likely to give. That's just how it is. So there would be some of that. But there's some of it is just tromping about - my world; this is how it is (F12B para.87).

It is certainly evident that in the view of some participants, the family meeting had had an impact on relationships within the family unit – that there had at least been a temporary increase in their sense of bonding, in their understanding of each other and some positive changes in their ways of being together. The impact of the meeting on the feelings of family members was also seen as a contributing factor to improved family relationships in some participating families.

## Impact on Feelings

All data relating to the impact on feelings as they were perceived to relate to the family unit and its functioning, were coded to the category 'Impact on Feelings'. Two sub-categories were identified and are entitled 'more comfortable with each other' and 'overall better'. These will now be outlined below.

## More Comfortable with Each Other

The sub-category ‘more comfortable with each other’ included all data relating to the ideas of feeling comforted, comfortable or supported within the family unit. The most reported feeling in this regard was feeling comfortable with each other, particularly during the meeting.

> We had a chat afterwards and I think we all felt reasonably comfortable with it and thought that it had been a good thing to do (F12B para.79).

And feeling supported were other feelings expressed in relation to the family unit

> You never know what tomorrow brings but if you've got this alone feeling that there's nobody out there - is anybody out there? Nod, nod - nobody out there - these people have been brought into a confidence that they wouldn't have been otherwise without the meeting (F11E para.44).

Other more general feelings were also expressed.

## Overall Feeling Better

A few of the participants commented that the family was overall feeling better as a result of participating in the family meeting. Any data relating to this were coded to the sub-category ‘overall better’.

Some were unclear as to why, but were conscious that the meeting made them feel better.

> It made us feel better, I’m sure, yes. I really do. I don’t know how it made us feel better but it did (F12A para.14).

Another family however indicated that the sense of it being a good thing was connected to the fact that they had said important things before it was too late.

> Yeah, and I think it’s a good thing to talk like we have talked. We don’t know how long *she* (name removed) will last (F11A para.106).

Apart from generally feeling better as a result of their participation in the family meeting some participants also speculated on how their experience may impact on their grieving process following the death of their loved one.  This will be outlined in the next section.

## Impact on the Grieving Processes

Any data referring to the possible impact of the family meeting on the participants’ later grieving process was coded to the category ‘impact on the grieving process”.  Two particular aspects of this possible impact were raised and so two sub-categories ‘may make it easier’ and ‘may give it a different focus’ were created.

### May Make it Easier

Any data indicating that the speaker thought that the family’s experience of the family meeting may make their grieving process easier was coded to the sub-category ‘may make it easier’.

Members of several families indicated they thought that generally their grieving process would be easier as a result of their experience of the family meeting.

> I was wondering then whether if you got to do part of the grieving before the person goes whether that makes it easier or not afterward (F12B para.85).

Others were a little more specific in their comments suggesting that those not present at the meeting may have more difficulty facing up to the impending death, or that it would make the mental part easier to deal with afterwards or that it might shorten the grieving period.

> It would take away a lot of the guess work and the leading up to, because that's what happened after my mother and sister. Everyone had their piece to say, but it wasn't really right or wrong. This way, I can see how you can, not to say you get over it quicker. I mean it's always sad, but I mean it's a lot more easier, quicker than what it is (F5G para.45).
>
> The grieving process might shorten just that little bit. That would be a benefit (F5I para.103).

It was also perceived that while the grieving process may or may not be shorter it may well have a different focus as a result of their experience of the family meeting.

### May Have a Different Focus

Members of two of the families indicated they thought that their grieving following the death of their loved one may well have a different focus to what it might have done if they had not participated in the family meeting. Data making reference to this was coded to the sub-category 'may have a different focus'.

One patient, recognising how important the talking and touching had been to her and to her family members, as well as remembering the experience of a friend where talking had not taken place before her death, felt that it was so much better for her, and would be so much better afterwards for the family as a result of this.

> I found that last night I was lying awake and thinking of some of my friends, one in particular, who died of cancer I suppose 25 years ago and she died in this hospital and she had a really good marriage but (name removed), her husband, could not bear to come and see her or talk to her and she was lying there crying and crying because he couldn't talk to her before she died. I thought weren't we lucky that we had yesterday (P6 para.13).

A member of Family 5 realised that their focus following the death of their relative would be much more centred on celebrating his life rather than on regrets, as had been their experience in the past.

> At least after *he (*name removed*)* dies we will still be able to talk about it and I think, yes, that's right, and part of that grieving has happened so that we can start to almost celebrate *his* (name removed) life rather than have regrets and talk about the good things that we remember about it (F5F para.26).

Although the interviews in most cases took place within a few days of the family meeting, some participants perceived that the experience would have a positive impact on the later grieving experience of their family members.

## Family Summarising Comments

All data of a general summarizing nature were coded to the category 'family summarizing comments' which had originally been named 'level 2 analysis/speakers experience of the family meeting/general positives, general negative. These data were coded to subcategories according to the family of origin of the speaker. It was found that most members of the families at some point during their interview made such a summarizing comment.

As indicated at the beginning of this chapter, the ideas and concepts coded into each sub-category, and the coding reference identifying the source transcript document, are shown in Appendix IX(2)). Appendix X(2)) indicates the number of summarising comments made by each family and in the case of families where more than one member made such a comment, the number of speakers is indicated. Examples of summarizing comments made by each of the families are shown on Table 18 on the following page.

*Table 18:Family Summarizing Comments*

| Family | Sample Summarizing comments |
|---|---|
| Family 1 | Excellent, I thought it was fantastic (F1D para.5);<br>Definitely benefited from it (F1B para.14)<br>I didn't imagine there would be anything else. (F1A para.10) |
| Family 2 | I think it went sort of pretty well (F2C para.10)<br>Tops, tops (family being together) (F2A para.72)<br>I think it was a beneficial thing. (F2B para85) |
| Family 3 | I think it was good (F3A para.11)<br>At any rate my view would be that it is good to have done it. (P3 para.75)<br>Given the people that we presented to you in that meeting I think it went very well. (F3B para.102) |
| Family 4 | It had been a good experience (Int. Notes P4 para.2) |
| Family 5 | I believe it helped everybody (F5A para.109)<br>I thought it was great the other day. I really do. (F5G para.9)<br>It would have been really good to have that sort of situation with his sister or his Mum ….. That would have been really good. (F5H para.6)<br>I think it is very good. I would recommend it to anyone. (P5 para.245)<br>I reckon it's a pretty good idea. (F5B para.8) |
| Family 6 | I thought the meeting yesterday was very beneficial for the three of us that were there. (F6B para.7);<br>I felt we all benefited (P6 para.11);<br>I think the meeting was probably beneficial to us all. (F6A para.15) |
| Family 7 | It was quite ok (Int. Notes F7A para.10)<br>The meeting was quite good and she really liked showing her photos (Int. Notes P7 para.14) |
| Family 8 | I thought it was very good (P8 para.5)<br>Yeah it was alright. (F8A para.47)<br>I did think it was good (F8B para.7) |
| Family 9 | There was minimal information (F9A para.14)<br>Very informal. Yes it was. (P9 para.7) |
| Family 10 | It was definitely helpful (F10A para.5)<br>I think it was helpful (p10 para.6) |
| Family 11 | All good – all good will come out of it. (F11E para.85)<br>I think it was very good for everyone concerned (F11B para.102)<br>I felt that the meeting went very well (P11 para.19)<br>I thought it was quite a good happening sort of thing. (F11A para.6) |
| Family 12 | I have to say thank you. I think we were fortunate – just fortunate that you came along and chose to talk to us. (F12A para.117)<br>I think it is absolutely beneficial (F12B para.38)<br>It was certainly worthwhile but I don't think it had a profound effect on me. (F12C para.14) |

## Summary

Whereas the previous chapter focused on data relating to the speakers' personal experience of the family meeting, the focus of this chapter was the speakers' observations of others' experience of the family meeting - patient, other family member or the family as a unit. Again most of the data pointed to this being a positive experience with some expected beneficial outcomes.

Observations about the experience of both patients and other family members included data that discussed the perceived degree of openness during the meeting of the observed person, the observers' impressions of the impact of the meeting on people's feelings, comment on new understandings that may have arisen for the observed family member as well as some other general comments. Overall it was perceived that the experience of other members of the family, both patient and non-patient, was a positive one resulting in possible longer term benefits.

The majority of speakers also made observations about the impact of the family meeting on the family unit, reflecting both on immediate outcomes and possible longer term impact. One important area of comment was about the impact of the meeting on the family's ability to speak with each other in the future about difficult topics such as terminal illness and death. These speakers generally considered that as a family unit they would find it easier in the future to speak about these matters. It was also perceived that the family meeting had had an impact on relationships within the family unit – that bonds had been strengthened opening the way for new ways of relating and fresh awareness of each other. Another observed outcome was that members of the family unit were feeling more comfortable with each other and more able to support each other in their grief. Some speakers believed their grieving process following the death of their loved one may be easier as a result of their experience of the family meeting.

Summarising comments, which reflected the speakers' overall response to the experience of participating in the family meeting, were extracted from the majority of interview transcripts and were recorded in Table 18 (p.197).

The third of the three major themes arising from the interview transcript data as well as interviewers field notes, 'The Implementation and Applicability of the Family Meeting', will be presented in the next chapter

# CHAPTER NINE - RESULTS THEME 3

## PATIENTS AND FAMILY MEMBERS SPEAK: THE IMPLEMENTATION AND GENERAL APPLICABILITY OF THE FAMILY MEETING

## Introduction

The third of the three major themes arising from the analysis of patient and family member interviews is entitled ‘The Implementation and Applicability of the Family Meeting’. This chapter will give a detailed account of the ideas and concepts embodied within the sub-themes, categories and sub-categories that inform this theme.

As illustrated in the Flow Chart Theme 3, Figure 5 (p.118), this theme is informed by three of the sub-themes developed in level 2 data analysis. These are: “Meeting Facilitation’ (coding reports 1.4), ‘How could it have been different’ (coding reports 1.5/6 – formed from the merging of 1.5 and 1.6) and ‘General applicability of the meeting’ (coding reports 1.11). Each of these sub-themes has a number of categories and sub-categories which are also depicted in Figure 5. The main ideas embodied in each sub-category are shown in Appendix IX.3 and their coding report references are also shown on this table. The number of coded items for each sub-category, the number of families that spoke of each issue and the families for which it was a particularly important matter, have been identified in Appendix X.3. As indicated these will now be presented in detail.

## Meeting Facilitation

The sub-theme ‘Meeting Facilitation’ included all data that described the speakers’ (patient or family member who had been present at the family meeting) observations in relation to the facilitation of the family meeting. Two categories: ‘the speakers’ experience of meeting facilitation’ and, ‘identified qualities needed for meeting facilitation’ were identified within this sub-theme. The ideas and concepts embodied within these categories will now be presented.

### Speakers’ Experience of Meeting Facilitation

The category entitled ‘speakers’ experience of the meeting facilitation’ included all data that commented on the speakers’ experience of how the meeting was facilitated. These data were allocated to two sub-categories: ‘how the speaker felt about their experience of meeting facilitation’ and ‘comment on specific techniques or parts of the meeting.’ The data coded to these sub-categories will now be described in detail.

#### How the Speaker Felt About Their Experience of the Meeting Facilitation

Some of the speakers verbalised their feelings which related to their experience of how the meeting had been facilitated. Only two of the coded passages referred to what were considered to be negative feelings, the rest of the comments expressing positive feelings.

About half the coded passages contained general positive feeling terms such as very good, quite good, great and fine. Some examples from the interview texts are shown below.

> I think you facilitated it really well (F3B para.102).

> I certainly felt as though it was well facilitated and you helped all of us converse and open up and that kind of thing. I'm pretty vocal so I was sort of sitting on the edge of my seat going I wonder if it's my turn. I've got stuff to say (F1C para.35).
>
> I think it was good (F10A para.140).

Most of the rest of the coded passages made reference to more specific positive feelings such as comfortable, relaxed, calmer, not pressured and easy. Some examples of these are seen in the following quotes from interview texts.

> Very gentle, yes, and I think that is the best way to approach it (P6 para.71).
>
> Very easy; yes. It's not like you are a stranger that's just come in. It's almost like we've known you for a while. I don't know why but that's the case (F12A para.26).

Only two of the speakers indicated that they had experienced negative feelings in relation to the facilitation of the family meeting of which they were a part. They were members of different families. One speaker was particularly frustrated by one member of the family who is known for talking a lot and felt they could have been kept quieter.

> One of my aunties, I just sort of wished someone had gagged her (F5G para.53).

The other speaker who had experienced some negative feelings indicated that they found some of the silences uncomfortably long.

> Participant: Otherwise you sort of just sit there in silence and wondering what's going to happen next, which can be a bit - - -(long pause)
>
> Interviewer: - - - uncomfortable sometimes for people.
>
> Participant: Yes.

> Interviewer: And you felt there was a little bit of that at the meeting.
>
> Participant: Yes; just a little bit (P8 paras.78-82).

The overall view expressed by those participants who commented on how they felt about the facilitation of the meeting was that it had been facilitated in a manner that enabled them to feel positive about their participation.

### Comment on Specific Techniques or Parts of the Meeting

Some of the participants also commented on specific aspects of the meeting facilitation and data relating to this were coded to the sub-category ‘comment on specific techniques or parts of the meeting’. Most of the comments that were coded to sub-category were made by a small number of individuals so are not considered to be widely held views. On the other hand many participants would not have been particularly conscious of the impact of facilitation on the meeting unless they experienced it as being particularly bad and so the comments that were made, even if few in number need to be given serious consideration.

Four comments related to things which the speaker considered had aided in the ease with which participants were able to speak during the meetings of which they were a part. These included: an easy approach, very open prompts which allowed discussion of a wide range of issues, giving everyone a chance to speak with minimal interruptions and inviting the patient to speak first and so set the scene of the meeting.

> I mean it must be the way you approach us but it’s very easy to talk with you (F12A para.24).
>
> I think there was enough opportunity to bring up whatever you wanted to (F8B para.21).

> I thought it was fantastic. I definitely thought that you gave everybody a really good chance to talk and you were quite good in the fact that there weren't a lot of interruptions (F1D para.16).

> I thought it was actually really good that you had Mum speak first so that we could find out what she was hoping to get from the session and a bit about how she was going to approach it because if she was going to go into it and not say much at all it makes it difficult for us then to open up as well (F8B para.23).

For one family the way in which the meeting had ended was of particular significance and value for them and was commented on by two of the three participants. One example is:

> I think it was interesting from the aspect of people actually verbalising things that they were going to miss about Mum and that kind of thing. I think that was nice, so yes (F2B para.15).

The other two comments coded to the sub-category ‘comment on specific techniques or parts of the meeting’ were made by members of two different families and related to techniques that were seen as avoiding potential problems. One comment made reference to a member of the family who tended to dominate the conversation and how that situation was facilitated in a way that prevented it becoming too much of a problem, except perhaps for the member F5G quoted above.

> I thought you did it very tactfully and very well. I knew what you were trying to do and I knew you were going to have problems (F5E para.74).

The other comment which intimated that potential problems had been avoided referred to the facilitator’s willingness to deal with an individual’s concerns prior to the meeting.

> The thing that was important to me was that I had rung you beforehand. I know I've already said that but it really was important, because I think I would have felt very uncomfortable if I

> didn't have that extra ally but it says on your introduction information sheet that - or does it - I just assumed you'd be available so I called you (F3B para.104).

In addition to comments about their experience of the meeting facilitation some participants identified specific qualities they thought were important for a facilitator of family meetings of the type used in this study. These data were coded to the category ‘identified qualities needed for meeting facilitation’. These are described below.

## Identified Qualities Needed for Meeting Facilitation

The category ‘identified qualities needed for meeting facilitation’, to which data relating to specific qualities identified as important for the facilitator of these family meetings were coded. Three sub-categories were identified. These were entitled: ‘general qualities’, ‘qualities for handling problems’ and ‘the value of the outsider’. These are described in detail in the following sections.

### General Qualities

A number of coded items identified general qualities which the speaker considered to be important for the facilitator of family meetings of the kind implemented in this study. These general qualities identified were related to the facilitator’s ability to attract people, to put them at ease by quickly gaining their trust and to make it easier for them to open up during the meeting. Some examples of comments coded to this sub-category are shown below.

> So that they can draw on perhaps - can perceive that there might be something that someone wanted to add further to something and they could sense that and pull them into the conversation and not let it go by without coming back to that person (F1B para.35).

> And you have such a lovely demeanour, a lovely manner, that to me, you kept them a lot calmer than they might have been. I just thought that the way you came across was really excellent (F5A para.112).

> This meeting was quite a lesson in going with the flow and getting them to talk about issues on which the study was focused (F.Meet.7 Notes para.5).

The quality of perceptiveness was also implied in the first of the above three quotes from interview text.

The ability to be tactful, already discussed above (F5E para.74) as an observed quality, which in the case of one of the family meetings in this study, proved important in preventing a difficult characteristic of one participant from becoming a big problem, was also identified as a useful quality for the facilitation of family meetings generally. Some other facilitator qualities which were identified as being important for handling potential problem areas were coded to the sub-category ‘qualities for handling problems’.

## Qualities for Handling Problems

The two facilitator qualities identified by several speakers as being important for dealing with potential problems were the ability to be sensitive to touchy issues and the ability to deal with those family members who interrupt or dominate the conversation. The ability to be sensitive to touchy issues included an ability to keep things on an even keel, to intervene in a way that prevented things from getting out of hand.

> So we're really close but there's little things that maybe you think 'Well perhaps we shouldn't broach that or maybe it might upset somebody.' You know? So you need somebody who can just keep things on an even keel I think (F12A para.10).

For some families the issue of speakers who dominate or interrupt others is potentially a very real problem and the ability of the facilitator to handle this situation was considered very important and in this study commented on by members of two of the families. For example:

> Yes. I appreciated that *(the facilitator came back to them when they had been interrupted)* and I knew that you were trying to get the answer (F5E para.79).

The other quality needed to assist in avoiding problem areas was noted in the field notes of the meeting facilitator in this study. This is the ability to adapt to quite different families in terms of the level at which they think, the way they interact with each other, and of course, their structure.

> There were just two people present at this meeting the patient and the husband. It was definitely a meeting with a difference. Both are fairly simple people in lifestyle and in mental capacity. Her capacity is also additionally impaired to a degree by her illness ….. It seemed that she has lived a very hard life with disabled children and bringing up a grandchild and also another disabled grandchild in the family (FM7 Notes para.4).

For those who have experience in working with families, it is easy to imagine that the meeting facilitator may well need other qualities not mentioned by the participants of this study, such as the ability to deal with expressions of anger and aggression, participants unwilling to remain silent while others speak and very strong emotional responses to the opening up of particularly sensitive areas. It is possible that the qualities needed to deal with these situations were not specifically mentioned by participants in this study because there were no situations when participants were out of control. One likely explanation for this is that families where this behaviour is common, or individuals who feared they may find themselves out of control, declined to participate in the study.

## The Value of the Outside Facilitator

The third sub-category of the category ‘identified qualities needed for meeting facilitation’ is entitled ‘the value of the outside facilitator’ and includes any data expressing a view about the value of having a facilitator from outside the family. Members of three different families commented on this issue. It was considered that the process of the family meeting was easier when facilitated by an outsider as they were likely to be more objective. Examples of data coded to this sub-category are:

> It was good to have you to sort of to facilitate the meeting…..and to instigate it and to get everyone together. I think if nobody sort of takes up that baton after the fact, or after this initial, this meeting. I think that maybe that could get a little bit lost (F5F paras.64&66).

> I’m not sure whether this is your role, but to be a third party if families aren’t coping would be important - or you know, we discussed afterwards the fact that we’re actually all together. But I do have lots of friends that two siblings don’t talk. And that would be very hard on the mother that’s dying. And so these sort of things Often can be helped by a third party, or just getting people to open up a little bit, yeah (F6B para.9).

It was emphasised, however, that it was important for people to feel comfortable with an outside facilitator.

> Someone that's neutral, they sometimes have a better frame of mind about things and can be a little bit more informative to you and help you to realise the things that you might be getting a bit too sensitive over and things like that, but yes, overall I found it great, really good (F1D para.8).

It is interesting that four of the coded data relating to the issue of an outside facilitator came from interviews of three different members of Family 1. This family was probably the most adamant of those that participated in the study, about their closeness and that they told each other everything, something not actually supported by some of the things said in the individual interviews. Perhaps, although none of them made this direct connection, their appreciation of the outside facilitator, was for them, related to the significant outcome of the meeting, which was, that a daughter in law had now become really part of the family (Chapter 7).

It is clear, based on the expressed experience of the participants, that the facilitator of family meetings, of the type used in this study, demonstrates a number of key qualities. These include the ability to quickly develop rapport and trust with patients and family members, the ability to have people feeling relaxed and comfortable, the ability to gently draw people out and encourage those who don't communicate readily to speak more openly, as well as qualities such as tact and perceptiveness which aide in the process of dealing with sensitive and problematic issues.

## How Could it Have Been Different?

The second sub-theme embodying data which informs the theme "The Implementation and General Applicability of the Family Meeting" is entitled 'how could it have been different?' The data coded to this sub-theme included everything that indicated ways in which the participants experienced the meeting either as just right for them, or suggestions they made about how it could have been better for them.

Five categories were identified which informed the 'how could it have been different?' These are entitled: 'who was present', 'another meeting', 'meeting timing ', 'needs the meeting did not meet' and 'other aspects'. These will all be described in detail below.

## Who Was Present

As indicated in Chapter 6, the participants of the family meetings conducted in this study were those who had accepted an invitation from the patient to attend. The number attending family meetings varied from two (patient plus 1) to eleven (patient plus 10). During the interviews following the family meetings some patients and family members commented on the numbers and composition of those present at the meetings. These data were coded to the category ‘who was present’. Three sub-categories were identified within this category and were called ‘numbers of people present’, ‘others wanted present’ and ‘children present’. These will be described more fully below.

### Numbers of People Present

Six different participants, none of them patients, from four different families, made at least one comment relating to the number of people present at the family meeting which they attended. It was apparent the number of people present at the meeting with Family 3 had been quite heavily influenced by the patient’s wife who was principle carer. She and one of their daughters, also present at the meeting, believed that the number of members invited had been determined by the carer’s view of the patient’s capacity to cope with people. Other evidence also suggested that family rifts, hinted at but not discussed openly, may well have influenced this decision.

> It might have been good to have other members but I felt it would have inhibited *my husband* (name removed) a bit to have a room full of people (F3A para.11).
>
> I think Mum and Dad *(patient)* would have felt more awkward talking in front of the others (F3B para.56).

For Family 10 where there was no evidence of rifts and in fact there had been strong expressions of family closeness, the meeting had never the less been restricted to the patient and his wife who, in her interview, expressed hesitation about including other family members in such a meeting.

> I mean our family's always been close …..But yeah, I sometimes wonder whether this type of thing with family, with brothers and sisters, open meetings for the family, rather than just the two of us would really be a good idea (F10A paras.169 &173).

Two family members, from different families, would have preferred less people to have been present – one because she considered she had a special relationship with the patient and wanted a private meeting with them,

> Interviewer: So when you say 'not the right environment' what particular aspects of it were not helpful for you?
>
> Participant: I think just having the others there. I feel my relationship with my Mum is quite different to everyone else's - my sister's and my Dad's and there's some dynamics there that will probably hold me back from saying what I really wanted to say (F2B para.6-7).

and the other because they found the numbers present (11) a bit overwhelming.

> Probably the only thing I would do different, I would say to the patient 'make it five or six people' type of thing (F5B para.102).

The above evidence suggests that those who specifically commented on numbers were in favour of keeping it small and in some cases to restricting it to people with whom they felt especially close.

## Others They Would Have Wanted Present

A similar number of participants, rather than commenting on numbers of people present at the meeting, spoke of other specific individuals whom they wished had been there. Patient three, whose family, as discussed above had experienced some rifts, suggested that it would have been good to have had the rest of the family present but doubted that they would have actually fitted in.

> Definitely *(would have been value in other family members being present)* but then there may have been others who would have found it a problem fitting in (P3 para.39).

For Family 5, estrangement of part of the family had also resulted in some not being invited to the meeting, a situation which was regretted by some who did attend.

> *My father in law* (name removed) and his wife and the other brother as well – it would have been good if everyone was there. I think it would have broken down a lot of boundaries within the family (F5F para.36).

Distance was another reason offered for not inviting some family members whom they would have liked to be present.

> Certainly *I would have wanted* (name removed), our oldest son who is in – and *his wife* (name removed) who are in *NSW* (location removed) (F1A para.58).

It was interesting to note that one patient, who considered the meeting would not have much impact on his family as they 'had it together', after the experience of the meeting thought there could be benefits in including extended family and including particularly his older sister.

> I'm just saying to you that it could have been *(beneficial to have extended family present)* - you might have got a different response from my sister than you would have from the rest of us (P1 para.22).

This small amount of data suggests that at least in some cases the family meeting was seen as having potential to heal or to strengthen family bonds.

## Children Present

The issue of whether or not children should be included was raised by members of five different families. In one case two children, aged seven and nine were brought to the meeting by their parents who affirmed that they wanted them present. The children were not interviewed. The mother of these children later commented that she thought it had been particularly beneficial for them to have had the opportunity to tell their grandmother what they most appreciated about her. Another member of this family who was present was also very happy that the children were included while a third member considered that it wasn't really the place for children.

> I don't really personally think that it is the kind of meeting that children need to be involved in (F2B para.76).

Two patients, who had grandchildren with whom they were close, considered that teenagers should be included in the family meeting but not younger children as they thought that the younger ones didn't really understand what was going on.

> I think probably teenage children - not children - but they *(teenagers)* should be involved in it because they have got the capacity to exactly know what's going on and they would be able to share their feelings and like anyone younger than that I don't think they've got that ability. Like *my granddaughter* (name removed) would say 'Oh, yes, I love you Nanna' but she wouldn't be able to say any more (P8 para.90).

Another participant on the other hand thought that if they were not included in the meeting they should definitely be involved in other conversations about what was happening.

> Well I think perhaps, once again, being a practical sort of person, I think we all have to face these things and one day we're going to have to face it whether we like it or not, so we might as well slowly get used to what's going on, and I think in the case of *my granddaughter* (name removed) that's how we have handled it (F12A para.106).

Children were excluded from this study because of the complicated issues involved in ethics clearance. It is evident however, in this small group of participants that there were some opposing views about the importance and appropriateness of including children in a family meeting of this type.

## More Family Meetings

All data making reference to the speakers' view about the usefulness of one or more extra family meetings, if this option was available, were coded to the category 'more family meetings'. Two sub-categories were embodied in these data. These were entitled 'yes' and 'doubtful/no'. The data coded to these two sub-categories is described below.

### Yes

All data that indicated a willingness on the part of the speaker to participate in another family meeting if it were available or to consider doing so subject to certain conditions, were coded to the sub-category 'yes'.

A number of participants, both patients and family members, made general statements that they could see value in having more than one family meeting and would be willing to be involved if these were available.

> I do think there would be value in having more than one meeting (F3A para.33).
>
> I'd like to see another one a bit closer as well (F5G para.94).

Others were able to be more specific about the value of one or more further family meetings. Several believed that it would be easier for the participants to be relaxed and open in a subsequent meeting.

> Participant: But probably if it happened again you might have even not been able to shut people up because you know - - - (long pause)
>
> Interviewer: People would have loosened up even more?
>
> Participant: Yes; yes (F11G para.12-14).
>
> I think perhaps the second wouldn't be as gruelling as the first and I think people would probably be more open at the second one, they know they can, it's okay to ask questions. Yes, definitely (F5E para.64).

It was suggested that the second time around people would know better what to expect, and that further meetings could be particularly helpful for families that don't communicate well.

> If it happens again I guess I'll know what to expect. And it could be more beneficial. It was a learning curve I think (F5I para.96).
>
> If you're an open family I mean everything pretty much gets aired, whereas, if you're one of those families that sort of keeps things to themselves, it may be useful (F8A para.112).

Other participants thought follow up was lacking when only one meeting was offered and that this follow up, in the form of spaced out meetings, could be important in providing a cushion for the family as they worked through the process of the death of a member. It would, they thought, also allow the possibility of dealing with as yet unfinished business.

> Certainly; yes, and particularly because as time goes by you do get into different phases of adjustment and you may sort of see something else that needs some planning, that type of thing, changed circumstances in the future. Yes, certainly with the grieving part of it you certainly go through various phases (F1A para.34).
>
> I think so. In fact even for our family if we had a follow-up meeting and discussed where things were at the next point and how things have happened and how we've changed what

> we're doing in the meantime I think I could - I would certainly be interested in that because it would give me an insight (F12C para.73).

Two participants who expressed interest in another meeting made it clear that their willingness to be involved would be dependent on an understanding that the later meeting(s) would cover new areas and not just repeat the first one.

> I certainly wouldn't be adverse to it; *(another meeting)* no. I think it would need to be different in some respects – perhaps the questions asked or it would need to have – it couldn't be a carbon copy of the same thing (F1C para.23).

Twenty of the participants indicated an interest in or could see value in being involved in one or more family meetings if this option was available. They considered that family members would be more relaxed in subsequent meetings and that they would have opportunity for follow up of unfinished business. In contrast only four indicated doubt or an unwillingness to be involved in further meetings.

### Doubtful/No

Any data, which indicated a doubt or an unwillingness about being involved in further family meetings, should these be offered, were coded to the sub-category 'doubtful/no'. Three reasons were offered for doubt or unwillingness about further meetings. For two participants it seemed too hard for them personally although one of these indicated that they would do it for the patient if he wanted it.

> I just found that really concentrated, just a bit too much for me I think, but however I'd do it again for my uncle. I feel that it probably helped him. But I imagine that I would like that kind of thing if I was ill (F5E para.8).

Another participant believed her family had taken their willingness to openness to the limit and that attempting to go further would not be constructive.

> No – it would be a one off – that we covered as much as they'd *(her parents)* be prepared to cover and if we had more meetings we'd be starting to get to more explosive material. …… My family wouldn't be prepared to go there – some might. (F3A paras.84&86).

This view was not supported by the other two participants of this meeting, the patient and his wife, who suggested that further meetings would be of value, although the facilitator of the meeting did notice some unwillingness to pursue particular topics of conversation.

> Overall there was a sense of willingness to be open and speak at depth about issues although at the same time an underlying feeling that there was a definite boundary that would not be crossed (FM3 Notes para.7).

The view that further meetings may be too stressful for the patient was also expressed, although in this case certainly not supported by the patient.

> A little problem I just thought of was having a couple of meetings might be a bit too stressful for the patient too (F5B para.47).

> I still reckon if it could be arranged I'd be in for it (P5 para.181).

In this study at least one member of three quarters of the families participating indicated that they believed there would be value in having more than one family meeting if these were appropriately timed and gave opportunity for the participants to discuss different areas of interest and concern. This matter also relates to an issue raised by a small number of participants and that is the timing of the initial family meeting in relation to the patient's illness trajectory.

## Meeting Timing

During level two data analysis, discussed in Chapter 6, data relating to the timing of the family meeting were coded to category ‘meeting timing’ and were thought to embody three sub-categories; ‘earlier’, ‘later’ and ‘just right’. Subsequent analysis however revealed only a small amount of data relating to the timing of the meeting and so it was decided to code it all to one sub-category entitled ‘earlier/later/just right’. These results will now be described.

### Earlier/Later/Just Right

Two participants suggested that having the meeting earlier would have been beneficial in their case. In one situation the meeting had been held six weeks after diagnosis of cancer that was already wide spread. This patient and her spouse, who had come from the country, had experienced difficulties with the diagnosis and initial treatment process and had felt unsupported.

> He emphasised again the value of having such a meeting very early on in the process from his experience of dealing with an illness like this in a family member (Int. Notes F4A para.14 – interview not recorded).

In the other case the patient, although they enjoyed the meeting, and could remember some of it the next day, was becoming cognitively impaired and one family member thought that it might have been better held earlier.

> I suppose if it was done maybe a bit earlier. A week or so earlier it might have made a difference (F9C para.14).

Only one participant suggested that perhaps the meeting could have been held a bit later, closer to his death, although he was also a strong advocate for having more than one meeting. He had been surprised by the emotional response of some family members at the meeting, expecting such a response to occur closer to his death.

> It's aired out lots of little things like that and I am just wondering whether maybe it should have been on later (P5 para.175).

Another patient expressed the view that their meeting had been just at the right time because he was only just coming to the point of being able to acknowledge that his death was rapidly approaching and that he would not be experiencing the reprieve he had in the past.

> I think it came at the right time (P3 para.103).

In a complex intervention such as a family meeting it is very likely that for any one family the best timing will not be the same for all of its members and that the patient's view of the right time would need to be the paramount consideration.

## Needs the Meeting Did Not Meet

It was evident during the interviews, although not overtly expressed by the participants, that the meetings did not meet all the psychosocial and spiritual needs of the patients or their family members. Unmet needs that were identified were coded to the category 'needs the meeting did not meet.' Although the identified unmet needs all were connected with an apparent need to talk one on one with someone, they were coded to two different sub-categories. These, which were entitled 'need to talk one on one' and 'things couldn't/wouldn't say at the meeting', are described below.

### Need to Talk One on One

Any data indicating a need to speak one on one with someone about concerns were coded to the sub-category 'need to talk one on one'. Two participants expressed an appreciation of the opportunity to do this at the interview or indicated that they thought a family member would have benefited from that opportunity.

> *(Quoting the participant after the tape had been turned off)* "It has been so good to be able to talk to someone outside the family about this. Thank you." (Int. Notes F2A para.10).
>
> I think probably seeing you would have helped her (*her sister*) a lot as well I suspect (F12B para.71).

Interview notes relating to three different families suggest that participants took the opportunity to speak one on one with the interviewer about issues still unresolved or general matters of concern that were not related to the family meeting, suggesting a strong need to have one on one conversation about their situation.

> It would seem that all those issues are still unresolved for him and that he does need to talk about them and work his way through them. (F4A Int. Notes para.6)
>
> She was clearly feeling a need to talk and spent a lot of time talking about things other than the family meeting (Int. Notes F10A para.15).

The need to talk individually is also obviously important to people.

### Things Couldn't/Wouldn't Say at the Family Meeting

Some participants indicated that there were concerns that they couldn't or wouldn't speak about in front of the family or had thought about since the meeting. Sometimes these comments were made after the recorder was turned off while preparing to leave. These data were coded to the sub-category 'things couldn't/wouldn't say'. Some of these data were concerns for either the patient or another family member which they did not want to express in front of them in a meeting context. For example:

> She is rather worried and afraid that he is giving up because he's not keen to continue further treatment that he does not see as serving any purpose (Int. Notes F10A para.15).

> She didn't talk about this in the family meeting but she did tell me at the interview that she was worried about her husband and family, which demonstrated more consciousness of her situation than I thought she had shown before (Int. Notes P7 para.14).

Other participants took the opportunity during the interview to express some of their personal fears and concerns they had not raised during the family meeting.

> She took the opportunity to share some of her concerns about her own health and the possible outcomes of that (Int. Notes F3A para.23).

> He was very willing and quite talkative although probably more interested in talking about how he felt about the whole event of his wife's illness rather than confining his comments to the family meeting. This was further confirmed when after the tape was turned off he started to cry and spoke for a further 10 minutes about his feelings about his wife's impending death (Int. Notes F2A para.8).

The data coded to the category 'needs the meeting did not meet' would certainly suggest that aside from any value there may be in the family meeting, there remains a need for some patients and family members to have the opportunity to speak alone with a person outside the family with whom they feel comfortable.

## Other Aspects of the Meeting

The remaining data related to the implementation of the family meeting were coded to the category 'other aspects'. These data fell into three main areas and were coded to the three sub-categories 'hear more from others', 'include other topics' and 'place/style of meeting'. These are outlined below.

## Hear More From Others

Some participants expressed disappointment that others present at the family meeting had not been more open, as they would have liked to have heard more from them. These data were coded to the sub-category ‘hear more from others’. Two members of one family indicated that they had hoped that their father (the patient) would have expressed more emotion in his discussion of the journey of his illness.

> I would have liked to have seen Dad speak on a little bit more of an emotional level. He tended to give a bit of a time line of events rather than - sort of a little bit military in his precision - rather than just open up and be relaxed and speak on more of an emotional level so perhaps for my father as an individual probing him a little bit more would have been good but just getting him to open up to the level that he did I was happy to see that (F1C para.13).

A member of another family would have liked the patient to have spoken more about the details of the illness.

> The only thing I could say would probably be if the patient, if they were so inclined, could possibly explain what they were going through, you know (F5B para.37).

For the member of a third family there was disappointment that the patient was apparently unable to acknowledge past hurts.

> I wouldn’t expect too much to be squeezed in at the end of life given that he’s not acknowledged certain things throughout his life but you know like I said, just a comment or a couple of lines alluding to that would have felt more satisfying (F3B para.35).

Other more general expressions of a desire to have heard more from another family member were also given. For example:

> I would have liked perhaps to have heard *his* (name removed) point of view on a few more things, but I don’t think that is his way (F9B para.167).

## Include Other Topics

Two participants made suggestions about other topics of discussion that they would have liked to have been included in the discussion.  These data were coded to the sub-category ‘include other topics’.  The specific topics suggested were: how to deal with the future, wills and documents and more religious discussion.  The following examples illustrate these points.

> I would have thought that the future – the prospects – I think that how you deal with that. How do you deal with the tomorrows or the unknown? (F11E para.50)
>
> It was presumed that all the documentation has been done.  That wasn't asked whether the Will, medical power of attorney - you see sometimes we say about her wishes (F11E para.54).
>
> We didn’t talk much about that side (*religion)* and I think that’s pretty important (F6A para.39).

## Place/Style of the Meeting

Several comments were made about the meeting style and one about the location in which the meeting was held.  These data were coded to the sub-category ‘place/style of meeting’. One participant while acknowledging that her mother considered she was entertaining a guest (the meeting facilitator) and hence chose the formal lounge for the meeting, she thought it would have been more natural for the family to meet in the kitchen and that they would have been more relaxed there.

> Mum always entertains, if you like, in the lounge room, but for me I would put the family meeting in the place where it would happen most naturally, and for our family we sit in the kitchen, so it would happen in the kitchen as opposed to the - the lounge room (F12B para.42).

The style of the meeting drew several comments. One family member had apparently been expecting a question/answer type survey but was quite happy with what he had while another, a member of a large family suggested that meeting in smaller sub-groups may have been more appropriate for them.

> See, to me, somebody like you getting them (names removed) alone together and speaking that would really have helped them more (F5B para.119).

Two members of different families (both males) would have liked the conversation during the family meetings to have been much more directed. What seemed to them, to have been a lack of agenda, left one of them thinking that not a lot had been achieved.

> I wasn't really sure what it was about, what it was aiming for really, I suppose….. It seemed to be going nowhere (F9C paras.6&10).

In this family lack of clarity about the purpose of the meeting may also have been in part due to poor communication within the family that had also resulted in some members feeling excluded.

One remaining item of data was a suggestion that following this study a brochure should be produced for patients to assist them in talking to their families about their illness and the matters of importance that arise in the family through this.

> So I hope you do go on with it and I hope you do get a little pamphlet out and just sift through it and just outline to me just little things, like your family appreciation of different things, and how to deal with - how do you talk to them about it (P5 para.247).

Although most of the data outlined in the category ‘other aspects of the meeting’ are comments made by one person only, they do, however, offer some valuable insights into conducting the family meeting and some of the expectations of those involved.

## General Applicability of the Family Meeting

The remaining group of data related to participants’ views of the general applicability of the family meeting to other families experiencing the terminal illness of a family member. These data were coded to the sub–theme (coding reports1.11) ‘general applicability of the family meeting’. Two categories, entitled ‘who would benefit’, and ‘promoting it the meeting’, were identified within this sub-theme. Each of these categories was also found to have sub-categories. These data will be outlined below.

### Who Would Benefit

Data expressing the views of participants about the suitability of the family meeting for general offering within the palliative care service, were coded to the category ‘who would benefit’. This category embodied three sub-categories; ‘everyone’, ‘special circumstances’ and ‘not for all’. These will now be described.

#### Everyone

The family meeting was widely considered to be something from which everyone could benefit and that it would be good to offer it to all. Data expressing this view were coded to the sub-category entitled ‘everyone’. Some examples of this view are:

> I think, I mean depending on the family, but I honestly think only a very distant family, a family that's got some real sort of issues I guess you could say would be the only ones that don't benefit from it (F1D para.30).
>
> But I think if - like it was listed in the list of things like x-rays as a necessity well people would go along with it and if they didn't like it well they'd say 'Well we're not coming to another one' but if they all had to go to one at least it might start them thinking. Even if they said 'No, not going there again' (F11G para.125).

While considering the family meeting to be very beneficial and something that should be available to all, some participants also recognised that it would not be for everyone and that there needed to be choice

> I think it's absolutely beneficial. I think maybe there are some families that wouldn't want to do it but I think if the option is there and they're told that it's helped other families that might actually help them get the benefit (F12B para.38).

It was also recognised that in some families the meeting could be quite tense but that these families too would also benefit from having the opportunity to meet in this way.

> I think it was a really positive thing and even if it did bring up with another family something that needed to be cleared well perhaps it needed - the air did need to be cleared after all, although it was maybe a little bit tense I think even in that situation that it would have been beneficial (F1C para.11).

### Special Circumstances

A smaller number of participants, while believing that the outcome for them of the family meeting had been positive, considered that offering the opportunity to meet this way, particularly to families with special circumstances would be the best way to go. These data were coded to the sub-category 'special circumstances'. Some of these special circumstances were identified and included: Families that had not experienced a family death before, situations where the diagnosis is recent, and those families where there is poor communication.

> I probably thought it was more helpful for people who don't know anything about that part, like the death, or haven't experienced it before (F5H para.4).

> Overall he was very grateful, to have the opportunity to be involved in the research and appreciative of this and emphasising the importance of having this type of meeting earlier in the experience following the diagnosis (Int. Notes F4A para.18).

> I certainly - if someone came to me and said 'Is it worthwhile doing?' I'd say 'Yes.' Particularly I would imagine if you'd got a family who - yes, I would imagine it would be hard for some of the others to communicate but it would be worthwhile (F12C para.71).

It was also considered beneficial for families with major difficulties – if they would agree to participate.

> Sometimes the not nice ones *(family meetings)* would also be healing I imagine (F3B para.92).

## Not For All

A significant number of participants also recognised that this style of family meeting would not be beneficial for all patients and their family members and some were also able to identify specific situations that may impact on its suitability for some people. These data were coded to the sub-category 'not for all'. One example of a very general comment is:

> I think some families would be interested (F2C para.55).

Five specific situations in which this family meeting model may not be applicable were identified by the participants. The issue of the timing of the meeting has already been discussed above but it was suggested that it would be important in determining some family's willingness to be involved.

> I think some people mightn't have arrived at a conclusion just yet *(early after diagnosis)* and may need to have time for things to gel in their own minds (P3 para.83).

It was also suggested that in families where people are just unable to face the situation, where not talking about it helps to maintain a sense that it is not happening, or in situations where people were afraid of what might come out at the meeting, it would be unlikely that such families would agree to participate.

> I think it would be ideal if you could get some way to get people, especially families, together to talk about things. As you have probably experienced, there's a lot who won't face it (F11G para.109).

> I mean I'm sure there are a lot of people- and they've had lots of opportunity to have chats with their loved ones and they may be too scared to approach it. They miss out on so much (F12A para.86).

Three participants, none of them patients, considered that the family meeting was probably quite demanding for the patient and that their decision to be involved or not must always be respected.

> Some people don't want to do that though. And that's what I found with a couple of others that were close to me, and I was close to them. They didn't want to talk, and they didn't want people visiting them and all this type of thing. And I really feel that that's extremely important. But you need to respect a person's wish (F11B para.56).

The other two circumstances that were identified as likely to make participation in this type of family meeting inappropriate were some cultural issues and families that were too volatile.

> I mean let's face it. Some families don't get on with each other (F6A para.61).

> ….you will probably have to consider languages and that because people's understanding might be a bit different - different cultures are different. They may think you're being invasive (P8 para.54).

The general consensus amongst participants who spoke about who would benefit from participating in a family meeting of this type was that it would be beneficial to make it generally available but that for a variety of reasons some families would be unlikely to take up the offer.

## Promoting the Family Meeting

A few participants, in the course of discussing the general applicability of the family meeting as presented in this study, also made suggestions about how it might be promoted to palliative patients and their families. These data were coded to the category ‘promoting the family meeting’. Two sub-categories were identified within this category and have been entitled ‘general comments’ and ‘specific means of promotion’. The details of this data will now be described.

### General Comments

The sub-category ‘general comments’ embodied data containing general comments about the promotion of the family meeting. Four participants emphasised the need for simple clear information about the meeting and its purpose, particularly making it clear that it was not religious in nature.

> I think it has to be put very simply to people – the kind of thing that you’re offering and the kind of things that they may get out of it, like just really simply this is what we can talk about (P8 para.54).

> A lot of them will say it sounds too religious based, although its not (F11C para.126).

It was also suggested that ‘family meeting’ was not a good name for the event although no other suggestions were offered.

> I just don't know about the name 'family meeting'. I just - and I don't know whether there's a better name - but to me that kind of indicated a lot more structure but just sitting here I can't think of a better name for it (F12B para.38).

Two participants suggested promoting the family meeting by putting emphasis on coping or on the opportunity to gain insight into the family.

> I think it would probably be important to mention somewhere along the line about coping, about coping with what's happening within the family, and not only with their immediate family but extended family also (P8 para.62).

> I would have been more interested if it had been marketed sort of two-fold. You're providing information to me to do a study with a view to this end, at the same time getting an insight into how has this impacted on your family as a whole - not how you think it's impacted but what they think has happened (F12C para.57).

A few participants also had suggestions about the means by which the opportunity to take part in a family meeting could be promoted. These data were coded in the sub-category ‘specific means of promotion’ and are outlined below.

## Specific Means of Promotion

Brochures, both those that were specifically devoted to explaining the family meeting and those which listed it as one of the services offered by the palliative care system, were recommended as a means of promoting the opportunity.

> With the Palliative Care, they've always got their little brochures. It wouldn't hurt to be tacked onto the bottom; just a couple of lines with someone's phone number (F11C para.122).

The value of personal, word of mouth promotion was not underestimated however.

> I think also making people aware of what services are available; what's available to them for assistance. I mean I know they have brochures but actually physically being made aware of them would be a lot easier than saying there's brochures; you can go and pick them up from wherever (P8 para.66).

Particular agencies, other than regular palliative care services, through which this type of family meeting could be promoted, were also suggested by three participants. These suggestions included religious groups, care agencies and hospice and cancer centres.

> But it could be done through some source, either religious or outside religion – that it’s a great thing (F6B para.13).

> And the agencies are so wide and varied anyway, because there's agencies on each section of Adelaide; north, south, east, west. There's so many in each one. If it was put to each one, you'd be inundated within a week (F11C para.163).

## Summary

The focus of this chapter has been on the speakers’ views, where these were offered, of the implementation of the family meeting as they experienced this, the general applicability of this family meeting model and the ways in which it could be presented or promoted to palliative care patients and their family members.

Generally the participants indicated that their experience of the meeting facilitation had been a positive one and some were able to elaborate on this by identifying particular qualities of the facilitator which they had observed or generally considered would be needed for the facilitation of such a meeting. The observations included the value of having an ‘outside’ facilitator who was able to handle the difficult moments in a sensitive manner.

The possible value of having more than one meeting for some families and the importance of the timing of the meeting were also raised. A few participants described some aspects of the meeting style that they would have liked to have been different. It was also evident that not all patient and family member psychosocial and spiritual needs were catered for by the family meeting. A strong factor in this regard was the very obvious need of some participants to speak one on one with someone outside the family. In some cases this was because they didn’t feel comfortable to raise certain issues at the meeting in front of the rest of the family. In some instances this need may have arisen after the meeting because certain issues, which had been stimulated by the meeting, resulted in them later wishing to say things they had not thought about during the meeting.

The majority of the participants indicated that at the least this type of family meeting should be offered to selected families with particular needs. Most however, while acknowledging that it would not be useful for all families, indicated that it should be available to any who wished to take advantage of the opportunity. A number of suggestions were made about how the family meeting could be promoted so that most palliative patients and their families could be made aware of the availability of this service should it be incorporated into the palliative care service.

In the next chapter the data obtained through the semi-structured interviews of fourteen staff members, from a variety of disciplines, who were involved in the care of the patients and family members who participated in this study, will be reviewed.

# CHAPTER TEN - RESULTS THEME 4

# STAFF PERSPECTIVES

## Introduction

As discussed in Chapter 4, fourteen staff members from a variety of disciplines, who were involved in the care of the patients participating in this study, were recruited to take part in semi-structured interviews. These interviews focused on three main areas of interest which were:

what factors determined which patients they referred to the study and which they did not refer,

observations of the outcomes of the family meeting for those patients and family members who participated and,

ideas about the suitability of this family meeting model for inclusion in regular palliative care service.

The data related to these three areas of interest were coded to three sub-themes which were: ‘recruiting’ (coding reports 1.14), ‘observations of patient/family member participants’ (coding reports 1.15) and ‘inclusion in regular services’ (coding reports 1.17). These three sub-themes were found to have categories, and in most instances sub-categories. The relationship between the sub-themes, their categories and sub-categories is depicted on flow chart (Fig 6). The main ideas embodied in the sub-categories, and the related node coding report references are shown in Appendix IX(4)) and the relative importance given to each main idea, in terms of the number of coded references to it, is shown in Appendix X(4).

The data embodied in the above sub-themes will now be described in detail.

## Recruiting

All data relating to staff members' process in recruiting patients and their families for the study were coded to the sub-theme 'recruiting' which was found to have four categories entitled 'family type', 'impact of being a study', level of illness' and 'other ideas'. The data coded to these categories, and their sub-categories, where they appear, will be outlined below. These data need to be considered in the light of the inclusion/exclusion criteria set for the study. As described in Chapter 4 any patient who was over the age of eighteen, who was able to read and speak English and was considered medically able to participate in the family meeting was eligible for referral to the study.

### Family Type

The family type, as perceived by the staff member, was considered, by the staff interviewed to be a significant consideration in the recruiting process. These data were coded to the category 'family type'. Three sub-categories were identified within this data. These were entitled 'those they would not recruit', 'signs of suitability they look for' and 'how they decide who is suitable'. The details of the data coded to these sub-categories are outlined below.

#### Those They Would Not Recruit

A total of ten of the fourteen staff interviewed made one or more comments about the type of family they would not consider recruiting for the study.

Families were considered unsuitable, by some staff members, if they were excessively emotional, very sensitive and likely to be distressed by the experience of the family meeting, or if the participating staff member had not met members of the family. Some examples are:

> But another man, another fellow, I didn't want to, because his family is too sensitive to be able to even consider it (S6 para.14).

> Most of the consult patients that I've seen, we're not interacting with the families in the same depth and at the same level, so I would be much less secure in involving (*them)* in a study of this sort (S12 para.7).

These, however, were not widely expressed views there being only three staff members who made mention of any of the above.

A different group of staff members, which did not include any who commented on the above factors, indicated that they would not refer any family that seemed to be in crisis, was by their estimation dysfunctional or in a situation where information was being withheld from either the patient or other family members.

> I guess families in acute and severe crisis tended not to be referred (S10 para.4).

> There were some cases that were probably far too complicated with too much history and already too much friction (S14 para.5).

> I suppose another thing that's just come to mind is more often everyone knows exactly what's going on but there have been occasions where I've been aware that I have been put to one side either by staff or a family member not to tell Mum, for example, what's the matter with her so that would obviously make difficulties if this kind of thing was to happen and it also goes the other way. I often find I'm working with someone who doesn't want their loved ones to know exactly what they know so that would make family meetings very difficult because there would be some conflict in exactly what's talked about (S5 para.13).

Again these were not widely expressed views, dysfunction being raised by two staff members and the other two considerations mentioned by only one in each case.

Four other criteria for exclusion were mentioned, each by one staff member only. These were: anyone they perceive as anti-religious,

> I think if anyone has trouble defining the difference between spirituality and religion then that would be something I would have to be careful with because more often than not when spirituality is mentioned here I find that a lot of people think it's religious (S5 para.7).

patients with cognitive impairment (although it should be noted that the exclusion criteria would have prevented someone unable to give informed consent from participating in any case), where the patient or family members are resistant to the involvement of more people from outside the family,

> Certainly there's that feeling that some of them don't like people – even the thought of a social worker coming in just to sort of normal help them out a bit; finances, are intrusive. They sort of no, I've got nothing wrong. You hear that initially sometimes too, there's nothing wrong with me. I don't want people involved in that. That's the feeling that a lot of people get when you try and bring others into it (S13 para.11).

Some cultural groups would not be considered for referral.

> I guess there are some cultural groups though that might be more difficult to do (S8 para.40).

While a number of reasons were offered as to why some families would not be considered for referral for a family meeting of this type, none of them were widely held views with only two being mentioned by more than one staff member.

## Signs of Suitability They Looked For

All data which gave an understanding of the specific things that the staff member would be looking for when deciding to refer a patient and their family to the study, were coded to the sub-category 'signs of suitability they look for'. Embodied within these data were a number of views that were more widely expressed than any of those discussed in the section above.

Families which were perceived as talkative or liking stories, or both, were considered suitable for referral to this study by at least five of the participating staff members.

> I thought about people that I was involved with that enjoy talking (S8 para.5).
>
> Because they are a family that would like to talk to you and would like to tell their story. Or if you're looking after them, they're saying I'd love to tell my children that I love them… This will provide them with that support in a safe environment to do that (S14 para.5).

Three staff members indicated that they had been looking for families that they perceived would be willing to participate.

> What I was really looking at was whether they would be happy to participate (S13 para.4).
>
> …willingness in terms of not adding my expectations if you like, on them that I think this would be a great thing to do (S9 para.12).

Evidence of some degree of family cohesiveness was considered important also, although the presence of moderate dysfunction would not necessarily rule a family out of consideration.

> So it's almost like we'd be kind of thinking along the lines of a family that has a degree of cohesiveness and may have some things that are unsaid that if put in this forum would be able to be brought out; yes (S2 para.11).

> We’ve tried not to just kind of cherry pick the easy to get on with families, and I would commend you on the methodology in that regard, in that you – we were very well acquainted with what you were trying to do in the study and that meant that we I think were more – that and the fact that you were there at every meeting and listening and trawling through the case presentations yourself meant that we were less biased than I think we otherwise would have been (S10 para.4).

Other characteristics that some of the staff participants were looking for when considering patients for referral were; those that seemed to be exploring or searching for answers and those that showed signs of social and existential distress.

> Certainly if they were exploring, asking, sort of exploring some of the issues around their life, they are the people I’m probably be more likely to suggest (S13 para.19).

> In terms of the specific criteria, I think one of the issues that I think about is the degree of existential distress that I think that I see in patients and families and I think the issue for me is that any talking about anything by anybody with those kinds of patients is therapeutic and so it doesn’t really matter for me whether it’s the spiritual program or any other program I think that there are significant benefits for the patient and family because if the patient’s distress is reduced it makes the carers or the doctors and nurses that are looking after that patient as well as the family – it makes their job a lot easier and if we use less medications because the patient is more adjusted to the situation then I think that there’s a lesser risk of harm coming to the family as a whole as a result of this normal and natural bereavement process.(S4 para.8).

Another important criterion for several staff members, in selecting appropriate patients and families to refer to the study, was the timing in relation to the illness trajectory. For example it was considered that for some, late (patient thought to be in the last days of life) was not good timing.

> The timing……We've had a couple of – it would have been wonderful (*to refer them)* had you got in earlier (S6 para.37).

This same person however indicated that if this type of family meeting were a part of the regular service, timing would not be quite as crucial as it might be more possible to just do a meeting as soon as it was perceived to be needed.

> And so you may plan to do something and put in the preparation to be very disappointed (*timing and illness progression)* And, I think if you were a counsellor here you would have to be prepared to do that. And it might be you're prepared to just drop everything and do it right now, this very minute (S6 para.17).

A number of other circumstances, which were suggested as appropriate indicators for referral, were raised, but in each case by only one staff member. These were: evidence that the patient or family members were not dealing with the illness, abnormal situations in terms of age or circumstances of the patient, evidence of unresolved anger and they had significant others in their lives.

> Other families you meet - you think they are not dealing with things quite as well as perhaps you think they should be and that they could benefit from being a part of that service (S1para.49).

> It might be if I saw that the family dynamics – like if it was – I suppose when you think of someone who's young and who's got parents and children and everybody is still there and they are grieving so much about the diagnosis but maybe something like this might help them, so that I take into account as well (S11 para.13).

> As far as if there was anger or anything like that I would still go towards that (S5 para.11).
>
> You’re looking at family meetings, so it means firstly people have got to have significant others that would function as family if it’s not family themselves (S12 para.3).

Within the group of staff members participating in this study, most widely expressed views about which characteristics made a family most suitable for referral to the study were:

talkative families and those that like stories

those that were perceived to be willing

those that were exploring or were showing signs of existential distress

those that showed some degree of family cohesion, although moderate levels of dysfunction did not disqualify families.

## How They Decided Who Was Suitable

While thirteen of the fourteen participating staff members had at least one specific criteria in mind when deciding who to refer to the study, nine of them also made at least one more general comment about how they came to a conclusion about which patients and families were appropriate to be referred. These data were coded to the sub-category ‘how they decided who was suitable’.

The most commonly expressed view (four staff) was gut feeling about whether the patient would be interested.

> Just on feel I think, more than anything else (S13 para.11).

Three staff participants, including one of those who indicated they went by gut feeling, did however acknowledge that the only way to be sure about whether the patient would be interested or not, was to ask.

> And my gut feeling would have said straight away, no, I don't think they'll be interested. But then I shouldn't probably do that because I think well it's worth the inquiry, to make that (S11 para.9).

> It's a judgement which one can really only know by offering, asking (S9 para.17).

Another view expressed by two staff members, one of whom had also indicated they went by gut feeling, was that they did what could be called 'general checking out of the family'. For instance had they been resistant in the past to offers of help, in addition to basic medical care, or how did they respond to suggestions that their illness might be impacting on their whole family and that opportunities to talk about that might be helpful.

> I usually just talk about how their illness impacts on them and their family, whoever that is, and whether they want an opportunity to be able to talk about their lives and how they are feeling and their families tell you how they are feeling as well and that's the context I put this study in to patients and then I give them your information sheets and tell them that you would ring them if they are happy for that (S3 para.9).

Two different views were each offered by one staff member. One staff participant indicated that they based their decision on their own experience of the communication style of the patient or family members they had met. If they were chatty they would consider referring them but if they had 'a let's get down to business approach' they didn't refer.

> I think I tend to look at the families and the patients that I've had contact with and put them into two boxes – the sort of families that like to talk about what's going on and a group that quite often doesn't and quite instantly we will just direct our interaction directly with the things at hand, so their pain, their symptom issues; that sort of thing (S1 para4).

The other method of deciding who to refer involved running down the list of patients each week and making a very quick decision based largely on the set criteria.

> I mean I think – I've been a prolific referrer because it's easy. I just – once a week I can go through our list and just say 'Yes, yes, no, yes' (S4 para.8).

This staff member was by far the most prolific referrer among the participating staff members.
It is apparent from these data that in addition to the inclusion/exclusion criteria set down for the study, family characteristics were an important consideration for almost all the staff when they were making decisions about which patients and families to refer to the study.

## Impact of Being a Study

The second category of data found to inform the sub-theme 'recruiting' describes the participating staff members' views of the impact of the study on their recruiting process, as compared to referring patients and their families to a service which is part of the regular offerings of the palliative care service. This category was entitled 'the impact of being a study'. Three sub-categories were identified and were called 'easier if routine', 'drawbacks of being a study' and 'advantages of being a study'. The details of these data will now be described.

### Easier if Routine

Five of the fourteen participating staff considered that recruiting for a family meeting, of the type investigated in this study, would have been easier if it was part of the routine service offered rather than being a part of a study.

> I think it would be easier if it was just part of the service (S4 para.28).

One reason offered was that perhaps the patients would be more willing to be involved if they considered it to be routine. Two participants expressed this view.

> But if it's something that you actually had as a routine, this is oh we want to fit you in for a family meeting; it wouldn't be such an intimidating process for some people (S6 para.52).

Others (three) indicated that the difficulty was more for them than the patients – that the study seemed like a big extra in the situation of heavy work loads.

> Yeah, but I think one of the other sort of inhibitors for us probably is your process – it's nothing that you've done - it's just this sort of over-ruling nature of our work and never having any time to think really. It's just like such a production line now with Palliative Care. As fast as the referrals are coming in they're dying and we're getting new ones all the time. You don't get time to sort of consciously think. So if it was more of a routine it might be easier (S8 para.71).

## Drawbacks of Being a Study

Some participants were able to identify some specific draw backs in offering this family meeting as part of a study. One such issue (raised by one participant) was that offering something as part of a study may be seen as an infringement of personal space, at a sensitive time by some patients and family members.

> I guess what I can think of as being a barrier to people actually taking it up is because it's part of a study people are instantly put on the 'Oh, no. We're not guinea pigs. This is an important time in our lives and we don't want to be I guess used as a study purpose' when it's their time not your time (S1 para.4).

Two staff members also expressed concern about offering something to palliative patients which was as yet unproven.

> If it was an on-going well established program I would consider things differently I think. But given that it is kind of in its inception (S2 para.19)?

The time limits imposed by a study were seen as a disadvantage also in that the focus in their recruiting was more likely to be on who is likely to say yes so that we can get enough in the allocated time, rather than working to promote to those who may benefit most from it.

> I guess because we know that your time is limited we're trying to come up with people who are seemingly likely to want to agree to the program so that's the barrier. It's considering the type of clientele and trying to kind of work out who would be more likely to agree to something at this stage of development (S2 para.29).

Another drawback which was raised by two of the staff participants was the lack of a culture in their particular service of being involved in research studies. An outcome of this was that recruiting for studies was not on the mind of staff routinely and in some cases there was a lack of confidence that it was a good thing for palliative patients to be involved in studies.

> And I guess our unit is not really – we haven't been involved very much in research of our own and there have only been a few situations where we've had investigators like this have come to us to help recruit and we are not good at it and I think when people talk about it being difficult to recruit palliative care patients for trials and studies and things but it's certainly hard if you don't ask for it (laughter) (S3 para.31).

## Advantages of Being a Study

Two staff member participants expressed the view that there were advantages to recruiting for a family meeting of this type, when it was part of a study as opposed to being part of the routine service. Interestingly they expressed almost opposing views about the advantage, although in both cases they saw the patients as being better off in some way. One felt that because it was a study, patients would feel freer to decline to be involved.

> I think most of those patients would have refused if they had any doubt. (S4 para.20)

The other participant expressed the view that patients were sometimes more willing to participate when they knew it was going to contribute to a study.

> …I don't think it being part of a study necessarily detracts from patients wanting to do it because we know that largely they want to …(S3 para.52).

> That's exactly right and that's certainly – I don't know if you are familiar with Carol Steinhauser's work that's something she describes that patients say that it contributes to their death being better (S3 para.54).

Overall eight of the fourteen participants expressed the view that involvement in a study put a different perspective on the recruiting process for them, compared to referring patients and families for a family meeting which was part of the routine procedure within their palliative care unit.

## Level of Illness

Another category of data, relating to the recruiting process and how participating staff made decisions about who they would refer to the study, was related to the level of illness of the patient. These data need to be considered in the light of the official selection criteria of the study which includes the clause that participants needed to be considered medically fit to take part in a family meeting (Chapter 4). No sub-categories were identified within these data.

The most widely expressed view in regard to level of illness (five staff participants) was that they would not knowingly refer a patient they considered to be unstable, very ill or close to terminal.

> I think the biggest one would be how terminal the person actually is at the time. (S1 para.49)

> There are some where the patients are so ill that we feel that perhaps that may be inappropriate (S12 para.7).

Issues of cognitive impairment, ability to concentrate and memory were also commented on by some (3) staff participants. Two of those who commented on this issue were clear that impaired cognitive function would exclude a patient from referral in the case of this study. For example:

> It's probably largely on where we think they are at in their illness and their abilities to participate – concentration and memory and those sorts of things would be the prime factors (S3 para.43).

On the other hand another participant did not consider that short term memory loss necessarily would mean that the patient would not still experience benefit from being involved in such a family meeting.

> I mean there's some of ours that are quite confused, yet are still able to converse, and bring back – they might have short term memory loss, but the long term memories; you could reflect on things they did in the past. So I think every single client it would be an individual decision. You can't have criteria that are black and white. There are too many shades of grey in this (S6 para.17).

## Other Issues

Several other issues relating to the recruiting process were also raised by either one or two staff participants in each case. These data were coded to category ‘other issues’. No sub-categories were identified within this category of data.

One participant recognised that the ideal way to recruit would have been to simply apply the set inclusion/exclusion criteria and not make other judgements about who should be referred.

> I guess given the fact that if you like we were sort of nominated to choose the people to offer a sort of service I think it may have been better if we just had set a date and any new referral to the service from that point forward was offered as a matter of fact, because I think every time you put a choice into something you are already putting your own biases on what you’re asking and there may have been a group of people that I may not have asked or not have thought to put forward because I presumed that they wouldn’t go that way so I think it probably would have been better just to roll across from this day forward every new referral to our service who lives in our area will be - - - that meets minimum criteria will be offered a chance to be included in the study (S1 paras.39&41).

Two of the participants suggested that the use of the term spiritual in the study title was a problem for them in making referrals.

> Do you think anybody would have got put off by spiritual? Do you think anybody thought it was more of a religious conversation, conversion (S14 para.32)?

The need to feel protective of patients in a very fragmented system was also seen as an inhibitor to making referrals for one participant.

> She admitted to being a bit protective of patients and feeling that they did not want to be exposed to yet another person as the service is somewhat fragmented in any case with not a lot of opportunity for continuity with patients (Int. Notes S7 para.7- interview not recorded).

A different participant thought that they had had trouble remembering to consider patients for referral because it was not consistent with the medical model in which they had been trained although this particular participant had indicated on the demographic data form that he and other participants completed (Chapter 4) that he considered spiritual/psychosocial care of patients to be very important

> It is not part of the medical model, is it, no, and so it is – it's outside of what – the way we were trained (S3 para.25).

It is evident that a range of factors influenced staff during their process of deciding who to refer to the study. Some of these, for example, degree of illness and presence of crisis are related to the selection criteria laid down by the study, such as the requirement that they be considered medically able to participate in the family meeting. Other factors are related to the system within which staff work and the culture of particular units. Factors such as very heavy case loads, the medical model training system, a lack of familiarity with research in palliative care and of course the time limitations imposed by the study itself, can be seen as examples of system related factors. Other influencing factors are more closely related to the staff's personal views about talking about the types of issues raised in the family meeting and their individual styles in working with patients. The tendency to be very protective of patients and the issue of whether patients are given the opportunity to decide for themselves if they are interested or not, rather than someone else deciding that for them, are examples of this.

## Staff Observations of Outcomes for Meeting Participants

The second sub-theme identified within the theme ‘staff perspectives’ was their observations of the outcomes of the family meeting for the patients and their family members. All data relating to these observed outcomes were coded to the sub-theme ‘staff observations of outcomes for meeting participants’ (coding report 1.15). Two categories of data were identified within this sub-theme and these will be outlined below.

### Positive Outcomes

All data pertaining to what were seen as positive outcomes of the family meeting, for patient and participating family members, were coded to the category ‘positive outcomes’. No sub-categories were identified within this category.

Half of the participating staff (total 14) had received either direct or indirect positive feedback of a general nature about the outcomes of the family meetings held as a part of this study.

> So, yes, overall a good experience (S11 para.37).
>
> I’ve certainly heard no adverse comment and I think people are very quick to make adverse comments…..And are very slow to be positive and say ‘This was a good experience’ so I have had no adverse comment anywhere, whether in our team discussions or from patients or families, so thus far I have heard nothing. I think you can see that as a positive (S12 para.13).

Some of the participating staff had received more specific positive feedback from either the patient or family member participants. These included comments such as: this should be for everyone, good for the whole family, and that it had not been as emotional as they had expected.

> He said it should be something everyone has (S3 para.23).
>
> She seemed to think it was very beneficial to her and those around her and I think the family were quite appreciative of the opportunity (S5 para.25).
>
> She thought it was going to be a lot more emotional (S5 para.37).

Two staff member participants made observations about significant changes they had noticed in their participating patients immediately following their (the patient's) involvement in a family meeting. One noted that their patient seemed to have a lot less pain issues after the meeting than they had had before and the other staff member commented that all the anxiety and distress that their patient had been experiencing seemed to have gone.

> (*One of the consultants said)* at the community meeting that one of the ladies had been in hospice that had lots of pain issues; that she seemed to settle after the meeting (S14 para.47).
>
> I saw her in out-patients last week and she is doing remarkably well. She's actually stayed out of hospital for four weeks for the first time. Her disease is progressing. She is certainly weaker but her anxiety and her distress have evaporated. Now of course it may come back again. There's no doubt about that, but I think that's – if it's this intervention that has done that well that's fantastic (S4 para.14).

As Indicated by this same staff member without a further longitudinal study it is unknown what the longer term benefits, if any, of this intervention would be.

> But it might be interesting to revisit it now after the death and after some time to see if they remember anything about it and how that helped, because I suspect it probably will (S4 para.8).

## Neutral/Mixed Outcomes

Some data were considered to be either neutral or mixed in relation to outcomes of the family meeting for patient and family member participants, as observed by participating staff. These data were coded to the category entitled ‘neutral/mixed outcomes’. No sub-categories were identified within this category.

Five of the participating staff indicated that they had received no negative feedback. With only one exception, these staff had also received positive feedback which has been discussed above. Examples of data coded to this category are:

> I’ve certainly heard no adverse comment and I think people are very quick to make adverse comments (S12 para.11).
>
> I have heard nothing negative myself (S6 para.63).

What were described as mixed messages were received by two staff members working at the same institution. They both named the same patient.

> However one of the patients, it was reported to me by somebody else, wasn’t happy with it. But then this particular patient herself gives mixed messages to everybody (S6 para.64).

In the short term at least, the feedback relating to patient and family experience of the family meeting, which was received by the participating staff members, was almost entirely positive in nature.

## Inclusion in Regular Services

The remaining sub-theme which emerged from the participating staff interview data related to their opinions about the suitability of the family meeting model investigated in this study, for inclusion in regular palliative care services. These data were coded to the sub-theme entitled ‘suitability for inclusion in regular services’. This sub-theme was found to embody five categories of data. These are: ‘a good thing’, ‘practical barriers’, ‘staff qualities’, ‘other barriers’ and ‘ incorporating into regular service’. These categories, which will be outlined below, were also found to have two or more sub-categories.

### A Good Thing

All data arising from staff participant interviews, that expressed the view that the inclusion of an intervention such as the family meeting model investigated in this study would be a good thing, were coded to the category entitled ‘a good thing’. Further analysis of these data revealed two sub-categories which informed this category. These were: ‘general positives’ and ‘there is a need’. These will be described below.

#### General Positives

A variety of adjectives were used by staff member participants to express the general view that they considered this family meeting model a good thing to include in the regular palliative care service. These data were coded to the sub-category ‘general positives’.

The most widely used group of terms, used by half (7) of the participating staff members, was valuable/useful/beneficial. The following examples illustrate this.

> That would be very beneficial if we could offer a service that was attached to our service (S14 para.53).
>
> I think it is an opportunity that suits everybody. I think it's an opportunity that's
>
> really valuable for people to have this (S5 para.11).
>
> It's a fabulous idea and yes we want to develop this. I would see it as something very useful (S8 paras.83&86).

Another group of terms, powerful/essential/brilliant/fantastic, were used by five of the participants when expressing their views about the family meeting model's appropriateness for inclusion in regular services.

> I think it's a brilliant thing. I think having it there on offer and having it as part of the system would be fantastic and I think lots of people would benefit from that (S5 para.65).
>
> It would be fantastic, absolutely fantastic. And look at our aging population in South Australia, at the over 65's, and their expectations are greater. People aren't going to go into a six bed bay and roll over and die peacefully (S6 para.116).

Others (3) were more moderate in their expression describing the possible inclusion of this model into regular services as being a good thing.

One of the participants considered that this study would be likely to get the attention of palliative care services and, while there would certainly be challenges, there could conceivably be attempts to integrate the idea of family meetings of the type utilized in this study.

> I think this work will certainly have the attention of palliative care services and while this may not be definitive it's likely to prompt further exploration of this… That's going to be an interesting process (S10 para.59).

Perhaps the ultimate recommendation came from one staff member who indicated that they would want to have the option of such a family meeting if they were dying.

> Well if I was dying I would want it offered to me (S13 para.64).

## There is a Need

About half of the participating staff members indicated that there are needs that would be met by the incorporation of this family meeting model into palliative care services. These data were coded to the sub-category 'there is a need'.

One of these identified needs was a need to talk.

> I'd like to see it being a nice – and I could think of people actually wanting to discuss their thoughts rather than discuss their – because they hate the medical meeting that's going to be where are you going from here. So the actual, if it was a family meeting, everybody having a yak, well fair enough, might enjoy that, and I think it could be of great benefit to the ethnic society, once we could get it all running and get people in there and speaking the right language (S11 para.35).
>
> It's a gift to everyone and I just think it's the last thing that the family can have to make sure everyone said what they need to say. There's nothing left unsaid and if that means bringing some dark things out as well as the good stuff I still think it's hugely beneficial; definitely (S5 para.73).

Another need which was identified was a perceived shortage within the current system for the opportunity for counselling and spiritual support for families within the palliative care service, especially in relation to those families where the patient is being cared for at home. It was considered that the family meeting model being investigated by this study would be a beneficial addition to the service in regard to the provision of spiritual and psychosocial care.

> I would view it (*including it in regular service*) very positively, yes. I think there's a huge need for putting something like that in place for families coming to terms with their loved one dying and the patient themselves. I don't think there's anywhere near enough spiritual support for families and dying patients. I think we could really develop something a lot more than what currently exists (S2 para.21).

> Yeah, and service and care and nurturing. And they expect counselling. And they need help to get there, and it's got to be cost effective of course. But why shouldn't they expect it? We're not in a Third World country (S6 para.118).

One participant considered that at the least this study, and what may follow from it, could provide much needed information about the most effective ways to work with families in the palliative care setting.

> I think it's an area that needs to be looked at. We're involved with family meetings (*of a medical/physical care nature)* every day. It's an intensive part and a very energy demanding part of our work and I think if we had some way of looking at them, exploring, finding out the efficacy (S12 para.9).

## Practical Barriers

As well as the overall enthusiasm expressed for the possibility of including this family meeting model as a regular service offering, staff member participants also identified the potential practical barriers to its implementation. All data relating to this issue were coded to the category 'practical barriers'. Two sub-categories were identified and are entitled 'funding' and 'staff time/numbers'. The data coded to these sub-categories will now be described.

## Funding

Funding was seen as the biggest practical barrier to including this family meeting model into the regular palliative care service and was referred to by ten of the participating staff. Some expressed this in terms of a general lack of funding in the system.

> If funding was taken out of it I wouldn't have a problem with it at all (S13 para.46).
>
> There's always the number one; money (S14 para.66).
>
> Whether or not it would be seen as a valuable financially rewarding product or project for palliative care by the funders, well I guess that would be the big issue, yes (S4 para.8).

Others were clear that in a climate of limited funding, decisions are made about priorities and that the culture of the system has an impact on these decisions. For example in a medical model based system funding for the provision of physical needs such as physiotherapy will take priority over the provision of spiritual needs.

> She said they can usually get enough funding for medical and nursing staff but it is very difficult for other areas (Int. Notes S7 para.18 interview not recorded).
>
> Yes, but also I think it does come back to priorities and management and conscious raising education in terms of what is deemed to be important or what's necessary. But I do know that – and that has to come from the top. …..And I think that mirrors the broad cultural priorities of, for want of a better term, the physical material and it's easier to deal with that, because the emotional is sort of... It's demanding and less definable (S9 paras.61,66).

## Staff Time/Numbers

Another matter raised by about one third of the staff participants (5) which, is related to funding, was staff time and numbers.  Data relating to this issue were coded to the sub-category ''staff time/numbers'.

The essence of this sub-category is that with ever extending patient lists in palliative care services and with current staffing levels, there is little or no time for interventions that are time intensive.  The following excerpt form an interview transcript text illustrates these views.

> I think in the current system it doesn't happen like it should.  And even if you were to increase funding, it would be very difficult I think just in practicalities.  But how it actually works in, even in you know – certainly the benefits – *the social worker (*name removed) did tell me, probably similar to what you do in terms of that for a family who he went and sat down with.  It would have taken him five hours from start to finish just to do that.  The family benefit was huge; it was wonderful.  But that was five hours of him sitting down with the actual family over two or three weeks. And it's something they were very open and accepting to have.  But it's difficult to organise, manage and if you do that with every patient, just pretty quickly, twice in people's time (S13 para.54).

## Other Barriers

Other barriers to the implementation of this family meeting model in the regular palliative care service were raised by two of the participants and these related to language and cultural differences.  These data were coded to the sub-category entitled 'other barriers'.

Increasingly patients and their family members who do not speak English are registered with palliative care services. Clearly, implementing this family meeting model with the use of an interpreter would have difficulties as the following suggests.

> Also we have a few non English speaking people so that will become a bit of a barrier I guess as well. I'm not sure how good a family meeting could be – I wouldn't think it would be ideal going through an interpreter to actually have that, because you've lost that ….and so it would be very plastic I would think. It wouldn't actually be a very meaningful, thoughtful conversation using an interpreter both ways (S1 para.31&33).
>
> Well language, yes. That, as we discussed right at the beginning, excluding those from a non-English speaking background, certainly biases the sample in our patient population. I can understand the practicalities of that, but yes, that's a problem (S10 para.6).

## Staff Qualities

In addition to the practical barriers to inclusion of this family meeting model into the regular palliative care service, which have been presented above, participating staff members also commented on staff personal qualities which would be needed, in their view, to facilitate such meetings. The impact of staff thinking, in relation to who is responsible for which area of care, was also raised as a relevant issue. Data relating to these issues were coded to the category 'staff qualities'. Two sub-categories, 'those needed' and 'generalist versus specialist' were identified.

### Those Needed

Comments about specific qualities they thought would be needed for the facilitation of family meetings of this type were coded to the sub-category 'those needed'. Four of the participants indicated that they thought many staff members were currently ill equipped to undertake this work. Three of these participants were specialist palliative care consultants and the other was a nurse.

> And sometimes being chronically nice, as we are at palliative care, we try to take on too many things and too much and things for which we're ill equipped (S12 para.40).

> And for us to then try and establish a rapport and put ourselves where we can do that or run a meeting where they're going to be open, or we're near it, is sometimes difficult (S13 para.59).

Four staff members indicated they considered that the facilitation of family meetings of this type was a specialised field. Only one of these had also indicated that they thought staff members were currently ill- equipped to facilitate such meetings. These participants all considered that this role of meeting facilitation would be part of the work of the social work team or grief and bereavement counsellors. It was also suggested that ideally there would be a separate position for this role although in the present system it was considered unlikely to happen.

> I guess I would be thinking of people with social work backgrounds, grief and bereavement coordinators; people who have done courses in dealing with the issues that are likely to come up I guess. I guess if there was a role for nursing also that it would be specific nursing not as part of a clinical role as well. There needs to be a separate person that's doing that work I think so it sets up the boundaries for the patients and their families and they see you as that person who is doing that, not the person who's about to help them shower as well (S1 para.17).

> I mean ideally it would be fantastic to have another person on the team but in the face of the hospice, for example, not having adequate social work or physiotherapy or other allied health worker support it would be very difficult (S4 para.33).

Three other qualities considered important for the facilitation of these family meetings, were identified by the participating staff members. The first of these was adaptability, the ability to relate to a whole range of family circumstances and also availability.

> …– the adaptability I guess of the person who's going to be providing those family meetings to actually fit in with the families and the carers and the people when it suits them and it suits you and you haven't got five other people you are already seeing on that one day they had (S1 para.17).

The facilitator's self awareness in relation to spirituality was also considered important by one participant.

> They're frightened, so you have to have some comfort with your own spirituality and I think you have to have some discipline to allow that to happen. …..you don't have to be a sort of professional Christian or Buddhist or whatever to be spiritually aware but you do have to learn how to be aware (S12 para.21).

Two other participants commented on the importance of having the ability to develop rapport quickly or were at least aware of the problems associated with not having that ability.

> You get some pretty interesting conversations. But sometimes they have them, you know, as you're walking out the door after the 10th visit, they'll actually just start to talk about those things when they feel safe. … Because quite often people, the barriers don't come down for some time. You need to build up that sense of relationship and feel safe (S14 para.87).

## Generalist Versus Specialist

Another area that arose in participants' reflection of the qualities staff would need in order to facilitate these family meetings, was touched on above by those who indicated they thought it needed specialist training. This related to the generalist versus specialist debate. To what extent should holistic care, particularly the psychosocial and spiritual aspects of care, be carried out by a team of specialists rather than one or two generalists? Data relating to this issue were coded to the sub-category ‘generalist versus specialist’. Four different staff members commented on this matter but one was particularly vocal about it. One issue raised was the constant tension that exists between getting the practical things done on the one hand, and spending time on the more nebulous, and often more interesting things that are also a part of holistic care.

> Yes, and what I see is sometimes it’s easy to get caught up in specialty sort of, almost specialty areas, and not focus on the actual practical that needs to get done. And at times you feel as though everyone wants to do the specialty things. The doctors might want to see the patients if they’ve got special medical problems and the social workers will see ones with special issues. And I think sometimes just to get – there needs to be an approach where you know, you get out there and do the practical and then start worrying about the stuff on top. That’s what I sometimes struggle with (S13 para48).

Two arguments were brought forward that supported the more generalist approach to care. The first was that there are times when there was an immediate need, for example for a family meeting, and going through the regular referral channels to specialists just takes too long.

> Right now the person that does it – and often it doesn’t happen – but often now it’s the person that’s right at the time. It’s a bit like the leader of the team is the one who’s right at that time. It’s not necessarily the medical director or the nursing director or the social worker, and that happens I think – it certainly doesn’t happen in any formal way (S12 para.50).

Another situation mentioned is that some patients do not want to deal with a lot of different people and would rather talk to someone they already know and trust who has been involved in their care.

> Every team meeting there’s some social workers who will put their hand up and say this is something we should own. And in talking to the patient, when you have that initial talk with

> them, they don't want anyone else involved at this stage. And so that is always a conflict (S13 para.37).

The question could however be asked as to whether those particularly pushing the generalist approach, such as S13 below, are really aware of some of the skills needed to facilitate a complex family meeting. Or perhaps it is some of the specialists protecting their patch?

> And I think that if you start adding more specialist roles, you end up with more and more conflict along the line of 'that's something the nurses shouldn't be doing' (S13 para.78)

> And then you come back to the team and they say well this needs social work input; the social workers put their hand up (S13 para77).

## Ideas for Incorporating It into the System

Twelve of the fourteen participating staff members made at least one comment about ideas for incorporating this family meeting model into regular palliative care services. These data were coded to the category 'ideas for incorporating it into the system'. Three sub-categories; 'promoting it', 'participation' and 'other' were identified and are described below.

### Promoting the Meeting

Consideration was given by some participants as to how patients would be told about this type of family meeting if it were incorporated into regular services. These data were coded to sub-category 'promoting the meeting'. Three particular issues were raised; the title of the intervention – especially in relation to use of the words spiritual or religious, concern about using the word dying and the inevitability of each staff member putting their own bias on the way they told patients about it.

> Because a lot of people do see spirituality as religious practice (S14 para.38). So if it were part of a regular service, would you be calling it by a similar name (S14 para.63)?
>
> When I talk about it I don't put it in the context of your family might want to talk about the fact that you are dying, I just say that the cancer or the terminal illness might create issues that people want to talk about but haven't had an opportunity or a forum to do that. It can create that, so I don't necessarily place myself in that uncomfortable position *(of mentioning death.* (S3 para.81).

It was also considered important that although such a family meeting would be voluntary, it would be important, if incorporating it into the regular service that it was seen as a normal thing to participate in and not something offered to those with special problems.

> How you integrate it – I think it's certainly got to be part of the team. It can't be coming from outside because you want it to feel like it's a normal process; that it is not something special that's added on (S13para.98)
>
> So that everybody – you just rock in and 'Hi!. Well we need to have a family meeting and this is just standard procedure and let's just get on with it.' I think that would be fantastic. (S4para.32)

### Participation

All data relating to the matter of to whom such a family meeting would be offered, in the context of the regular palliative care service, and the number and timing of such meetings were coded to the sub-category 'participation'. Six different participants addressed the matter of which patients should be offered the opportunity for a family meeting, if it were made available in the regular palliative care service. Opinions ranged from those who considered that it should be a normal part of the process and offered to all, to those who were definite that for various reasons it should only be offered to a selected group.

> I don't think I can see any major barriers, just I think the natural I think selection from the people we see and that may be influenced by their religious background, and by their cultural background, but that they would be given the opportunity to include or not include themselves and that's I guess the difference (S1para.31).

> Exactly, and because it is time consuming and money consuming intervention, if you can focus it then to those who have a better chance of benefiting then obviously that makes a lot of sense (S10para.57).

It was acknowledged, however, that how it would be decided who to offer the family meeting to, would not be straight forward.

> Yes, and Kissane's study – one of the things I found most interesting about that was the, for want of a better word 'dysfunctional families', if you lump them together, they are the people, the groups that you might think you would want to target and who might benefit but then there were two quite distinct sub-sets of those, one of whom did seem to benefit and another sub-set who didn't. So that was counter intuitive and it may well be the case - - -*( for this model) (*S10para.63).

The practical issues of how many meetings would be made available to each family, were they being offered in the regular service, and the timing of those meetings in relation to illness trajectory and the stage at which they were referred to the palliative service, were raised by five of the participants.

> I guess that's the other issue – is if it evolves as a normal part of the service and it's no longer a study what would be the presumed interaction, the follow-up? Would it be five meetings or would it be open ended or it would be whatever was needed and could the staff that was provided to provide the service be able to accommodate the flexibility in what those people actually need (S1para.29)?

> Time, I suppose; timing of it. We get some very late referrals and do you need to establish a kind of relationship before this sort of discussion is entered into. I can't think of anything else. Probably timing is a big one. When do you offer it (S14para.74)?

### Other

Several other issues of relevance to the process of incorporating this family meeting model into regular services were raised, by one participant only in each case, with one exception. These data were coded to the sub-category 'other'. It was pointed out that cultural differences would need to be considered both in terms of cultural appropriateness of such a meeting and in the degree to which truth in relation to death is acknowledged. The almost global value in story telling was however considered to be a cross cultural factor.

> I think the professionalism *(of interpreters)* is improving, but it's still the case that – in fact we very recently had major issues with filtration of what was being said by an interpreter, but that is the reality and it may still be if you can demonstrate that this is a useful practice that it can translate with adequate use of interpreters into our setting. I hope that's the case because we more often than not are dealing with people from non-English speaking backgrounds and I have a gut feeling that the sort of telling of a family story is a really powerful intervention and that should cross cultural barriers (S10para.14).

Other participating staff considered that if introduced this type of family meeting would need to be coordinated with other services such as Domiciliary Care.

> We can coordinate with district nurses, domiciliary care for the purposes of communication and family counselling, that we could offer this service and so people could take it up right at the beginning or at least be aware of it (S1para.27).

It was suggested that it could be started with a trial run, perhaps in a hospice first.

> A hospice unit would be the most appropriate place to get some of this going (S11para.24).
>
> I think that ideally it would be – I guess people could be invited if they would like to have – that would be one way; to invite everybody and then see what the response is. And you could have a trial period or something like that (S9para.41).

One staff member who has a plan for running a group with nurses around spirituality thought that that may well be good as a lead in to later implementing the family meeting model investigated in this study.

> If it *(his proposed training group)* helps them to be less judgemental and more open to journey with the patients that's what I would hope. But we'll see (S12para.25).

## Summary

This chapter has focused on the three main areas of discussion with the staff member participants. These were recruiting for the study, their observations of outcomes for the participating patients and family members and their ideas about the suitability of this family meeting model for incorporation into regular palliative care services.

The issue of recruiting participants for this study was discussed by staff members from the perspectives of the things they considered, apart from the criteria for inclusion that were laid down for the study, when deciding which patients to refer. Almost all of the staff members acknowledged that they had applied extra criteria that either excluded a patient or made them more eligible in their view to participate in the study. The impact on their decisions and willingness to approach patients for a study, compared to letting them know about something which was a regular part of the service, was also commented upon.

Some of the participating staff had made their own observations as well as receiving direct feedback from patients and family members involved in family meetings, while others had depended on indirect feedback. Almost all of this feed back was positive in nature. Others considered that because they had not received any negative feedback that was a good sign.

Various aspects associated with the possibility of including this family meeting model into the regular palliative care service were raised. Generally, in theory at least, it was considered to be a very good idea and one that could bring much value for some families. On a practical level the biggest barrier to its implementation was seen as being funding availability and the associated staff shortages and hierarchical lists of needs. These problems, did not however, inhibit some of the staff member participants from making practical suggestions about how, and to whom it could be promoted were it possible to include it in services.

In the following chapter the major results identified in this and the previous three chapters will be brought together in a discussion of what, in relation to this family meeting intervention, worked for whom and in what circumstances.

# CHAPTER ELEVEN – DISCUSSION

# BRINGING IT ALL TOGETHER

## Introduction

This study has implemented and investigated the efficacy of Murphy's family meeting model (Murphy, 1999) as an instrument of the spiritual care of palliative patients and their families. Consideration has also been given to the suitability of this model for inclusion in regular palliative care services. Murphy's family meeting model was chosen as the focus of this study because it offered the possibility of meeting most spiritual needs as identified in the literature (Kellehear, 2000), it takes into account the needs of staff (Gordon & Mitchell, 2004; Murphy, 1999) and it has a unique focus on the whole family, a factor that has been identified in the literature as having a significant impact on outcomes for family members (Kissane & Bloch, 2002; Nadeau, 1998; Parkes, Relf & Cauldrick, 1996; Waldrop, Milch & Skretny, 2005). The literature review demonstrated that while a variety of spiritual care programs, or programs that include spiritual care, have been proposed, with the exception of the Dignity Therapy Model (Chochinov et al. 2005), no evidence was found that these programs have been assessed. This study therefore offers new insights in the important area of the provision of spiritual care to palliative patients and their families.

Pawson and Tilley's (1997) concept of "reasonable evaluation", outlined in Chapter 2 will be used as the basis for the discussion of the outcomes of this study. The key issues of: what works, for whom, in what circumstances and why, will be addressed to the extent to which these are revealed by the data. The implications of these outcomes for the inclusion of this family meeting model in regular palliative care services will also be discussed.

In this chapter the first person has been utilized when describing the personal experience of the researcher in the role of meeting facilitator or interviewer. The third person is used in the rest of the chapter.

## What Works?

The data relating to the question of what works will be discussed from three main perspectives. These are: the meeting style as presented, promoting and recruiting for the family meetings and the meeting facilitation.

### The Meeting Style as Presented

In the context of this study, the meeting style as presented can be considered to have worked if the stakeholders had a predominantly positive experience of it and report what they consider to be positive outcomes. In assessing whether or not this family meeting model "works" it will also be necessary to consider if the spiritual needs of patients and family members (as identified in the literature) were met.

Chapters 7 to 10 present the results of this study, the first two of these in particular focusing on the experience and outcomes of the meeting for the patient and family member participants. The results have already been presented in detail but several common themes emerged across these chapters which expressed what worked, or did not work for these participants. These were: 'the experience of being open', 'an emotional experience', 'new understandings emerged' and 'it had an impact on family relationships'. These will now be discussed in more detail.

## The Experience of Being Open

Most of the patient and family member participants made positive comments about their own experience of openness during the meeting and/or their observations of other family members' experience in relation to openness. Their comments about openness included: experiencing others as being more open than usual, observing benefits of the family being open together, things were said that needed to be said but in their family context would not have been said in any other circumstances, the experience of openness during the meeting had set the scene for more open communication within the family in the future and openness had given opportunity for review which had been a valuable experience. Of the participants who made these comments, about three quarters of them indicated that things were said or other outcomes achieved, due to the openness experienced during the meeting that would not, in their view, have occurred otherwise. Researchers who have worked with families (Kissane & Bloch, 2000; Murphy, 1999) suggest that a greater degree of openness is likely to result in greater understanding and cohesiveness within the family.

There was only one family in which no one made any comment about their experience of openness during the meeting. Although they had spoken freely about other family members during the initial contact, only the patient and his wife were present at the family meeting. They had been quite clear that they considered they had a very open relationship. Although things said by each of them during one on one interviews would suggest that their communication is not quite as open as they claimed, it is very likely their experience of openness during the meeting was what they considered very normal and therefore did not merit comment.

The outcomes of the interviews suggest that a family's own assessments of their degree of closeness and openness with each other are not necessarily a good guide to the likelihood of beneficial outcomes of the family meeting, especially in terms of saying or achieving things that would not otherwise have occurred. For example every participating member of more than half of the families involved in the study reported a positive experience of openness during the meeting. It is of particular interest to note that in four of these seven cases, prior to the meeting, these families had expressed very strong views about the high level of communication within their families and that their primary motivation for taking part in the study was to assist research and not because they felt they needed or would benefit from such a meeting.

About one third of the participating patients and family members, all of whom experienced positive outcomes from the greater degree of openness, also identified things which they considered had been inhibitors to a greater openness than they experienced during the meeting. The inhibitors to openness that were offered included: painful topic of discussion, individual personality issues or family culture, unwillingness to talk about death or aspects of it and feeling they could have been more open if clearer guidelines had been laid down. While it is obvious that life time habits and personality issues are not going to change in the course of one meeting (or even several), it is apparent from these results that unfamiliar events, such as the terminal illness of a loved one and family meetings at which thoughts and feelings are discussed, can result in unexpected positive outcomes.

The fact that some of the participants of this study specifically identified their experience of finding value in review is also consistent with the findings of other studies such as those of Caldwell (2005); Kuhl and Westwood (2001) and LeFavi and Wessels (2003), who not only found that life review was an important process for those near end of life but could also be instrumental in the finding of meaning and purpose which have been identified by Kellehear (2000) as spiritual needs. The very high rate (91%) of satisfaction reported by Chochinov et al. (2005) in the implementation of the Dignity Therapy Model, which offers patients the opportunity to tell their story (or to review their life) and to make this available later to friends and family, in the form of a tape, is further confirmation of the great importance this can play for patients and family members at the end of life.

It is apparent that this style of family meeting as implemented in this study worked for the majority of individuals and family groups who participated, in providing an opportunity for greater openness than was usual for those people.

## It Was an Emotional Experience

A big majority of the participating patients and family members found taking part in this style of family meeting to be an emotional experience.  Most who commented reported experiencing what they regarded as positive emotions such as happiness, comfort, hope, support and reassurance, feeling the pain eased (emotional pain of family members), getting real or in touch with the situation in a way they had not before.

It should be noted that all those (except one) who found that the meeting had brought them face to face with the reality of their impending death, or that of a relative, regarded this as a necessary, difficult, but overall positive experience.  The exception was a young woman from a family which demonstrated dysfunction and which acknowledged the existence of a great deal of unresolved grief. She stated that she preferred not to know anything about death or those dying, although she had agreed to attend the meeting because she loved and respected her dying uncle.  This young woman believed that as a result of the meeting she would now be unable to look him in the eye because she could no longer pretend that he was not dying.

This outcome for this young woman suggests that for some people, the family meeting intervention may result in them facing a reality they felt they are not yet ready to face. While this response was exceptional, even among the eleven members of her family who attended this family meeting, facilitators utilising this model need to be aware that not everyone has the capacity – whether it be lack of coping skills or large amounts of unresolved grief – to experience benefit from facing the reality of the impending death of a loved one. Further investigation may be needed to establish ways of identifying individuals most at risk.

Nearly half of those who felt emotional during the family meetings also reported experiencing what they called negative emotions, although some of them also made it clear this did not mean that they thought they were bad emotions or ones they should not have experienced in the circumstances. For some, their negative experience was related to the level of intensity of either their own emotions, or their observations of others' intense emotions. They felt that this intensity was nearing a level with which they might be unable to cope. Although information was given to each participant about available help, should they feel the need of it, there were no reports of any of the participants seeking such assistance.

It is also of interest to note that for one of the participating families (Family 9) the only comment relating to feelings and emotions experienced during the meeting was when the patient indicated that she felt glad that several of her family members were there. The other three participating members of this family made no comment at all about emotions and feelings experienced. Field notes, made following each family meeting, showed that this was the only family meeting in which there were no tears. One explanation for this is that the members of this family do not express their emotions in front of each other. It is also worth noting, however, that half of the participating members of this family did comment on greater openness and outcomes that would not have been otherwise achieved and three quarters of them indicated that they had come to new understandings as a result of the meeting. These results show that although most of the participants found this type of family meeting to be an emotional experience this is not necessarily related to positive outcomes for the family or for individuals.

It is clear that for almost all of the participants of this study, participating in the family meeting was an emotional experience. The majority of the patients and family members experienced emotions they described as either positive or at least not inappropriate or unhelpful in the circumstances. For a small minority of participants it is possible they experienced emotions of a type or intensity which they felt unready to deal with. The type of emotion or degree of intensity of emotional experience, as described by the participants, was not related to the presence or absence of positive outcomes from the meeting.

## New Understandings Emerged

Another major theme that arose both in participants expression of their own experience and in their observations of others' experience, was 'new understandings emerged'. A majority of the participants reported coming to a new understanding either about themselves, other individuals within the family or the family unit as a whole, as an outcome of their experience of the family meeting. The experiences included: being appreciated and valued in a way they had not before, getting things in a better perspective, understanding how others were thinking and feeling when they hadn't before and understanding things about the past they had not known before. In none of these instances was the arising of new understandings reported as being a negative experience.

It is interesting to note, that among the participating families, there appeared to be a connection between the arising of new understandings and which family members attended the family meeting. Three of the twelve family meetings involved only the patient and their spouse and these three families were the only ones in which no member commented on having come to any new understandings as a result of the family meeting. In every other family at least half of participating members indicated they had come to at least one new understanding. Perhaps these three couples were normally quite open with each other and so there was not a lot of new understanding possible. Possibly supporting this view is the fact that two other couples also did not indicate coming to any new understandings although other members of their families who were present at the respective family meetings did do so. It is also possible that the three couples, who participated in the meeting without any other family members present, either restricted their communication to a level normal to them, or kept it at a lower level than normal due to the presence of the meeting facilitator and so, in either case, precluded the likelihood of any new understandings arising.

It could also be speculated that the number of family members present at the meeting has an impact and that smaller groups are likely to give rise to fewer surprises, although this view is not supported by data in this study. Of the four families in which three members participated in the meeting, in three cases all participants reported coming to new understandings and in the fourth case two of three members did so.

The emerging of new understandings of either self or of others was a significant outcome of the family meeting both in terms of the number of participants who had this experience and the significant impact this new understanding had for some individuals and family groups. It is reasonable to suggest that these new understandings may have had an impact on mutuality and family cohesiveness both factors likely to contribute to spiritual well-being and identified as spiritual needs as spirituality is defined in this study (Kellehear, 2000).

## Impact on Relationships

Nearly half of the participating patients and family members observed that the experience of the family meeting had impacted, at least in the short term, on relationships within the family. With two exceptions these impacts were seen as being of a positive nature and included strengthened family bonds, initiating new ways of being together, increasing awareness of mutual support, clarifying roles and status within the family, greater confidence that raising these issues would not offend others, feeling more comfortable with each other and making more space to enjoy the things that make them happy together. These outcomes are consistent with the meeting of spiritual needs, within the context of situational transcendence, as described by Kellehear (2000). Table 19 (p.281) further elaborates the meeting of these needs.

The two examples of family members, who expressed disappointment that one particular aspect of relationships within the family had not changed as an outcome of the family meeting, even though they had both experienced other positive impacts on relationships, raise relevant issues in assessing what worked in the application of this intervention. One example of something that did not change as the participant had hoped was the way information about the patient’s illness was disseminated in the family on a need to know basis, as determined by the patient and their spouse. This participant clearly felt left out and was of the opinion that if greater openness and trust were demonstrated in this area, this would result in a greater sense of closeness among members of the family. This example stresses the need for mutuality, an identified spiritual need (Kellehear, 2000), which for this participant had not been met.

In the second case the failure of the patient to speak about, or show remorse for, a past major hurt he had inflicted upon one of the family members, was the source of disappointment to the family member concerned as she saw this meeting as likely to be the last opportunity for this to occur. She did however, also come to her own realisation that the meeting experience had never the less been one of release from further desire for an acknowledgement of the wrong.  She knew she had done all she could to provide the opportunity and in the end could not really expect a dying man to change many years of silence on the subject.

Murphy (1999) does not consider that the family meeting, as he had described it, is an opportunity to justify and explain past wrongs.  He does however indicate that it is an opportunity for acknowledging the way things were and perhaps for reframing them, or seeing them in a different light which can come from hearing another's perspective of those events.  In the situation described in the paragraph above a better outcome may have been for either the patient to be able to say, 'this happened and I know you were hurt' or for the family member to say 'this happened and I was hurt but I can now let go of that.'   As it turned out, for this particular family member, simply providing the opportunity for this matter to be spoken about openly, even though the speaking did not occur, was sufficient to enable her to let it go.  So in this, the meeting gave her the release she needed.  There is no way of knowing whether the patient felt the need of any release on this matter or not.  He did indicate, however, that he thought his family now understood him better as a result of the meeting.

It is clear that a significant number of the participants experienced a positive impact, at least in the short term, on relationships with other family members as a result of the family meeting.  Further investigation would be needed to determine if this family meeting intervention can have longer term impacts on relationships within the family.

## Staff Observations

Although staff members participating in this study were not present at the family meetings, their reported observations of patients and family members following their participation in the family meeting, added significant information to an understanding of what worked.

More than half of participating staff members reported receiving unsolicited positive feedback of a general nature from patients or family members. Such feedback included comments such as: very good, very beneficial and should be available to everyone. Four staff members were able to report more specific observations of outcomes for patients and family members. Two families were considered by staff members to be coping better since the meeting while one patient demonstrated considerably less anxiety and another had had less pain issues. While these are indicators that the family meeting worked, there is of course no conclusive evidence that these improvements were a direct outcome of participation in the family meeting. A number of staff members expressed interest in having the opportunity to determine possible longer term outcomes for reduction in pain issues and decrease in anxiety. Although these are positive outcomes of the family meeting, if in fact they are related to involvement in the family meeting, they were not the primary focus of the intervention. It is worth noting, however, that McCoubrie and Davies (2006), in their study involving 85 patients with advanced cancer, in which they utilized three questionnaires to assess anxiety, depression and spirituality, found a significant negative correlation between both anxiety and depression scores and overall spiritual well-being scores. However, they found no correlation between religious well-being scores and anxiety and depression.

No negative outcomes of the family meeting for either patients or family members were observed by staff members. Some staff members also reported that they had received no complaints from patient and family member participants in spite of the fact that some of these people had complained about other quite unrelated matters.

Although staff feedback about the outcomes of the family meeting for participating patients and family members was limited, all of it was of a positive nature.

## Did the Family Meeting Meet Spiritual Needs?

In assessing the Family Meeting Model for its effectiveness in providing spiritual care to patients and family members, consideration must also be given to determining if in fact it did meet participants' spiritual needs.  As discussed in Chapter 2, considerable work has been done to identify the spiritual needs of palliative patients, although family members have not so often been specifically targeted. It was found in this literature review that Kellehear's model of needs (Kellehear, 2000) offers a comprehensive summary of spiritual needs as identified in the literature.  The outcomes of this study, in terms of 'what works' are consistent with Kellehear's model of needs.

A summary of a comparison of the needs identified by Kellehear and the outcomes of this study is shown in Table 19 below. This includes outcomes of the study that have been identified above as main themes and also outcomes from small numbers of participants that were not specifically discussed in this chapter but have been presented in the results chapters.

*Table 19: Summary of Spiritual Needs Met Compared to Kellehear's Model of Needs*

| Identified Need (Kellehear, 2000) | Met by Family Meeting Intervention |
|---|---|
| Situational Transcendence: | |
| Purpose | Yes – have achieved something meaningful, have made a contribution |
| Hope | Yes – especially hope for better ways of relating in the family because of new understanding |
| Meaning and affirmation | Yes – in what they had achieved, in how they were valued by family members |
| Mutuality | Yes – better understanding of self and others & awareness that they were not alone |
| Connectedness | Yes – stronger bonds and awareness of common experience |
| Social presence | Yes – greater awareness of support for and from each other |
| Moral and Biographical Transcendence: | |
| Peace & reconciliation | Yes – varying degrees of this although not as much as some had hoped |
| Reunion with others | Yes – for at least 3 of the families |
| Prayer | No - prayer was not a part of these family meetings although it could be if wanted by the family. |
| Moral and social analysis | No - specific examples of this in these family meetings although possible if desired |
| Forgiveness | No - specific examples in these meetings although it was implied by some reunions |
| Closure | Yes - many things said that would have been unsaid brought closure |
| Religious Transcendence: | |
| Religious reconciliation | Yes - particularly for one participant who felt re-orientated to their spiritual perspective |
| Divine forgiveness and support | No - not specifically identified but was implied and could be more specifically discussed if participants wanted this. |
| Religious rites/sacraments | Yes - in a broad sense in some of the meeting closures. Certainly possible to include them if families wanted it. |
| Visits of clergy | No - not in the traditional sense. Clergy may well facilitate such a meeting (and this case did) but their role is that of facilitator and not as clergy specifically. |
| Religious literature | No - religious literature would not normally be available in the context of this type of meeting although it could be for families with specific religious needs, who requested such information. |
| Discussion about God, eternal life and hope | Yes - when this was raised by the participants. |

It can be seen from the above table that eleven of the eighteen identified spiritual needs were met by this intervention for at least some of the participants. In two of the remaining needs i.e. forgiveness and divine forgiveness and support, although they were not specifically identified as having been experienced they were implied in some of their stated experience. The other five spiritual needs identified by Kellehear (2000), most of which are more specifically related to religion, were not identified as having been met (or not met) by the participants of this study. During the meeting the participants were given the opportunity to raise religious matters if they wished. As the facilitator of these meetings I believe that these needs could have been met, and that I would have felt able to facilitate their meeting, if members of the participating families had indicated a need to discuss these issues.

It can be concluded that the spiritual needs which were identified by the participating patients and family members were met and that this family meeting has the potential to meet the other needs identified in Kellehear's model, if they are in fact needs of the participating family.

As indicated in Chapter 1 the researcher and facilitator of the family meetings implemented in this study is an ordained clergy person within the context of a particular Christian community. As far as I know none of the families were aware of this. At all times questions about whether I had a religion were answered honestly with the following response:

"Yes, I am an active member of a Christian community but I have a broad view of spirituality, recognising that religion is a part of spiritual expression for some people and not for many others. My purpose in this study to look at spiritual needs in what ever way you understand those to be. I certainly will not be promoting any particular religious point of view. Religious issues will be discussed only if you raise them."

Patient twelve, who was adamantly atheistic in his spiritual stance, checked this out thoroughly before agreeing to participate. Both he and the participating members of his family experienced what they regarded as valuable outcomes from the family meeting experience. One example is that every member of this family who participated in the meeting indicated that things had been said that would not otherwise have been said and that a greater degree of mutual understanding and some closure had been achieved through this. These experiences fall within the criteria of spiritual needs as defined in this study.

It could be argued that when the facilitator of the family meeting is a clergy person there is a possibility that something is added in terms of ‘a visit from clergy’ that might not otherwise be present but such a discussion is beyond the scope of this study. It is appropriate to conclude that ‘visits by the clergy’ in the traditional understanding of that, were not provided within the context of these particular family meetings.

It became apparent to me as the one on one interviews progressed, although it was not specifically identified by any of the participants, that the needs of some individuals to speak one on one with someone, perhaps particularly someone outside the family group, had not been met by the implementation of the family meeting. A number of the participants raised issues during the interview that had not been raised during the family meeting or had only been mentioned in passing during the meeting, and which were not a discussion of the experience of outcomes of the meeting as they saw those. In some cases it was clear that these matters had been things they thought about only after the meeting and so in a sense were an outcome of the meeting in that they were possibly stimulated by their experience of the meeting. In other cases it seemed likely that the interviewee felt they couldn’t or wouldn’t raise these matters in front of the other members of the family. It would seem that the family meeting does not eliminate the need for some patients and family members to have the opportunity for one on one discussion of some areas of spiritual need with a suitable person. This is certainly consistent with the findings of Sherman, McSherry, Parka, Calabrese and Gatto (2005) who found that patients and caregivers were much more willing to “just talk” than they were to fill out questionnaires (p172).

Two participants, both male family members, stated that the family meeting had not met their needs because it did not discuss issues of medical treatment or the subject of wills. They had been expecting a more structured meeting style that included discussion of these matters. There are of course implications here that these participants were not clear about the purpose of the meeting. While it is certainly important that these particular needs are met, they are not spiritual needs as defined in this study, and were therefore outside the scope of this particular style of family meeting.

## What are the Implications for Inclusion in Regular Palliative Care Service? - What Works?

It can be seen that the family meeting model as proposed by Murphy (1999), depending on the skills and the views of the facilitator, may not cater for all spiritual needs of all patients and family members. In this study spiritual needs, as they were expressed by the participants, were met. In particular these participants experienced a greater degree of openness, a range of emotions that they were able to express or verbalise, new understandings of themselves and other family members and improved relationships within the family. It is of particular note that the majority of all patient and family member participants found that things had been said that would not have otherwise been said which resulted in greater closure and understanding.

These results suggest that for some families at least, this style of family meeting ‘works’ in meeting important spiritual needs, some of which are apparently not being met by other services available to the participating families.

## Promoting and Recruiting for the Family Meeting

The promoting and recruiting methods used in this study can be considered to have worked if they were successful in recruiting a range of family types at an acceptable recruiting rate.

As discussed in Chapter 4 participants for this study were recruited from among patients who were registered with one of two metropolitan palliative care services. Service 1, through which the recruiting process began and continued for a period of twelve months, has about 1,300 new registrations each year. Service 2, which was involved in recruiting for the study for only the last three months of the recruiting period, has about 1,200 new registrations each year. The senior staff of both services indicated that a very high percentage of their registered patients would meet the selection criteria for this study, although in service 2 there were more patients who were not eligible because they did not speak English. The approximate total number of patients available for consideration of referral during the recruiting period was about 1,600. Only sixty-six referrals were made and this represents a referral rate of about 4%. This is comparable with the study of Ewing et al. (2004) in which attempts to identify patients through primary health care providers, for participation in a palliative care study resulted in referral of 4.2% of the estimated potentially eligible population.

In this current study successful recruiting of those patients referred also proved to be challenging. The overall recruiting rate of those approached was 23.7% being 16.3% for Service 1 and 31.3% for Service 2. Reported recruiting rates in palliative care studies vary considerably. Hopkinson, Wright and Corner (2005) reported rates as low as 17% for survey type studies. On the other hand, Chochinov et al. (2006) reported a success rate of 87% in recruiting palliative patients to a study requiring participants to rate their personal experience on a 22 item scale. A range of figures have also been quoted for studies involving interviews with palliative patients. Examples of these are:

Emanuel, E., Fairclough, Wolf, and Emanuel, L. (2004) 87.4% of a possible 1131 patients were interviewed and Tan (2005) 13 of 21 referred agreed to an interview (57%). Although the recruiting success rate in this current study seems low by comparison to most of those quoted above it is also more complex than any of these, involving the agreement of the patient and at least one of their family members to participate in a family meeting, as well as in an individual in depth interview.

The recruiting processes of this study can be considered to have worked in that they resulted in a suitable number of recruits for the purposes of this study. However a higher referral and recruiting success rate may have been possible and certainly would be more economical in terms of both staff and researcher's time. Factors which may have resulted in a recruiting are discussed below.

### Impact of Human Research Ethics Committee Requirements for Study Approval

Some studies (Ewing et al., 2004) have pointed to inconsistencies and over control by human research ethics committees as inhibiting factors in the successful recruiting of representative samples in palliative care studies. This cannot be regarded as a significant factor in this study. The study protocol was approved by four different ethics committees. In two cases the chief researcher and one of her supervisors was asked to personally attend a meeting of the committee to answer questions. In one case it was clear the committee was relieved to be able to personally meet the person they were "about to let loose on such a vulnerable population." The only possibly inhibiting factor identified in relation to ethics approval of the study is related to the requirement that patients only be approached for the study after referral by medical staff. Factors related to the difficulties of this process will be discussed shortly.

## Staff Application of Selection Criteria

As described in Chapter 4 it became apparent during the study that staff members were applying selection criteria that were not part of the study protocol. As this was perceived as potentially having considerable impact on the type and number of recruits for the study, the issue of how staff members made their decision about who to refer was discussed in the staff interviews. The results of these discussions are reported in Chapter 10. It is clear from these results that reasons given by staff members for considering criteria other than those set down by the study protocol fell into two main categories; those related to the system in which they work and those related to personal attitudes and beliefs.

The system factors cited by participating staff that were seen to have impacted on the likelihood that staff consider a patient for referral were; heavy work load and the fact that psychosocial and spiritual issues were seen to be outside the standard medical model and therefore at best took a much lower priority in the thinking and consciousness of medical staff, even though these same staff when filling out a demographic questionnaire indicated that they thought spiritual care was ether “very important” (the majority) or “important”. Ewing et al. (2004), Chibnall, Bennett, Videen, Duckro and Millier (2004) and Ling, Rees and Hardy (2000) also cite these issues as inhibiting factors in the recruitment of palliative care patients to research studies.

Differences in the ‘systems’ of the two participating palliative care services (identified in Chapter 4), in relation to the following factors were also observed: culture in relation to research, personal introduction of the researcher to the potential recruit by the referring staff member, attendance at team meetings by the researcher, and the degree of information the patient received about the study before being approached by the researcher. This latter factor ranged from ‘cold calling’ (the patient un-aware that they had been referred to a study) to contacting patients who had already really agreed to participate in the study as a result of the information given to them by referring staff.

Service 2 included the researcher in regular team meetings, personally introduced the researcher to each potential recruit and in every case gave the patient some information about the study prior to introducing the researcher. In Service1 the first of these two factors did not occur at all and the third one only in a minority of referrals. As numbers were low and recruiting in Service 2 took place over a three month period compared to twelve months for Service 1, it is not possible to be conclusive. However, the fact that the recruiting rate (the number who agreed to participate versus the number approached) was twice as high in Service 2 would certainly suggest that the ‘system’ differences between the two services may have had an impact on recruiting success rate.

Staff reported during the interviews that their attitudes and beliefs about death, spirituality and peoples’ willingness to speak about these things had an impact on their decisions about who to refer to the study. These factors fell broadly into two areas; those relating to protecting the patients and those relating more to protecting themselves. There was no difference observed between the two services in relation to these factors. Non medical based decisions were made about what type of family would benefit from the meeting, be most likely to say yes, be able to handle the family meeting and what type of family would be likely to regard it as intrusive. Some staff members claimed to make these decisions on a gut or intuitive level.

Some of these criteria which were applied can be regarded as paternalistic or overprotective of patients. Ewing et al. (2004) and Sheman et al. (2005) describe this attitude of staff as being an impacting factor on both the type and the number of recruits in research involving palliative patients. This does raise issues of ethics which are broader than the beliefs and attitudes of individual staff members. Miller and Wertheimer (2007) , in their discussion of paternalism in research ethics, argue that the ‘overall structure of research regulation is paternalistic’ (p.27). They also claim that some paternalism is justified but never-the-less does impact on recruiting outcomes. An example that would apply in this current study is the nature and content of information sheets. Ethics committees in their attempts to protect patients, assess protocols for risk, sometimes, without adequate information – for example adopting the view that talking about death would be too upsetting for patients when current literature actually indicates the opposite (Emanuel et al., 2004; Takesaka, Crowley & Casarett, 2004). In their attempts to assist the autonomy of patients in making choices about their involvement, they insist on large amounts of information being included in information sheets that either the patient may not want to read or does not really understand.

Miller and Wertheimer (2007) also discuss the concept of soft and hard paternalism. A decision that restricts the autonomy of a patient (such as deciding not to tell them about a study) is defined as 'soft paternalism' if it is based on an evaluation of impaired ability to make decisions. In the case of this study an example would be the selection criteria set down in the protocol excluding those considered medically unable to participate in a family meeting or cognitively impaired and unable to give informed consent. In the view of Miller and Wertheimer (2007) such paternalism is justified. Hard paternalism on the other hand, is seen as restricting the choices of someone who is capable of autonomous action, in the guise of protecting them from perceived dangers of their voluntary decisions, against their will or consent. The decisions of staff participating about which patients to inform about the study, which were described above, can be seen as an example of 'hard paternalism' and in the view of Miller and Wertheimer (2007) are unjustified. Whether justified or not there would be little doubt that such selection bias did impact on the representative nature of the participants of this study.

In this study there was also some evidence that other factors impacted on staff members' readiness to approach potential participants about the study. Some staff stated they felt inadequate about discussing matters relating to spiritual care, couldn't imagine that patients would want to talk about dying or were reluctant to promote something which was as yet unproven. Hopkinson, Wright and Corner (2005) also describe such inhibitions. One participating staff member, in this current study, stated that their focus on ‘those that they considered likely to say yes’ was motivated by the time restrictions imposed by the study. In other cases, although they were not clearly stated, there were implications of concern about rejection and also the possibility that approaching someone who turned out to be uninterested may impact on their relationship with the patient. These factors can be seen to affirm Murphy’s (1999) assertion that both for their own well being, and for their ability to offer truly holistic palliative care, it is vital for staff members to be at peace with their own spirituality and the concept that death eventually comes to us all, rather than being something ‘that is the ultimate enemy, to be either defeated or denied but never indulged.’ (Chibnall et al., 2004, p.421)

## Could Recruiting in this Study Have Been Improved?

There remains the question of whether these factors impacting on recruitment can be overcome in future research and whether there are features of this current study which could have been better managed to improve recruiting outcomes. As the researcher I found that usually the only opportunity to personally explain the study to family members occurred if one or more family members were present when I first approached the patient about the study or when I followed up this first visit to hear the patient’s decision about their involvement. Information sheets were always left for family members but it was apparent that in some cases family members came to the meeting very unclear about the purpose of the meeting. It is quite likely that in many cases family members did not read the information sheets and made decisions about their involvement based solely on the information passed on by the patient. In the context of a study, this situation could probably only be improved with a greater commitment to involvement by the staff who are more likely to have access to members of the family.

Sherman et al. (2005) reported that staff members became more invested in the research project when the researcher developed collegial relationships with them. In their study this was achieved by meeting with staff to inform them fully about the project and providing updates from time to time. In this current study, this process of informing staff was undertaken in both participating palliative care services involved. The development of a collegial relationship was made much easier in Service 2 by the invitation to be included in the regular team meetings and by personal introductions by staff to the referred patients. This was supportive for the researcher, but also may well have had a favourable impact on referral rates and recruiting outcomes considering the differences between the two services in relation to referral and recruiting rates which have already been discussed above.

Steinhauser et al. (2006) in their two year longitudinal study of seriously ill patients and their carers identified three factors which increased recruitment and retention of participants. It was found that if researchers first of all accessed hospital data bases to ascertain which patients met the selection criteria as laid down by the protocol, and then approached physicians with a personal letter of recommendation to the patient for their signature, recruitment rates were higher and samples were more representative. This process did not remove the physician’s right to decline to sign any particular letter on any criteria they chose to apply. This approach, had it been applied to this current study, may have resulted in improved outcomes compared to being dependent on medical staff suggesting who would be a suitable recruit.

Another finding of Steinhauser et al., (2006) was that immediate attempts to establish participant – interviewer rapport improved outcomes of recruitment and retention. As has been discussed in Chapter 4 all patients referred were approached quickly in this study and every attempt was made to rapidly develop rapport with potential participants. It is certainly probable however that the personal letter from the physician approach, utilized by Steinhauser et al. would have resulted in improved outcomes compared to the ‘cold calling’ that took place for many referrals made by Service 1. It was also found by Steinhasuer et al. that enrolling carers as study participants rather than having them occupy the role of gatekeeper was beneficial in recruitment and retention. As this current study involved implementing family meetings carers were automatically potential participants. There was, however, evidence in some cases, as indicated by the number of patients keen to be involved but whose family members decided it would be too much for them (Table 9, p.84), that they did sometimes act as gate keepers. This can be seen as another example of paternalistic behaviour and the possible imposition of personal preferences on those who are in a dependent position.

Apart from the above, other reasons given for not participating were; that talking in a group was too threatening, there was too much on and they wouldn't benefit. These are similar to reasons for non participation identified by Sherman et al. (2005) which were presented as 'too much stress' and strained or conflicted relationships'. In the current study only two potential participants openly identified family conflict as a reason for not participating, although it could be speculated that other reasons given could have in some cases been a cover for family conflict. Some participating staff also gave family dysfunction as a reason for not referring some patients and so some families with conflict did not get the opportunity to consider participation.

Although the recruiting and referral methods utilised in this study were successful in obtaining sufficient participants within the required time frame, and these families came from a range of socioeconomic backgrounds, culturally they were very homogenous. There is also evidence that the use by staff members of criteria other than those set down in the protocol, resulted in selection bias.

## What are the Implications for Inclusion in Regular Palliative Care Service? – Promoting and Recruiting

Two issues arise from the above discussion about the recruiting and promoting processes of this study which have implications for the possible inclusion of this family meeting model into regular palliative care services.  These are; ‘to whom would it be offered?’ and ‘how would it be promoted within the service?’

The majority of the patient and family member participants indicated that the opportunity to have a family meeting of this type should be made available to all families although a few of these participants were particularly conscious that it would not be suitable for all families – some would not benefit from it and others for various reasons would not be able to deal with it – and that the patient’s wishes should always be respected.  Four other participants indicated that it should be offered in special circumstances only, such as for families that didn’t talk to each other or for families that had special problems.  The remaining participants did not comment on the implementation of this model into regular services. It is of particular interest to note that of the participating members of the most overtly dysfunctional family taking part in this study, three-quarters were quite clear that it should be available to everyone.  In this case though, it was the determination of the patient that ensured this particular meeting took place.  He expressed his confidence in its value very strongly.

> If we had something like this, if it’s not mandatory but that it is easy to access meetings like this to everyone, I’ll die feeling better. (P5 para.188)

This view that a family meeting of this type should be generally available is certainly supported by experts such as Kissane and Bloch (2002); Nadeau (1998) and Waldrop, Milch and Skretny (2005) whose work in recognising the value of working with family units, rather than just the patient, has already been reported in Chapter 2.  Kissane and Bloch, however, do also indicate that some particularly dysfunctional families may not have the skills to benefit from a family intervention so a means of identifying those who would benefit would be desirable.

As reported in Chapter 5, one of the specific questions raised with participating staff members during their semi-structured interviews was “What would be the benefits/drawbacks to offering this type of family meeting as part of the regular service?” Every participating staff member indicated that it would be a good thing to be able to offer this service to patients and preferably to make it a ‘normal’ part of the service. Most, however, indicated that due to current staffing, current funding, and the fact that in the current medical model it would not be a high priority, decisions would have to be made about who to offer the service to, as well as the number of meetings offered per family and the timing of these meetings in relation to the disease projectory. In this working climate, an appropriate screening tool to enable the identification of those families most likely to benefit from this intervention would probably be helpful, if such a tool were available. The Family Relationship Index (Kissane & Bloch, 2000), which identified those families most likely to benefit from family therapy, in relation to bereavement outcomes, could be further investigated for its possible usefulness in this context.

Implications for promoting this type of family meeting within the regular palliative care service were commented on by patient, family members and staff participants. The general consensus of opinion among those who commented was that it should be promoted as a ‘normal’ part of the palliative care process and something that, although voluntary, was recommended. The suggested method of promotion was, simple and clear information about the purpose of the meeting, making it clear it was not religious in nature. This latter point is also consistent with the findings of Sherman et al. (2005) who reported that participants did not want to be asked about God (p.171). It was suggested that this information be included in printed material about the palliative care service but that it also be personally promoted to patients by staff. This is relevant to the discussion above about the seemingly greater success rate in recruiting which was associated with personal introduction of potential participants to the researcher by staff. It would also be consistent with the findings of Steinhauser et al. (2006) that a letter of personal recommendation by the physician resulted in higher recruitment rates.

It is apparent that the main issue in implementing this family meeting in the regular palliative care service, in view of current funding and staffing levels, would be deciding which patients to offer it to. It is clear that although simple written descriptions of what is to be offered are needed, a very important element in promoting such a service would be the personal recommendation of staff involved in the patient's care.

## Meeting Facilitation

The meeting facilitation process can be considered to have worked if the participants of the family meetings reported feeling comfortable with it, and/or found it helpful, and if the family meeting facilitator was comfortable with the process and was able to handle any difficulties that arose.

Some of the patient and family member participants commented on the facilitation of the meeting and how that had impacted on their experience.  These participants came from eight of the participating twelve families.  Comments included: very good rapport, gentle approach, relaxed style, no pressure and problem areas handled tactfully.  Only two participants identified things that had been a problem for them which were expressed as 'person X needs gagging' and 'some of the silences were too long'.  The remaining participants did not comment specifically on how the meeting was facilitated.  There are a number of possible reasons for this which include; the fact that most of those who did comment had some professional background which would give them a consciousness of meeting facilitation processes and the impact it can have on outcomes. Perhaps the rest didn't have this type of awareness and their experience may have been neither great nor bad in relation to facilitation and so did not merit comment. Another possibility is that their experience was negative in that regard and they did not want to offend the researcher by making comment.

## Facilitator Skills

A few of the participants, all of whom had commented on the facilitation process, also identified qualities which they had observed in the facilitator which they considered to be essential for the success of such a meeting. These included: a manner that gains trust quickly and draws people out, perceptiveness and sensitivity to touchy issues, being adaptable to different families, an ability to make people feel comfortable in what could be a very uncomfortable situation and the value of having an outsider as facilitator. More than half of the participating staff members also commented on qualities that they perceived would be needed for the task of facilitation. Interestingly the only two mentioned which were not also identified by patients and family members were; ‘aware of own spirituality’ and ‘specialist family skills’.

Some of these qualities, such as the ability to develop rapport and trust, perceptiveness and sensitivity are well accepted as necessary for working with people either in groups or with individuals and were also identified by Steinhauser et al. (2006) as qualities likely to result in better outcomes in palliative care research. The value of the facilitator of the family meeting being able to stand back a bit from the emotional issues of the family, and of the vital nature of them being aware of their own spirituality and issues around death, was certainly heavily emphasised by Murphy (1999) in his discussion of the family meeting model. Skalla and McCoy (2006) also stressed the need for staff members in palliative care services to explore their own spirituality, whether working with individuals or family groups. The need for family therapy skills (which are more complex than those needed for working with individuals alone) was certainly stressed by Kissane and Bloch (2002) in their discussion of the training and experience of the therapist in relation to their Family Focused Grief Therapy Model.

## Impact of Researcher Being Both Facilitator and Interviewer

As discussed in Chapter 5, in this study I was both the facilitator of the family meetings and the interviewer. While it has already been argued that this process is not a breach of the rigour of the study it is pertinent at this point, from the perspective of what worked for the facilitator, to consider my personal experience of meeting facilitation as well as considering any possible impact of this on the participants reporting of their experience of meeting facilitation.

I found that facilitating family meetings of this nature was a very demanding but rewarding experience. As facilitator I was exposed to, and trusted with, some very intimate and painful stories as well as some very uplifting stories of courage and achievement. I was aware that my personal resources of awareness of my own spirituality and its expression, as well as a sense of peace about my own mortality served me well. I am certain that for anyone doing this type of work on a regular basis such resources would be essential to their own well being. My training and experience in counselling and in working with families were also very important elements in my confidence that I could do this work, in my ability to handle the difficult parts and I think in my apparent success in aiding at least some of the participants to feel at ease and to open up in a way that they would not have otherwise done. It is hard to be certain if those who did not comment on the meeting facilitation did not do so because they did not want to cause me offence. Factors such as body language during interviews, and the willingness on the part of some participants to express negative views about other parts of their experience of the family meeting, are certainly not conclusive but would suggest that protecting me as the facilitator was probably not a common feature.

### What are the Implications for Inclusion in Regular Palliative Care Service? – Meeting Facilitation

It is apparent from the above discussion that the success of the family meeting, in the opinion of some of the participants, was due in part, to certain qualities and skills of the facilitator. The importance of these qualities has also been supported in the literature. It follows then that if this family meeting model were to be implemented in regular palliative care services that facilitators would be needed who demonstrated these qualities and skills. As already discussed the majority of the participating staff members were aware of the need for these things, and in some cases considered that many staff members would be ill equipped for facilitating such meetings. The raising of the generalist versus specialist debated by two different staff members (Chapter 10) would raise the question as to whether those promoting the generalist view – the family meeting be facilitated by who ever happened to be on the scene when the need for one was identified – really understood the qualities and skills required.

The outcomes of this study suggest that if this family meeting model were to be implemented in the regular palliative care service, attention would need to be given to what skills and qualities would be needed for successful facilitation, and what training would be required for staff involved in the facilitation.

## For Whom Does it Work?

The stakeholders in this study were palliative patients, their family members, staff and the meeting facilitator who in this role acted as pseudo staff. Consideration must be given to the question, ‘Did the family meeting model work for each of these stakeholders, as they were represented in this study?’ It is also necessary to consider how representative the study group was of the relevant population should this model be implemented in the regular palliative care system and the degree to which the experience of those participating is generally applicable.

## Patients and Family Members

To some extent, in the presentation of results in Chapters 7, 8 and 9, and in the discussion above of what worked for the particular participants of this study, the issue of ‘for whom did it work?’ has been addressed. It is apparent that most of the patients and family members experienced positive outcomes of the family meeting in one or more of the following areas: spiritual needs were met, increased openness, opportunity to recognise and express emotion, new understandings about self and other, improved relationships and a good experience of meeting facilitation.

The demographic data presented in Chapter 4 and the geno grams and family profiles provided in Appendices VII and VIII respectively, also provide background information about individuals and families. This data is descriptive in nature being derived from researcher observations during the family meetings, in depth interviews in which this information was not specifically sort, and on informal discussion in preliminary meetings. The number of participants is also relatively low and so it is not possible to draw conclusions about the relationship, if any, between individual or family characteristics and outcomes of the family meeting. However, there are some observations worthy of note.

An examination of the results of this study suggest that a family’s own estimate of its closeness and degree of openness in communication are not reliable guides to the likelihood of members of the family experiencing greater than normal degree of openness in themselves or others during the family meeting, or to whether they are likely to come to new understandings about themselves or others as a result of this meeting. For example, none of the families considered themselves as openly expressing emotions, although some did have family cultures that made it alright for some, e.g. females to be emotional, but not others. This is consistent with the concept positive self-presentation and impression management (Michener, DeLamater, & Myers, 2004). The results show that most family members, of eleven of the twelve participating families, experienced what they considered positive emotions or feelings, observed unusual expressions of these in other family members or experienced what they considered to be negative emotions but ones that were necessary or at least appropriate in the circumstances. The question then arises, ‘Could there be a reliable way of determining which families would most benefit from this intervention which works with a very subjective area of care?’

Kissane and Bloch (2000) reported that 50% of families, on the basis of their family functioning, are at risk of maladaptive outcomes of bereavement. In their study, family functioning was measured using the Family Relationship Index Scale with focus on the attributes of family cohesiveness, expressiveness and level of conflict. They also stressed that in some cases minority views, for example expressed by one member of the family only, at times turned out to be the most accurate estimate of family functioning and should not be discarded when determining family risk of maladaptive outcomes. Unlike the study of Kissane and Bloch, which focuses on adaptive outcomes to bereavement, this study focuses on the provision of spiritual care, so no direct comparisons can be made. However, as has already been suggested, it is possible that the utilization of the Family Relationship Index, which Kissane and Bloch recommend for routine use for all palliative patients and their families members on registration with the palliative care service, may give a reliable guide to which families would benefit most from a family meeting such as the one assessed in this study. Further investigation of this issue is needed.

Although, in this current study there was a range of families from the perspective of socio economic status, (viewed from the perspective of type and location of housing, employment type and educational levels) religious expression or lack there of and evidence of family conflict, there appeared to be no relationship between these factors and positive outcomes from the family meeting as they have been described.

Another area of interest in relation to which patients and family members are most likely to benefit from this type of family meeting, is the nature and characteristics of those who declined to participate in the study. Reasons that were given, although for ethical reasons these could not be actively solicited, are summarised in Table 19. It is certainly possible to surmise that poor family communication, low cohesiveness; low levels of emotional expression and family conflict may have been contributing factors to the decision not to participate, in some cases. However definite conclusions cannot be drawn from these results.

It is clear that the family meeting as implemented in this study had beneficial outcomes in the general area of spiritual needs for most of the patients and family members who participated in this study, although it is not possible to identify particular characteristics which would be predictive of positive outcomes.

## What are the Implications for Inclusion in Regular Palliative Care Service? – Patients and Family Members

On the basis of the outcomes of this study it would seem that the best option would be to offer this type of family meeting opportunity to all patients who register with the palliative care service, recognising that some would certainly decline to take up the offer and that some who did would not necessarily experience dramatic benefits. However, in a health system, which is struggling to maintain current levels of service, it is unlikely that extra staff would be employed to enable this intervention to be offered to all patients. Of course it can be argued that an intervention that may in the longer term reduce the need for individual therapy could save money. If further work was done to determine which families would most benefit from such an intervention, such as developing a suitable screening tool, which could be simply applied as part of regular admission data collected, this intervention could be more easily applied in the present health care system. While many positive experiences and outcomes were identified by the participants of this study, there is no information about longer term outcomes for surviving family members. No doubt an evaluation of the cost effectiveness of this intervention would need to include an investigation of the long term outcomes.

Another factor that would need to be considered when further evaluating this model for routine use is the issue of whether the intervention is limited to one family meeting only, as was the case in this study, or if more than one is offered. In this study almost half of the participants (from nine different families) indicated an interest in having more than one meeting while only four indicated that it would not serve any purpose for them. Again in terms of cost effectiveness, criteria other than the families' willingness to participate in further family meetings, may need to be applied.

## Staff

To some extent the issue of whether or not the family meeting intervention worked from the perspective of staff, has been addressed in the discussion of 'what worked'. To the limited extent to which staff members received feedback from patients and family members or were able to make observations of their own, they considered that it worked from the perspective that it did no harm and in some cases may have been responsible for definite positive outcomes. The overall view was that this family meeting was a very good and useful intervention.

Matters relating to the promotion of the family meeting and recruitment for this study have been discussed at length in the section of this chapter entitled ‘What Worked’ under the section ‘Promoting and Recruiting for the Family Meeting’. For some of the participating staff members the recruiting and promoting aspect of the study could be considered not to have worked in that they found it difficult, uncomfortable and they decided to utilize selection criteria other than those laid down by the study protocol. More than half of the participating staff members indicated that for a variety of reasons they would have found it easier to approach patients and family members about the family meeting intervention if it had been part of the regular service offering, rather than a research study. Their discomfort was related more to conducting research with this population than to the nature of the intervention itself, although a few did demonstrate personal discomfort with speaking about death and spiritual matters, considering them very personal issues that most would not want to talk about in their family group. Some of the staff participants made no comment on whether offering this intervention as a study was more difficult than it would have been if it were are part of the regular service.

## What are the Implications for Inclusion in Regular Palliative Care Service? - Staff

Although staff members generally considered this family meeting intervention to be one which would have positive and necessary outcomes for patients and family members, a number of implications for its inclusion in regular service were raised. As discussed in the section about the qualities required for meeting facilitation, the participating staff members were very aware that good self awareness in relation to their own mortality and spirituality and some specialist skills would be required for staff working as facilitators of these family meetings. Staff self care would also be an important factor. These observations are not only consistent with the views of Murphy (1999) who developed this model, but have also been identified by Sherman et al. (2005) and Steinhasuer et al. (2006). In practice, if this intervention was implemented within the regular palliative care service, care would need to be taken that staff who take on the role of facilitators, although not necessarily coming from any one particular professional role, are trained in the necessary skills and personal attributes that have been identified as making effective and safe facilitation possible for both participating patients and family members and staff facilitators.

## In What Circumstances Does it Work?

The differing circumstances possibly impacting on outcomes, about which some data are available in this study, are the location of the patient at the time of referral (home/hospital/hospice) and the cultural environments of the two palliative care service providers. Other circumstances which may have impacted on the outcomes, apart from family nature and characteristics which have already been discussed are; the nature of the illness (malignant or non-malignant), the time since diagnosis and the prognosis of life expectancy from the perspective of the patient and family members. A few patient and family member participants did comment on the best timing for the meeting in relation to illness trajectory, but in general this study did not provide data relating to these latter circumstances.

### Location of the Patient at the Time of Referral

The recruitment success rates, as they relate to the location of the patient at the time of referral, are presented in Table 4. For the participants of this study, patients who were at home at the time of referral were approximately twice as likely to agree to participate as those who were in a hospice and about three times more likely to participate than those who were in hospital. Five of the participating patients are known to have died within two weeks of the family meeting intervention. Three of these were in a hospice at the time of referral and two were at home. These factors, although certainly not conclusive, numbers being too small to have statistical significance, suggest the possibility that willingness to participate may be improved for patients living at home, but would seem to be unrelated to imminent death. It could be speculated that the increased success in recruiting patients who were living at home could be attributed to them feeling more comfortable and at ease in their own home and more comfortable inviting family members to participate in a familiar setting. On the other hand some patients may well consider that having a stranger facilitate such a meeting in their home to be an invasion of their privacy. Sherman et al. (2005) in their longitudinal study of palliative patients (both those with cancer and those with AIDS) recruited and collected data from inpatient residential facilities, outpatient clinics and patients' homes. They provide no data relating to the relative success in recruiting and data collection in these differing circumstances, although they found that some patients recruited as in-patients, on discharge were likely to drop out of the study. The increased involvement of participants in other activities once discharged was one of the reasons offered for this lack of continuation in the study. Difficulties experienced in contacting patients at home were also cited as a problem.

### What are the Implications for Inclusion in Regular Palliative Care Service? – Circumstances

There is insufficient data relating to the location of the patient at the time of referral and the likelihood of them agreeing to a family meeting to draw any conclusions about the impact of location if this intervention were to be included in regular palliative care service.

## Palliative Care Service Provider Environment

Factors which contribute to the 'environment' of the palliative care service provider such as staff attitudes to spiritual care, care priorities, attitudes to patients – whether paternalistic or autonomous, staff time availability, staff training, attitudes to research in palliative care and budgetary considerations have all been discussed in this chapter. Both the participating palliative care services are part of the public system in the same city, so it is probable that over all policy and budgetary issues are similar for both providers.

As already presented, differences were however observed in relation to research culture, willingness to be involved in terms of including the researcher in the team, personally approaching patients and giving personal introductions of the researcher to the patient. A higher percentage of those referred were recruited in the environment which provided these circumstances compared to the one that did not. Again low numbers do not allow for definite conclusions. There is no evidence in this study that there was any difference in the outcomes of the family meetings for patients and family members recruited by the two different services.

### What are the Implications for Inclusion in Regular Palliative Care Service? – Service Environment

These findings, although not conclusive, suggest that the implementation of this intervention in regular service would more likely be successful in an environment where the intervention was supported by team members, where clear guidelines about referral to this program were available and adhered to, and where there was sufficient funding for appropriately trained staff to have sufficient time to implement this intervention.

## Summary

In this chapter the outcomes of the study have been discussed from the perspective of what worked, for whom and in what circumstances. The implications, if any, for the implementation of this family meeting model in the regular palliative care service have been considered.

For the patient and family member participants of this study the family meeting model as described by Murphy (1999) and implemented in this study was successful in providing opportunity for the meeting of most spiritual needs as identified by Kellehear (2000). The most commonly identified outcomes for patient and family member participants were: an experience of increased openness of communication – particularly the opportunity to say things that would not have otherwise been said and to review life stories, positive and constructive feelings and emotions were felt and expressed, new understandings were gained and significant relationships were strengthened and renewed. Their experience of the meeting facilitation was generally positive. These outcomes suggest that although the participant sample cannot be regarded as representative, due to the recruiting issues discussed, for those who participated spiritual care was provided that had not been made available to these people in the current system.

Staff data suggest that the family meeting as implemented worked for patient and family participants where feedback was available. Staff generally considered that this model would add value to patient and family care but raised a number of significant issues related to the practical implications of including this model in regular care within the palliative care service. These concerns included funding to provide appropriately trained staff with sufficient time to implement an intervention which they considered to be time intensive. It is evident that budgetary requirements have implications not only for staff attitudes, but for health care system administrators. The current dominance of the medical model in determining priorities within the health care system, including palliative care, result in spiritual care, while being considered important, taking a low priority for funding.

A summary of the outcomes, limitations and implications of this study are presented in the following chapter.

# CHAPTER TWELVE

# THE FINAL REPORT

## Introduction

This chapter will summarise the outcomes of this study in relation to the specific research questions identified in Chapter 1, the limitations of the study, and the implications of the study for both further research and for practice.

## Outcomes Arising From the Research Questions

### What was the Experience of Patient Participants of a Family Meeting Conducted According to Murphy's Family Meeting Model?

The major aspects of their experience of the family meeting, identified by the patient participants were:

- Life review was beneficial.
- It was good to be open and real with other family members.
- Many gained new understandings of self, of other individuals and of the family as a unit.
- Many experienced positive feelings such as feeling comfortable, pleased, appropriate and/or balanced emotions.
- It gave them a chance to make a contribution both to their own family and possibly to other families.
- They observed family benefits such as the strengthening of relationships, as an outcome of the meeting.

## What was the Experience of Family Member Participants of this Meeting?

The family member participants identified the following major aspects from their experience of the family meeting:

- The experience of being open in the way presented was difficult but was aided by the facilitation and resulted in things being said that would not otherwise have been said.
- For many the family meeting resulted in new understandings of self, other family members and of the family unit.
- Some saw it as an opportunity to make a contribution both to the patient and possibly other families in the future.
- Most experienced a range of feelings such as: warm, comfortable, supported, grateful, emotional, nervous and sad.

## What Were Staff Members' Observations of the Impact of This Meeting on Participating Patients and Family Members?

Both the feedback to staff from participating families and staff members' observations of outcomes for participating families were limited, but never-the-less positive or neutral in nature. They included:

- Some patients had less pain issues afterwards.
- Some patients and family members showed less anxiety and distress after the meeting.
- Many comments of a general positive nature such as this intervention 'should be available to everyone'.
- The lack of any negative feedback about the meeting experience was considered significant.

### What are the Stakeholders' Views about the Suitability of This Intervention for Inclusion in Regular Palliative Care Service Offerings?

Most patient and family member participants, while recognising that not all families would want to participate in a meeting of this type, considered that it should be available to all. They suggested that if it were offered as part of the 'normal' routine services available, that more families would be likely to agree to participate and so experience benefits from it.

Every participating staff member indicated that they thought this type of family meeting was very good, potentially beneficial to patient and family members and that there was a need for this to be available in palliative care services. They indicated that for practical purposes they would find it helpful to have a way of identifying those families most likely to benefit from such an intervention. Staff members also identified potential barriers to its inclusion in the regular services. These barriers included:

- A lack of availability of funding, due to priorities of the current medical model based system of service provision, would make offering it to all families impossible
- A lack of suitably trained staff with sufficient time to implement this type of intervention would also make offering it to all families impractical
- Language and cultural issues would make it inappropriate for some families.

## Limitations of the Study

Although there were some differences such as a gender imbalance among the family members, the majority of whom were female (although amongst the patients gender was fairly evenly distributed), differing socio-economic backgrounds and differing degrees of commitment to involvement in religious activities, the sample was never the less considered to be fairly homogenous. The average age of participating patients was 68.7 years (range 59-82 years) and so the experience of younger patients has not been considered in this study. The average age of the participating family members was younger (52.8 years) and the range larger (16-84 years), however, two–thirds of them were over the age of forty and only two under the age of twenty-five, so the experience of younger family members is not well represented. Only two of the participating patients had non-malignant illnesses and with only one exception all patients had been given the initial diagnosis of their disease at least six months prior to their participation in the family meeting. It is not known whether factors such as age, type of diagnosis and time since diagnosis have any impact on the experience and outcomes of the family meeting intervention. The families who participated in this study were all Caucasian, Australian born and used English as a first language. Of those who practised a religion or were nominally associated with one, all were Christian. It is clear that no conclusions can be drawn about the impact of other cultural, language and religious influences on the outcomes of the family meeting intervention.

The selection bias introduced in the recruiting process when some staff applied criteria other than those laid down in the study protocol, when referring patients to the study, possibly also contributed to the homogeneity of the sample. Those with the most obvious family dysfunction or distress about their circumstances were not given the opportunity to participate. The outcomes for these families and the challenges of facilitating meetings for them are not known. As the protocol approved by the Human Research Ethics Committees involved did not allow for any active collection of demographic data from those who were referred but declined to participate, the degree of bias introduced in the self selection process of patients referred is not clear. It is unlikely that the sample studied can be considered representative of the population that met the selection criteria as laid down in the protocol.

## Implications for Further Research

There are a number of implications for further research that arise from this study.

Further research needs to be undertaken with more heterogeneous groups, which considers the appropriateness and efficacy of this intervention for participants of differing cultural, religious and language backgrounds, as well as different age groups, especially younger people, both patients and family members.

In view of current funding priority policies within the palliative care service and the health system generally, which would likely limit availability of funding for the provision of this intervention, a screening tool that effectively identifies families most likely to benefit from this intervention may be appropriate. The Family Relationship Index, as utilized by Kissane and Boch (2000) may be a suitable instrument to trial in this context.

The longitudinal benefits of this family meeting intervention, as an instrument for the provision of spiritual care, need to be assessed to determine whether the benefits observed in this study are transient in nature or likely to improve outcomes for patients in the time of their remaining life and surviving family members. A suitable assessment tool, able to measure the possible outcomes of this family meeting intervention, may need to be developed.

## Implications for Practice

The outcomes of this family meeting intervention, for the participants of this study, were generally positive and spiritual needs that clearly had not been satisfied by other available services were met, indicating the potential for this intervention to add value to the service offered to palliative patients and their family members. Although the results cannot be generalized to the whole palliative care population and their family members, this study does add to our understanding of the value of working with family units rather than just patients as individuals, in the provision of spiritual care in the palliative care service. Working with families is likely to be more complex and time consuming than working with individuals and this presents a challenge in the current funding and staffing climate in palliative care services. This study does add to the evidence that working with family units is an important and necessary part of holistic palliative care which includes the spiritual domain and which conforms to the WHO recommendations of attending also to the needs of family members.

If further research, as suggested in the above section, did substantiate the spiritual and psycho-social outcomes of this family meeting intervention for palliative patients and their family members, there would be a number of implications for practice to be considered. These are:

- Can funding policy priorities be changed to include a service which, if definitely established as meeting identified psycho-social and spiritual needs of patients and family members, is also consistent with stated priorities of holistic care in palliative care service provision? A measuring tool which can more quickly identify the outcomes of this intervention may need to be developed to assist further research and staff in future application of this intervention to regular palliative care service.
- What training and support would be needed for the staff facilitating such meetings?
- Would such an intervention be offered to all families or only to some? If it is only offered to some families, how could those most in need be identified?

## Concluding Statement

Murphy’s family meeting model, as implemented in this study, was effective in meeting some previously unmet spiritual needs of the patient and family member participants. Most of these participants considered that this intervention should be generally available to palliative patients and their family members. Participating staff observed some positive outcomes for patients and family members that may be attributable to the family meeting intervention. Staff members also considered that this intervention was potentially very beneficial and was needed in the palliative care service, although barriers to its implementation were also identified. This study has added to our understanding of the value of working with family units in the provision of spiritual care in palliative care services. The implications for further research, which is needed to substantiate the outcomes of this study, have been described.