A LITERATURE REVIEW OF THE VALUE OF FAMILY CONFERENCES IN PALLIATIVE CARE

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1, Marietta Van Den Berg declare that this Literature review is my own work. This dissertation is part of the requirement for the M Phil. Palliative Care degree from the University of Cape Town, South Africa. This is the revised and corrected version, submitted for remarking. It has not previously been submitted for any degree or examination at any other University.

Signed: Signed by candidate

12 Day of December, 2002.

This dissertation is part of the requirement for the M Phil. Palliative Care degree from the University of Cape Town, South Africa.

I wish to dedicate this work to my husband Michael Klerck,

who entertained our kids on endless weekends,

who cooked and shopped, encouraged and supported me.

Mostly it is dedicated to him for always seeing in me

the best person I can possibly be.

SUMMARY

Terminal illness affects the family as a social group severely, impacting on all aspects of the family's functioning. The burdens and stressors experienced by families coping with terminal illness has been well described, and include physical, emotional and spiritual components. Recognising the interconnectedness of the patient and his/her family and friends, and facilitating the process of coping is the challenge and privilege of Palliative Care Teams. Family Conferences are an intervention with which to aid and facilitate the recovery of 'balance' within a family, by providing for their needs for information, support, good communication from and relationship with the Palliative Care Team.

The Palliative Care Team at 2 Military Hospital have been holding Family Conferences, but have not examined their practice, outcome, or benefit to the patient and relatives, nor compared this to common practice elsewhere. Family Conferences at 2 Military Hospital are held to educate and inform the patient and family, to prepare them for the difficult tasks ahead, and to offer support. A retrospective audit demonstrated that Family Conferences were mostly held within 3- 6 months of death. It seems that the timing of Family Conferences held in 2 Military Hospital is determined by the patients' symptoms and progression of disease, rather than as a planned intervention. This introspection led to the literature review.

The purpose of this literature review is to find, and evaluate the literature for empirical evidence regarding the value of Family Conferences in caring for dying patients and their families. The questions that guided the literature search included the time to introduce Palliative Care, whether Family Conferences are an accepted practice in Palliative Care, and whether Family Conferences form part of good quality end of life care. Literature addressing the timing, the method, the aims and value of a Family Conference, was also researched.

Family Conferences are regarded as part of good practice by Palliative Care experts. They are usually held at transitional points in the disease trajectory, those times when patient and families are expected to experience an increased need for information, support and preparation for what is to come next. The transitional points include the time of diagnosis, start of treatment, recurrence, progression of disease, or any major event in the clinical course of the illness. A central focus of the Family Conference concerns communication. The Family Conference addresses not only communication between the Palliative Care Team and patient and his/her relatives, but also communication within the family.

The guiding theory for holding Family Conferences seems to be that meeting the needs of the family may assist them through the tasks of grieving, thus improving coping skills and preventing future complications.

All parties involved in Family Conferences seem to benefit, from the patient and relatives to the Palliative Care Team. These benefits from the point of view of the patient, includes care plans based on his/her need, opening communication channels, reducing anxiety, and shared decision-making. From the point of view of the relatives the benefits from a Family Conference are an increase in the likelihood of a supportive relationship between relatives and the Palliative Care Team, more meaningful involvement in the care of the dying person, empowerment to solve problems, and preparation for the future. The Palliative Care Team experience trust and confidence in them from the family after a Family Conference, as well as increased co-operation, and an opportunity to offer additional assistance where required.

The literature appears to provide little empirical evidence to validate the use of the Family Conference, nor to elucidate the role and format of the conference. Additionally, the possible affects of the Family Conference on the patient and family requires investigation. This leads to the question of whether there are barriers to research in Palliative Care as a whole, and/ or specific problems with conducting research on Family Conferences in Palliative Care.

Various factors have been identified that complicate the research process in Palliative Care. Those factors that specifically affect research into Family Conferences include, lack of sufficient time to evaluate the benefits of the Family Conference for the family, as well as the highly personal and emotive nature of the topic.

Clearly further research into the value that Family Conferences have for dying patients and their relatives is indicated. In the South African setting, the different experiences of the Family Conference by the various ethnic and cultural groups must be taken into account, since generalising might be difficult.

CONTENTS

INTRODUCTION

2 Military Hospital is one of three Military Hospitals in South Africa and is situated on Wynberg Hill in Cape Town. It serves employees of the South African Army, Navy, Air Force and Medical Services, their dependants, as well as retired soldiers and their spouses, and veterans from the First and Second World Wars .

The Palliative Care unit is a combined Rehabilitation and Palliative Care unit, and has three core functions:

- To provide an administrative, information and counselling service to all patients diagnosed with cancer. This means that the unit receives referral/ notification letters for all patients diagnosed with cancer, but do not necessarily become involved with the patients unless they, or their primary treating doctor finds it necessary.
- To provide a comprehensive interdisciplinary Palliative Care service to patients with incurable disease, where progression of disease is expected. This includes patients with cancer, HIV/AIDS and progressive neurological disease.
- To provide a comprehensive combined interdisciplinary rehabilitation service, excluding patients with substance abuse or isolated psychiatric conditions.

Many members of the Interdisciplinary Team attend to patients requiring Palliative Care as well as those requiring Rehabilitation. There is of course also an overlap where some patients might require both at the same time, such as a patient suffering from a hemi paresis after surgery for a brain metastasis. Because of this situation, the team is familiar with Family Conferences as an educational and supportive tool as utilised in the field of Rehabilitation.

The team at 2 Military Hospital have been holding Family Conferences for Palliative Care patients and their families for the six years that the unit has existed, but have not examined the details or benefits of their practice, nor compared this with what is happening at other units.

The first step in examining current practice was to describe the circumstances under which a Family Conference is held, the method of holding a Family Conference, the expected benefits, and the feedback from patients. This was a collaborative effort involving the Palliative Care doctors, nurses, chaplain, and social worker.

On examining the possible reasons for holding a Family Conference, I realised that conferences were often held in crisis management situations, and the question arose as to the optimum time to hold a Family Conference. This question has been a point of discussion in our team, since it is my suspicion that we should be holding Family Conferences earlier in the course of the illness. Attending a Family Conference soon after the diagnosis of a colleague-patient with inoperable stomach cancer, and seeing the relief on the faces of the family members when they realised that their beloved husband and father was not being abandoned by the medical profession, but being handed from one field of expertise to another, emphasised the uncertainties regarding the timing of a Family Conference.

In order to assess current practice at 2 Military Hospital regarding timing of Family Conferences, a retrospective audit was performed on 34 patient files. This audit measured the timing of the Family Conference on the disease trajectory of those 34 patients.

The combination of the self examination and the audit allowed me a clear view of what we are doing, but not of whether our practice complies with accepted best practice elsewhere, nor whether we are enhancing the quality of life of dying patients or their families. Questions regarding best possible practice in terms of Family Conferences led to the literature review on Family Conferences in Palliative Care.

AIMS AND OBJECTIVES

Aims

1. To describe current practice at 2 Military Hospital regarding Family Conferences held by the Palliative Care Team
2. To measure the timing of Family Conferences held at 2 Military Hospital.
3. To explore, evaluate and process research evidence for empirical answers regarding the value of a Family Conference in the care of the dying.[1]

Objectives

1. To describe current practice at 2 Military Hospital regarding Family Conferences held by the Palliative Care Team by:

- Clarifying the concept of Palliative Care
- Clarifying the concept of a Family Conference
- Describing the experience of Family Conferences at 2 Military Hospital in terms of the theory, method, stated aims, and expected outcomes, as well as anecdotal feedback from patients, and/or families.

2. To measure the timing of Family Conferences held at 2 Military Hospital.

- To establish at what point in the disease trajectory Family Conferences are being held at 2 Military Hospital by:
  - measuring the time from diagnosis to Family Conference, and
  - measuring the time from Family Conference to death.

- To make deductions regarding what influences our current practice.

3. To explore, evaluate and process research evidence for empirical answers regarding the value of a Family Conference in the care of the dying.[1]

- To evaluate the literature on Family Conferences for evidence of research into outcome, validation of method, theoretical basis, and descriptions of practice elsewhere.
- To seek answers to specific questions:
    - ❖ Is a Family Conference accepted as part of good quality end-of-life-care and how has this been tested?
    - ❖ What are the role and aims of a Family Conference in Palliative Care?
    - ❖ What is the best timing?
    - ❖ Does a Family Conference improve the quality of end-of-life-care, and how?
    - ❖ Have the benefits been measured or proven?
    - ❖ What are other units doing and have they tested their practice?
    - ❖ Could we test our practice by measuring the outcome of our Family Conferences?

Families seem to gather together at the significant events on any person's lifeline, at birth, rituals of religion (christenings, confirmations, rites of passage), marriages, birthdays, and especially in times of serious illness, disability and death. These events involved the person experiencing the significant event, as well as their family and friends.[3, 4] Because families are irrevocably interested and/or involved in all that happens to a person, they should be and are increasingly included in the processes of diagnosis and treatment of various conditions.[5] One of the occasions when it is particularly relevant to include the family is when incurable illness has been diagnosed, and/or the patient is dying.[6]

Recently I attended a Family Conference arranged by our Hospital's surgeon who five days prior to the meeting had performed a laparotomy on a retired doctor in his sixties. The objective of the operation was to perform a gastrectomy for gastric cancer, but the tumour was non-resectable, and metastases to liver and abdominal nodes were discovered. The patient, his wife and daughters attended the Family Conference. Although the patient had already been informed of the surgical findings, the intention of the conference was to repeat and explain the information, and offer support to the patient and family, as well as to introduce them to the Palliative Care service.

The most powerful impression remaining with me after the Family Conference was how despair turned to relief on the faces of the patient and his family on hearing that although the surgeons could offer nothing more, there was a team who could.

Under usual circumstances we would not have met and become actively involved with the patient and his family until later, as the disease progressed and caused symptoms.

This conference led us to examine current practice regarding Family Conferences in 2 Military Hospital that has culminated in the audit and literature review. The hypothesis that stimulated the audit and literature review, is that Family Conferences can improve the quality of life of a patient living with incurable cancer, and also improve the eventual outcome for the family of such a patient. My hypothesis is also that such Family Conferences would have more value if offered as soon as possible after diagnosis of incurable illness.

METHOD

Describing practice of Family Conferences at 2 Military Hospital

The key role players, present at most Family Conferences were informally interviewed individually and asked four questions, namely what events precipitate the holding of a Family Conference in our unit, what are the aims, what is the method of holding a Family Conference and what are the benefits to patient, family and staff members. The answers were written down, compared, and then summarised. The role players interviewed included Palliative Care doctor, Social Worker, Chaplain and Nurse. The patients or relatives were not interviewed since I was trying to establish our current practice as experienced by the regular role players at Family Conferences in our unit.

Audit of the timing of Family Conferences at 2 Military Hospital

The files of all the patients that had died of cancer in the past 2 years were examined. Those that had attended at least one Family Conference (I included only formal pre-booked family conferences, not the impromptu kind that is often held at the bedside) were investigated further to establish whether the following dates were recorded:

- The date of histological diagnosis of primary incurable disease, or progression of the disease so that it became incurable
- The date of the first family conference held by the Palliative Care Team (subsequent Family Conferences were not taken into account)
- The date of death

This data was then tabulated and analysed to discover how many Family Conferences were being held within 3 months of diagnosis, and how close to death the Conferences were being held.

Literature review

Strategy for the literature study

The primary theme for choosing suitable literature was Family Conferences in Palliative Care, which yielded two articles, one by Liebman et al from 1975, and another by Miller et al from 1991. The theme was extended to include theory on Family Conferences in general, and on Family Conferences in Family Practice and Intensive Care settings where reference was made to caring for the dying, or cancer patients. This was in order to find theoretical grounding against which to measure our definition of a Family Conference as well as our practice. Additionally the theme was extended to include literature on communication with dying patients and their families, the impact of terminal illness on families and various authority's, patients' and relatives' views on the most important elements of good quality end-of-life-care. This was in order to make deduction regarding whether Family Conferences formed part of good quality end-of-life-care.

Baseline reading

The 'Bible' of Palliative Care, *The Oxford textbook of Palliative Medicine*, 2nd edition, by Derek Doyle et al (2001) contains a chapter on caring for the family of a terminally ill patient. The chapter was helpful in that it discussed communication with the family, as well as the needs of the family. However, Family Conferences are not discussed specifically, and therefore three other sources were used in conjunction with *The Oxford Textbook of Palliative Medicine*, as baseline reading. These included *Family Therapy and Family Medicine* by Doherty and Baird (1983), *Talking to Cancer patients and their relatives* by Faulkner and Maguire (1994), and lecture notes on the Family Conference, Blitz, University of Pretoria post-graduate diploma in Family Medicine.

Search Methods

The search for literature was a lengthy process conducted in stages since the initial theme gradually expanded. This was due to the scarcity of literature on Family Conferences especially with the focus on Palliative Care. The bibliographies of particularly relevant articles sometimes provided leads to other helpful articles. Additionally articles sometimes referred to concepts developed by other authors, which was then valuable to read more about. An example of this was a reference to 'Transitional points' in an article by Pasacreta et al (1998), which comes from a book by Holland (1989) on Psycho-oncology. This concept is completely new to me, and most helpful in deciding the best time to hold a Family Conference.

Database searches were performed, using MEDLINE and PUBMED on the Internet. The search terms used singly or in combination were: Palliative Care, Terminal Care, Hospice Care, Family Conferences, family meetings, quality of life, end of life issues. With the assistance of the Librarians at 2 Military Hospital, and University of Cape town, and colleagues at 2 Military Hospital other literature was located. This included textbooks, other articles, and lecture notes.

Including and excluding literature

The literature included addressed:

- Family Conferences in any clinical setting where dying patients are cared for.
- Communication with patients and their families in Palliative Care.
- Patients' & families' opinions on what constitutes good quality end-of-life-care.

The literature that was not the primary focus, but contributed towards the review included:

- The impact of terminal cancer on families.
- The timing of Palliative Care.

Literature was excluded if it did not relate in some way to the central theme of communication with the families of dying patients, and how that relates to good quality end-of-life-care. There was no defining criteria on the type of studies, hence all the literature I could find complying with the theme was included. Literature written in languages other than English or Afrikaans was excluded.

Results of the literature search

Articles and books:

Informative literature included *Family Transitions* by Falcov (1988), *Communicating with dying people* by Lugton (1987), Palliative Care guidelines from the Royal College of Physicians, an article on the impact of terminal illness on families, and two instructive articles recommending a method of holding a Family Conference. The one was in an ICU setting (Hampton Atkinson: 1980) and the other in a Family Practice setting. Although interesting neither gave insight into how the recommendations were arrived at, nor how they were tested.

Reports on other studies

Two articles reported on other studies. Tolle (1999) examined studies done previously and from them made deductions regarding what determines where people die and how satisfied the families are with the decision making process. Andershed (2001) reported on 4 previous qualitative studies conducted by the author herself, and from them developed a theoretical framework for describing relatives' involvement in Palliative Care. The latter produced a helpful concept of relatives' involvement being described as ' in the light' or 'in the dark'. The metaphor is effective, but some of the deductions made thereafter uncomfortably optimistic, namely, that the patient will die a good death when the relatives are involved ' in the light'.

Surveys

These comprised the bulk of articles found. Two of these were conducted in a Hospice setting, and one in an oncology setting, but the majority originated in Family Practice, and one from ICU. The surveys were conducted mostly with questionnaires, occasionally augmented with interviews. Those performed in a Hospice setting addressed end-of-life-issues, and specifically what patients and relatives regarded as important. Four very interesting surveys were conducted by the same group of doctors in a Family Practice setting in the USA. The surveys asked theoretical questions about Family Conferences, such as asking both patient and doctors under which theoretical conditions they would like to attend or offer a Family Conference, what the expected level of involvement of the doctors would be in these Conferences, and what the perceived value would be. Whilst interesting, there would probably be more value in assessing real situations rather than theoretical ones.

Case reviews

Two articles addressed Family Conferences in Palliative Care directly. A case review by Liebman published in 1975 illustrates the value that Family Conferences had for one particular family. Miller records verbatim questions asked by families in Family Conferences over a period of time, categorises and summarises the questions to make deductions regarding what issues should be addressed in Family Conferences. This was helpful in comparing our stated aims and methods with the issues raised by the families quoted in the article.

Focus groups

The other large category of articles used focus groups consisting of patients, family members and different categories of health care workers to explore issues such as what constitutes a good death, what the needs of spouses or other family members are when a loved one is dying or what skills physicians need in providing good quality end of life care. This provides relevant information since all role players are included, offering many viewing points of the same issue, in real circumstances. One should be careful to remember that such data cannot necessarily be transferred directly from one culture group or population to a next.

Interviews, reports on projects implemented, anecdotal accounts and letters.

There was a whole collection of different articles in this group, mostly addressing communication issues, the needs of families of dying patients (ICU rather than Hospice) or illustrating the role of communication in good quality end-of-life-care.

Pretest-posttest study with a control group.

There was one such study, examining anxiety levels in the families of patients transferring from ICU to general wards. The hypothesis is that by increasing the level of knowledge, providing support and a chance to ventilate, by means of family conference prior to transfer, that the family will experience less anxiety. The group that received the intervention was compared to a control group transferred in the usual manner. The State-Trait Anxiety Inventory self evaluation questionnaire was used prior to and after the transfer in both groups. Not surprisingly, this research showed significant reduction in anxiety in the families that attended the Conference. Whilst hesitant to make deductions for Palliative Care practice, this study nevertheless points to the possibility of finding the same to be true of Family Conferences held in Palliative Care, and perhaps this needs to be tested.

THE CONCEPT OF A FAMILY CONFERENCE

What Constitutes A Family Conference

The Oxford English dictionary defines 'conference' as a meeting of a group of people for consultation or discussion, the word originating from the Latin *conferre "to bring together"*. This is exactly what a Family Conference is, a structured meeting, at a previously agreed time and place between the patient, his or her family, and members of the Health Care Team in order to bring the role players together, and discuss certain issues.[6] Family Conferences are held in many different settings and circumstances, such as Family Medicine, Psychiatry, Rehabilitation, Intensive Care settings, and also in Palliative Care. This document concerns Family Conferences held with dying patients and their families. The Family Conference is part of a holistic bio-psycho-social approach to care that recognizes the role that families play in patients' lives.[5] The conference is usually negotiated between patient and team members, and is preceded by a discussion with the patient concerning the aims of the conference and the issues to be discussed. (Note that the term Family Conference is regarded as synonymous with the term Family Meeting)

A Family Conference is not family therapy, and also does not replace the so-called 'bad news interview', where the diagnosis of cancer, or progression of cancer is related to the patient, with or without family members present.

Additionally a Family Conference is not solely about giving information, but also presents an opportunity for open communication between all parties, and for support

- It is very difficult to determine when a person is terminal, and what the context of care is, would it be for the last months, weeks, or days.
- The term itself suggests that the spectrum of possible interventions or help has reached its end, that there is no time, opportunity or ability to do more.
- Terminal suggests a preoccupation with death, rather than with living, and whilst Palliative Care practitioners accept the inevitability of death, the treatment, counselling or interventions we offer affirm living rather than dying.[7]

Hospice Care

Palliative Care has its roots in Hospice Care. The Hospice movement as pioneered by Dame Cicely Saunders and others, entails a philosophy of care, affirming amongst others the right of people to die with dignity and in comfort. Whilst Palliative Care still embraces the basic philosophy of Hospice Care, the field has grown in terms of knowledge, research and academic status. The word hospice is a historical one that has many different uses in the modern world. It may be a 'home' for the dying, but it may also be specific kind of care offered within a large general hospital, or home care. In some European countries the older use of the word is still understood, a home for the homeless.[7]

relief from pain and other distressing symptoms... integrates the psychological and the spiritual aspects of care... offers a support system to help patients live as actively as possible until death... offers a support system to help the family cope during the patient's illness and in their own bereavement" .[7, 9]

The Palliative Medicine Institute of South Africa (founded in 1998 by Dr Selma Browde, formerly Professor of Radiation Oncology at the University of the Witwatersrand) has expanded the World Health Organisation definition. The Palliative Medicine Institute states that *"Palliative Medicine is the active comprehensive care of the physical, emotional, psycho-social and spiritual needs of the patient and the family with the aim of relieving suffering. It starts at the moment of diagnosis of any illness and continues for the duration of the illness. If and when the illness becomes incurable then Palliative Care will play the major or the total role"* .[10] In the opinion of the writer this definition addresses the important issue of palliation mentioned and illustrated on page 28 and 29. For the purposes of this document Palliative Medicine, or Palliative Care (as provided by the interdisciplinary team) concerns the active total care provided to patients with incurable illness and their relatives.

Terminal Care

Often Palliative Care is viewed as an optimistic term for Terminal Care. The word terminal poses three problems:

The concept of palliation (according to the Oxford English Dictionary: *".... to mitigate, to alleviate, to lesson pain, to give temporary relief"*) should not be confused with the field of Palliative Medicine. All doctors have the responsibility to provide palliation whilst providing curative care. The term palliation embraces all forms of treatment that is not curative, such as symptomatic medication for colds and influenza or postoperative pain control.

Palliative Medicine is that field of medicine that seeks to help patients that have been diagnosed with incurable progressive illness where the expected outcome is death, to live as independently, productively and comfortably as possible for the time remaining for them.[7]

Palliative Care

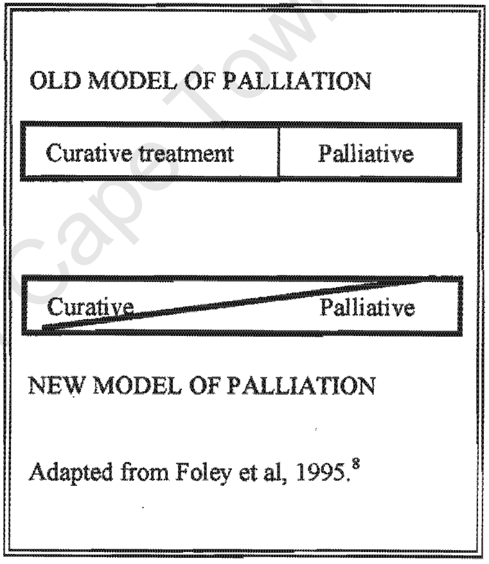
Palliative Care is a term used to describe the care provided by a team of Health Care Professionals that include Doctors, Nurses, Therapists, Clergy, Social Workers, and also Volunteers.[7] The World Health Organisation definition of Palliative Care is: "*the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of Palliative Care is achievement of the best quality of life for patients and their families. Many aspects of Palliative Care are also applicable earlier in the course of the illness in conjunction with anticancer treatment*". To expand and explain the definition: "*Palliative Care: ... affirms life and regards dying as a normal process... neither hastens nor postpones death... provides*

THE CONCEPT OF PALLIATIVE CARE

There is a commonly held belief that Palliative Care is synonymous with Terminal Care or Hospice or pain control.[7] It is therefore important to differentiate between the different terms, Palliative Medicine, Palliative Care, Terminal Care, and Hospice Care.

Palliative Medicine

Whilst Palliative Care involves all of those elements, it is much more.[7] Palliative Care includes caring for terminal patients, embraces the Hospice philosophy of accepting death as normal, but has developed into a field of medicine that strives to address the physical, emotional and spiritual needs of dying persons and their families.[7] In 1987 when Palliative Medicine was recognised as a medical speciality in Great Britain, the definition stated: " *... the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life*" .[7]



Adapted from Foley et al, 1995.[8]

to be offered to the family.[5] The components of information sharing and advising that would occur with progress reports to the family or information giving sessions are part of the Family Conference. The emotional support offered to the patient and family, the space that is created for the airing of the emotions of the patient and family, and the slightly more formal format of the Family Conference differs from ordinary consultations with the family.[11]

THE DESCRIPTION OF A FAMILY CONFERENCE AT 2 MILITARY HOSPITAL

When A Family Conference Is Held

In the Palliative Care unit of 2 Military Hospital a Family Conference is held after admission to the unit with the diagnosis of incurable illness, when the cancer progresses, or when the patient is dying. The patient, his/her family or the staff may request a conference, to address specific issues or concerns. A Family Conference may be held when there are practical problems to address, such as a patient who has deteriorated, but was still residing alone without a caregiver prior to the progression, and now needs help at home.

2 MILITARY HOSPICE

This is a combined Rehabilitation/Palliative Care Unit providing a service to serving and retired members of the Army, Navy, Air Force and Medical Service, as well as their dependants.
It is one of three Military hospitals in South Africa and is situated on the Wynberg hill in Cape Town.

At times a Family Conference will be held during the handing over of a patient from the Surgery or Internal Medicine department to Palliative Care. Often more than one Family Conference will be held during the course of the patient's illness, depending on how many emotional issues there are, what practical problems emerge, the actual course of the illness and the need of the patient and family.

The Aims Of A Family Conference

THE AIM OF FAMILY CONFERENCES AT 2 MILITARY HOSPITAL

- Educate and Inform
- Prepare
- Support

The practice of holding Family Conferences at 2 Military Hospital developed out of the mutual needs of the Health Care Team, patients and relatives. The unit is a combined Rehabilitation/ Palliative Care Unit and routinely hold Family Conferences to work with the families of disabled patients. This was extended to include Palliative Care patients.

- The initial aim is to inform and educate. The conference is held to establish what facts the relatives are familiar with, what their information needs are, and what their interpretation and understanding of the facts of the illness is. The disease process is explained, including the normal reactions and changes that occur within a family when a member is seriously ill.

- The second aim grew out of the first, namely to prepare the patient and family for the future. This includes being prepared for progression of the illness and for what would be required in order to cope or care for the patient. Additionally, practical issues such as where the patient wishes to die, who is to be the primary caregiver, wills and other financial issues are addressed.

- The third aim occurred naturally in that the presence of various members of the team at the conference (Social Workers, Ministers of Religion and Psychologists) as well as the process of holding the conference offered support to the family.

The Structure Of A Family Conference

The method of holding Family Conferences at 2 Military Hospital was arrived at unscientifically, and developed by trial and error. Regardless of whom requested the conference, the unit secretary and patient negotiate the time and place. Deciding who attends is usually left to the patient. There are occasions when the patient is not included, such as when the patient is comatose, or very frail. The members of the team who attend always include the treating Doctor, Nurse, and Chaplain. Other members might attend if available or involved, such as the Psychologist, Social Worker, Occupational therapist or Physiotherapist.

Usually the conference is held in the Palliative Care Unit, in a quiet sitting room area that is secluded and can be protected from interruption. Sometimes the conferences are held around the bedside.

The Palliative Care doctor who is treating the patient usually chairs the conference.

The phases of a Family Conference

- Opening Phase: All attendees are welcomed, and introduced to one other. An explanation of the purpose of the conference follows, as well as the assurance that Family Conferences are a normal part of the unit routine.

- Summary and closure: Usually the issues that have been discussed and the decisions taken are summarized, and the method of contacting the various members of the team is repeated at the closure of the conference. Before closing the conference the doctor will check again that all attendees are satisfied that all relevant issues have been mentioned and addressed.

The Value Of The Family Conference

The perceived benefits of the Family Conferences from the point of view of the team at 2 military hospital are:

- That all parties involved heard the same information first hand.
- The channels of communication are opened paving the way for future communications.
- The team has a chance to evaluate the family dynamics and support systems and offer help where indicated.
- And the team has an opportunity to act as advocate for very frail or elderly patients.

Without having asked the family, we imagine that the value for the patients include:

- An expression of availability and interest by the various disciplines.
- A show of respect for the role of the family (especially important in Africa).
- Dispels myths, fears, uncertainties and whispered incorrect facts.
- Makes the family aware of the available support systems.
- And opens up the discussion about important issues amongst the family members.

The most important advantage we have witnessed is that the family have time to prepare and plan together, as well as identify and solve some of the problems that the serious illness and impending death of one member will cause.

Feedback from patients and relatives.

Within 2 Military Hospital no formal evaluation of the value of these Family Conferences has been done. We continue to hold them because of encouraging comments from patients and families such as *"Why could this not have been done earlier"*, and *"We feel so much better for being prepared"*. The patient is visibly relieved once the facts of the disease are out in the open, and the family members seem less distressed once they are fully aware of what is happening. It is our impression that the relationship between staff and relatives is easier, more open, with more interaction after a family meeting. Because the patient and family have become aware or certain issues or problems during a Family Conference, they are able to address theses issues. The family seems empowered to play a role in caring for the patient after a Family Conference.

This is illustrated by the fact that they ask more specific questions, state their opinions regarding treatment, and engage with the patient and staff in terms of decision making.

There has also been one family member who commented that the conference concentrated too much on the negative (the medical facts) and not enough on hope.

"Hope is expectation and desire combined" according to the Oxford English Dictionary. This is a very helpful definition since it alerts one to the fact that unless what one is expecting and desiring is defined, there is great danger of being misunderstood. The Palliative Care Team's role is to help the patient and family to define a realistic goal to hope for, to transfer their hope, rather than give up hope. For example, when talking to relatives whose family member has incurable cancer, giving medical information that confirms the finality of the diagnosis and prognosis will take away the hope the family might have for a cure. However, depending on the nature of the illness and condition of the patient, hope may be found in other goals, such as surviving to attend a family wedding, or to greet a new grandchild, or for good pain control.

The Willingness of Patients and Relatives to Attend Family Conferences.

At 2 Military Hospital Family Conferences are offered, but not forced upon patients and their families. There have been very rare occasions where certain member of the family has refused to attend a Family Conference.

It is to be expected that not everyone will wish to attend a Family Conference and this may be due to feelings of denial, anger, feeling unable to talk about the pending loss, or believing that talking about negative things will make them happen. Most of the time patients and families seem eager to attend Family Conferences, sometimes having heard from other patients that our unit holds such conferences and telephoning to request to be seen, even when they have curable cancer and have not been referred for Palliative Care.

It is our perception at 2 Military Hospital that most of the patients with incurable illness and their families are willing to attend Family Conferences. When tested hypothetically by Kushner, the patients studied indicated that they would like to have Family Conferences under certain circumstances, such as serious medical illness.[12]

The Willingness of Health Care Team Members at 2 Military Hospital to Attend/Hold Family Conferences.

The Health Care Team caring for dying patients at 2 Military Hospital includes Doctors, Nurses, Chaplains, Social Workers and Psychologists. The aim of this team is to provide active holistic Palliative Care to dying patients and their families by addressing the following aspects:

- The physical comfort of the patient.
- The emotional and spiritual needs of the patient.
- The concerns of the family regarding information, preparation for the future, and skills in caring for the patient.
- Providing support for the relatives.
- Encouraging realistic goal setting and expectations, whilst encouraging independent, meaningful living.

The members of the team are very keen to hold Family Conferences since it allows the team insight into the family dynamics and support systems, and provides an entry point from which to work in offering assistance. In a study by Kushner and Meyer they question, the physicians but not the team's interest in Family Conferences. It transpired that under the theoretical circumstances of the study, the number one situation in which physicians would want to hold a Family Conference was when a family member was dying.[13]

The practical reality at 2 Military is that the first Family Conference is held once Palliative Care becomes the main focus of treatment for a cancer patient. Seeing the visible relief in the faces of the patients and their families the few occasions that a Family Conference has been held at the time of diagnosis of an incurable illness (such as inoperable stomach cancer), led us to ask some questions regarding the optimal time to hold Family Conferences.

AUDIT OF CURRENT PRACTICE AT 2 MILITARY HOSPITAL

I decided to examine at what point in the patients' life with cancer Family Conferences were held in our unit. I conducted an audit, selecting 34 patients from 2 Military Hospice records in order to examine how long after diagnosis they attended a first Family Conference, and how long after the Family Conference was held they died. See table on page 47.

Inclusion Criteria

All had died of cancer in the past two years, and had attended at least one Family Conference. The selection was partly determined by the availability of the date of histological diagnosis of primary incurable cancer, or of histological/radiological diagnosis of progression of cancer that made it incurable. Inclusion was also determined by the availability of the date of the first Family Conference, and date of death. Subsequent Family Conferences were not taken into account.

Results of the Audit

Of the 34 patients, 28 (82%) attended a Family Conference in the last six months of life. Almost half of the Family Conferences were held within 3 months of diagnosis. The average time from diagnosis to Family Conference was 230 days (7.6 months). The average time from Family Conference to death was 114 days (3.4 months). The average survival rate was 343 days (11.43 months).

There is tremendous variability in the results, with some patients attending a Family Conference on day of diagnosis, and others at 1027 (almost 3 years) after the diagnosis. Deaths occurred sometimes on the same day as the Family Conference, or up to 3 years later.

Interpretation of results

The variability of the results indicates that Family Conferences are held rather randomly within the unit, and not at a specified time. On page 34 there is an indication of a range of circumstances that could lead to a Family Conference being convened, supporting the impression that the conferences are being held as required, rather than according to a protocol or plan. The danger of continuing this practice is that Family Conferences become a crisis management intervention only, rather than fulfilling the wider role of facilitating the tasks of grieving.

Within the variability there are some interesting facts. In 8 patients where the Family Conference was held within 3 weeks of diagnosis, the average survival was 3.6 months from diagnosis (Patient number 4, 5, 14, 17, 18, 23, 29, 33 in table page 47). The patients suffered from inoperable or widely metastasised disease at time of diagnosis. In these cases the patients had symptoms requiring treatment from the time of diagnosis, which could have prompted early referral to the Palliative Care Unit. The more advanced the illness is at time of diagnosis, the more the distress experienced by the patient and family is likely to be, since all the tasks of grieving are compressed into a shorter time.

It is my suspicion that referral of a newly diagnosed patient with advanced stage of cancer occurs soon after diagnosis partly because of helplessness and inadequacy felt by the treating doctors in managing the immense distress experienced by the patient and relatives.

In a few cases there was a long time between diagnosis and Family Conference. These cases were usually breast or prostate cancer with bony metastases, where progression had been slow, and referral occurred only when pain control or mobility became a problem (Patient number 12, 15, 32).

In cases where the Family Conference had been held soon after diagnosis, and the patient had survived for a good many months or years after the conference, it must be remembered that it is probable that more than one conference could have been held. The data only reflects the first Family Conference (Patients 14, 18, 22).

Discussion

This audit confirmed that Family Conferences were mostly being held once the patient had started to deteriorate, and required more active Palliative Care. The majority of Family Conferences were held in the patients' last six months of life, probably because this is the time that the patient and family require active Palliative Care intervention. The more advanced the illness at time of diagnosis, the higher the likelihood of a referral soon after diagnosis.

The randomness of the Family Conference timing, as reflected by the variability of the data, is worrying. Of concern is that the Family Conference is not fulfilling its stated purpose, but rather becoming a crisis management intervention, or a warning of immanent death. The results of this audit suggest that some standardisation is required in terms of holding Family Conferences at 2 Military Hospital.

Timing Of The Family Conference In The Disease Trajectory Of Cancer Patients At 2 Military Hospital

Patient Number	Number of Days from Diagnosis to Family Conference	Days from Family Conference to Death	Number of Days from Diagnosis to Death
1	394	98	492
2	328	21	349
3	92	219	311
4	9	91	100
5	0	65	65
6	502	49	551
7	553	67	620
8	157	1	158
9	394	210	604
10	63	58	121
11	130	26	156
12	714	70	784
13	76	24	100
14	1	155	156
15	681	19	700
16	193	180	373
17	39	0	39
18	0	381	381
19	30	142	172
20	31	782	813
21	77	53	130
22	35	145	180
23	16	66	82
24	167	109	276
25	106	88	194
26	488	243	731
27	24	62	86
28	442	18	460
29	13	23	36
30	191	48	239
31	105	121	226
32	1027	182	1209
33	19	9	28
34	709	45	754
	230	**114**	**343**
	0	**0**	**28**
	1027	**782**	**1209**

RESULTS OF LITERATURE REVIEW

The Timing of Palliative Care

Traditionally Palliative Care is offered during the last days of life. The development of Palliative Medicine as a specialist field has broadened the view of Palliative Care. Palliative Care is now regarded as being appropriate when curative care is not, once there is an established diagnosis, there is clinical evidence of active progressive disease and death is inevitable in the near future.[7] Some would extend that further; the World Health Organisation believes that the task of providing effective Palliative Care would be easier if it were offered throughout the illness.[9] Vachon and others have shown how poorly handled information giving, and lack of recognition and management of anxiety at time of diagnosis can contribute to problems later in the course of the illness.[7] In 1994 the Policy Framework for Commissioning Cancer Services stated that: "*Palliative Care is required for many patients early in the course of their disease, sometimes from the time of diagnosis. It should not be associated only with terminal care. The Palliative Care team should integrate in a seamless way with all cancer treatment services to provide the best possible quality of life for the patient and their family*".[14] In the United States of America referral to Palliative Care services depends largely on what the medical insurance is willing to pay for, currently for the last 6-7 months of a person's life.[7, 8] Dr Selma Browde and the Palliative Care institute of South Africa would have Palliative Care integrated into mainstream medicine and has expanded the definition to include curable illness.[10]

The current debate regarding when Palliative Care is appropriate is currently based on various expert's opinions, and likely to differ depending on the needs of a particular setting. For example in South Africa with a raging HIV/AIDS epidemic, Palliative Care is likely to play an extended role, especially since Anti-retroviral treatment in mostly unaffordable and unavailable. This means that in a country where HIV infection cannot be transformed into a chronic debilitating disease by means of anti-retrovirals, Palliative Care would include an expanded range of interventions from time of diagnosis, through to the terminal stages.[15] The resources available in a particular setting also tend to influence the time when Palliative Care starts.[16, 17] If the medical insurance will only pay for 6 months of Palliative Care, then that is likely to be an influence on the time of referral.[18] For the purposes of this literature review, it seems that the accepted timing of referral to Palliative Care is as soon as a particular diagnosis with it's prognostic implications are made, rather than the patients clinical condition at the time of referral, or any given time. [7, 9, 14, 16, 18]

Case reports [18, 19] indicate that referrals usually occur once the patient has distressing symptoms, or other problems that require Palliative Care intervention, and this usually is within the last six months of life. This is similar to what is experienced in 2 Military Hospital.

It is also important to ask what the patients and their relatives think is the most appropriate timing for referral to Palliative Care. One study by Navari and Stocking indicated significant reluctance on the part of a sample of highly treated, well-informed, severely physically impaired adults with advanced symptomatic cancer, to accept referral for Palliative Care.[20] This was in a community where Palliative Care and Hospice services have good penetration, seeming to suggest that the real difficulty was in accepting the poor prognosis, and that referral to Palliative Care emphasizes that prognosis. This would definitely suggest a patient-barrier to acceptance of earlier referral to Palliative Care, but might also reflect the result of later referral. This statement is made in view of the fact that the Palliative Care philosophy places strong emphasis on counselling and preparation, and whilst accepting death as inevitable, focuses on living.[7]

Thus in summary, logic would state that Palliative Care should commence when the patient requires it. The most appropriate time, and the definition of the point at which patients require Palliative Care must still be tested. It is the writer's opinion that the availability of services, the particular problems of different settings, as well as individual patient and physician choice will dictate when referral to Palliative Care occurs. It would not be possible to conclude from the literature whether there is time more appropriate than current practice, for Palliative Care referral within 2 Military Hospital.

Is a Family Conference an Accepted Part of Palliative Care?

In practice there are two models of Palliative Care. In the usual model care is centred on the patient and their symptoms. The patient and his/her well-being is not only the most important element of providing good Palliative Care, it is also what doctors are trained to manage. The second model adds the dimension of preventative health care by addressing issues within the family during Palliative Care, reducing the likelihood of complications later.[21] It has been shown by Colin Murray Parkes and others that by facilitating the grieving process, the ability of family members to cope as well as their future health benefits.[21] To implement a system that addresses the needs of the family is more demanding, and it is probable that few doctors have received formal training in counselling.

In the Palliative Guidelines of the Royal College of Physicians a Family Conference is offered to patient and relatives as soon as possible after admission to a Palliative Care unit, as an element of good practice.[22] The Family Conference is mentioned in the Palliative Care setting by means of case reports, or in retrospect when examining the decision- making process during a person's last days.[17, 19] One study examined the questions asked during Family Conferences held routinely as part of their practice.[23] Miller and colleagues' verbatim reporting adds to the information regarding what patients and their relatives would like to have addressed during Family Conference. The study supports the impression held by the writer that Family Conferences are part of the routine practice of Palliative Care teams.[23]

Good communication within the team, collaboration and coordination of Palliative Care services is increasingly required as people chose to die in home or nursing home settings, and a Family Conference is a manner in which these functions can be fulfilled.[24]

The literature is not prescriptive regarding the holding of Family Conferences, but it seems to be common practice, and accepted as good practice. Whether it is best possible practice has not been tested in terms of benefit for the patient and family.

Is a Family Conference a Part of Good Quality End-Of-Life-Care?

There are two aspects to this issue: why would a Family Conference make a contribution to good quality end-of-life-care, and secondly why the format of a Family Conference? What constitutes good quality end-of-life-care has been the topic of great interest to Palliative Care practitioners. The answers regarding what elements are essential to good quality end-of-life-care should be obtained from patients, relatives and the Palliative Care Team. Once the requirements of good quality end-of-life-care have been established, it must be asked whether holding a Family Conference would meet any of these requirements. Finally it must be established whether a Family Conference would be the most appropriate intervention to meet some of the requirements of good quality end-of-life-care.

Amongst the many different surveys done to establish what patients, relatives and healthcare workers regard as being essential to a good death, there seems to be consensus that besides physical comfort, having adequate access to information, having an opportunity to express their emotions, being prepared and being supported is of utmost importance.[25, 26] Both Steinhauser and Teno used focus groups to identify themes in describing the components of a good death. Steinhauser's focus groups included patients, bereaved relatives and different members of the team involved in end-of-life-care. The six themes identified concerned pain and symptom management, decision-making, preparation for death, completion, contributing to others and affirmation of the whole person.[25] This is very similar to the five domains of patient-focussed, family-centred care described by Teno et al. namely physical comfort and emotional support, decision making, individualized care, attending to the family's needs and ensuring co-ordination of care.[26]

Hampe identified eight needs of grieving spouses, and then investigated whether the spouse could recognize their needs, and whether they considered those needs met by the staff.[27] Although this study dealt with only one aspect, namely the grieving process, the needs of the spouses in the study were along a similar theme: need for information, to be prepared for death, for acceptance and support from health professionals, to ventilate emotions, for comfort and support from family members, the comfort of the dying person, and to be with and helpful to the dying person.[27]

Furukawa used the primary categories described by Leske regarding the needs of families of dying patients to audit whether her Critical Care Unit were meeting these needs.[28] Of interest to this review are the three categories described by Leske, namely assurance (that the patient is comfortable, cared for, trust and confidence in the healthcare system, and for hope); proximity (contact with and information about the patient) and information.[28] Although all these studies have limitations, such as being conducted in specific communities (Steinhauser amongst United States of America veterans, Furukawa in an Intensive Care Unit), or addressing one aspect of dying (Hampe researching the grieving process), common themes emerge regarding those elements that are important to address in good end-of-life-care.

The stressors experienced by families caring for a dying member have been well described and include role changes, challenge in developing new skills, financial as well as psychological and physical burdens.[7, 21, 29] A Family Conference offers the opportunity to address many of these needs, as well as a forum to identify and assist with the stressors.

At the top of the list of situations in which many family therapists would suggest holding a Family Conference is when there is serious illness or a death of a family member.[5, 6] (Christie-Seely 1984 & Schmidt 1978 as quoted by Kushner & Meyer). Kushner tested this by asking patients and doctors in which hypothetical situation they would most want to attend or hold a Family Conference.[13, 30]

The result confirmed that hypothetically at least, patients and doctors were most interested in attending Family Conference when a family member suffered from serious illness, or was dying.

It seems that even if patients wished to talk to their doctor about certain psychosocial issues, they would refrain from doing so unless given a cue by the doctor that this would be acceptable.[31] A Family Conference would afford an opportunity for such issues to be addressed.

In an Intensive Care setting, research has shown that a large percentage of deaths involve difficult end-of-life decision-making.[32] These deaths often occur against a background of acute illness (unexpected), emotionally charged atmosphere, and a setting that is focused on life-saving care.[32] Many authors advocate Family Conferences as an effective intervention to meet the needs of family members in an Intensive Care setting. Some of the needs of relatives in an Intensive Care setting are similar to the requirements of a good death as sited by patients, families and health care workers in a Palliative Care setting.[28, 32, 33]

NEEDS OF PATIENT AND RELATIVES DURING END OF LIFE CARE:

- Physical comfort [18, 23, 25, 26, 27, 28, 50]
- Information & preparedness [18, 23, 25, 27, 28, 50]
- Skills [23, 26]
- Support & relationship with staff [26, 27, 28, 50]
- Opportunity to express emotions [27]
- Shared and clear decision-making [18, 25, 26]
- Spiritual comfort [50]
- To achieve a sense of Completion [25, 50]
- To be seen as a whole person [25]

The needs that coincide include the need for information, good level of communication with the staff, opportunity for emotional expression, and support.

The skills expected by and most appreciated in their physicians by the relatives of terminally ill patients include cognitive (symptom management) and affective skill (emotional support).[34] A close second in terms of importance are communication skills.[34] These skills are required and used in holding Family Conferences.

It seems then that what is clear from the literature is that there is consensus amongst the role players regarding what elements of care constitute good quality end-of-life care, and what the needs of dying patients and their families are. The fact that individual differences should be taken into account is not disputed. The responsibility of the Palliative Care Team is to provide for these needs, and to facilitate good end-of-life care. (See Definition of Palliative Care) Since these elements of care and needs include information, being prepared, opportunity for emotional expression, and support, a Family Conference is a method by which these needs could be met. There is little literature providing evidence as to whether a Family Conference is the only or the best method by which to provide for these needs.

What is The Best Time to Hold a Family Conference?

The suggestion of timing for a Family Conference in an Intensive Care setting is as soon as possible. This is in order to prevent an entrenched pattern of communication between relatives and staff, and also to establish expectations realistically.

Holding the Family Conference as soon as possible after admission to the Intensive Care Unit allows the needs of relatives to be established, in order for them to be addressed.[33] Whilst some of these issues might also hold true for Palliative Care settings, the most appropriate time to hold a Family Conference has not been established. The Royal College of Physician guidelines suggests holding a Family Conference as soon as possible after admission to a Palliative Care Unit.[22] Patients are however treated in a wide variety of settings (Hospitals, Hospices, Nursing homes, at home, and as out-patients) and not always admitted which still leaves a question as to when in the disease trajectory would be the most appropriate time to hold a Family Conference.

Communicating with and supporting the relatives of a dying person is particularly important at the so-called transitional points of the illness [35] (A phrase from Holland in Chapter 6 of the text book on Psycho Oncology, 1989). These times of increased vulnerability and emotional distress include the diagnosis, starting treatment, recurrence, and treatment failure and disease progression.[35, 36] At each stage the aim of the intervention would differ slightly, but they would always revolve around information, support, setting expectations, and shared decision-making. In case studies, the transitional points of recurrence, treatment failure or disease progression would usually be the times that patients would be admitted, readmitted, or referred to Palliative Care.

TRANSITIONAL POINTS

- Diagnosis
- Start of treatment
- Treatment failure
- Recurrence
- Progression of disease

(Holland, J. 1989:75)

The transitional points would also be the time at which a first or successive Family Conference would be held.[18, 19] It might be important to remember the practical point that the first conference could turn in to a crisis management session and a follow up conference might be required to complete the work that has begun.[37] It has been shown that these times are the most distressing to patient and family members, and therefore the need for intervention would be highest.[7, 35] If a Family Conference is accepted as a method of addressing these needs/issues, then it would seem logical to hold Family Conferences at the transitional points in the trajectory of disease, or whenever individual patients, or families feel the need for such an intervention.

Practical Applications

There is a scarcity of literature on the method of holding a Family Conference in a Palliative Care setting. The background theory that is described in general family medicine or Intensive Care settings originates from family therapy.

If one uses the Egan model of counselling and support as a basic framework [36,38], there is remarkable similarity in the methods suggested by other authors.[5, 6, 23, 35, 37, 39]

PROCESS OF A
FAMILY
CONFERENCE.

- Engage
- Explore
- Understand
- Action
- Closure

(Egan model (1982) of counselling as quoted by Lugton 1987:85)

The basic steps include establishing a relationship with the family, exploring, understanding, action and evaluation, and then closing the contact.[36, 38]
The advice given to physicians regarding conferences that will invariably include discussing clinical information is to prepare thoroughly.[7, 23, 39, 40, 41] The relationship between doctor-patient and relatives is based on trust, which is never so severely tested as in a Palliative Care setting where life and death issues are at stake and emotions run high.[41] To be unprepared and to seem to falter would be a mistake.

Establishing a relationship is more than introduction of the attendees to each other, it is also engaging the patient and relatives in the process, and contracting the terms (goals, time limit, etc).[5, 39]

Exploring the current level of knowledge of patient and relatives comes next. This includes exploring their need for additional knowledge, other concerns, and main stressors. Depending on the situation, this could be problem focused. Providing an opportunity for emotional expression is advocated. Exploring the impact of the illness on the family could be helpful and leads onto the next phase of understanding.[23]

The aim is to promote the patient and family's understanding of the process, of the stressors and of a normal coping reaction in a family. Information is shared during this phase, advice given if asked, expectations discussed.

The family should be encouraged to assess their internal and external resources, and to decide how and when to mobilise them. Communication within the family should be facilitated as far as possible.[39]

The next phase of the conference concerns action and evaluation. The patient and family should be assisted to plan how to address certain issues, and solve the problems they have identified. This could concern physical care-giving, making of a last will, financial issues, dealing with children, roles within the household, where to die, and any others that might be appropriate for a particular family. Anticipation of the future is usually an element of this phase, preparing for any difficulties that might arise, in order to reduce anxiety and reassure both patient and family members.[36]

When as many issues have been addressed as can be done realistically in the time available, the closure of the conference follows. The availability of the staff should be re-emphasized, and the method of contacting the correct person for help repeated. Follow up meetings can be scheduled depending on mutual needs.[39]

Whilst no specific format for a Palliative Care Family Conference has been described, the key elements suggested by family therapists [5, 6, 37] for family counselling are very similar to those suggested by Intensive Care practitioners [32, 33], and those practiced in Palliative Care.[19, 23]

Whilst there is an obvious need to test a format for a Family Conference in Palliative Care, it is acceptable to base that format on known counselling models such as Egan. The specific content discussed and proceedings of the Palliative Care Family Conference should be tailored to address specific needs identified by patients, relatives and physicians to be important in Palliative Care.

Every counselling session is essentially different because individuals vary, as do their needs, and the purpose of a framework is to provide some structure to ensure that all the issues are addressed.

What is The Aim of a Family Conference?

Terminal illness is a family experience [7], and the impact on the family has been well described.[7, 21, 29, 36, 37, 40, 42] Since the role of care giving also usually falls to the family, the family has to cope with practical issues as well as the overwhelming emotional issues surrounding death.[23] Palliative Care has the ability to prevent a family crisis, and facilitate the confrontation of many of the physical and emotional issues.[7] Issues of communication often influence not only the level of involvement of the family in caring for the dying, but also the nature of their experience.[43]

Difficulties with communication during terminal illness have been described according to different patterns. Hinton describes 3 patterns of restricted communication: avoidance to prevent distress; avoidance to appear positive and to cope; and maintaining a previous pattern of not discussing emotional issues.[44]

Cable speaks of closed awareness (patient does not know of illness, relatives and staff do); suspicious awareness (patient guesses that something is wrong and tests relatives and staff); mutual pretence (all in the know but pretend not to) and open awareness (where energy is released to deal with appropriate issues).[45] Whilst not all family communication styles are restricted, many families do have difficulty in establishing open comfortable discussion about the emotions that serious illness and/or impending death cause.[21, 42] One of the aims of the Palliative Care Team is to facilitate an open communication within the team of staff, patient and relatives.[22, 44, 45]. A Family Conference is one of the interventions that can improve communication.

Andershed & Ternestedt describes family involvement with terminal care of their dying relative as being *"in the light"* (as in enlightened), or *"in the dark"* .[43] In their research being involved in the light meant that relatives were well informed, had a trusting relationship with the staff, and were involved in a meaningful way in the care of the patient. Those relatives who felt uninformed, not acknowledged by the staff, and were isolated in their involvement were described as *"in the dark"*.

The theoretical basis for the research is Antonovsky's theory regarding coherence (1987). He found that people could experience an inner sense of coherence even under extremely stressful circumstances if 3 key elements were in place. These were comprehensibility, manageability and meaningfulness.

If people could understand what was happening to them (comprehensibility), were confident in the resources available to them (manageability), and felt that the problem was worth investing energy in (meaningfulness), then they could maintain an inner sense of coherence.[43] The assumptions Andershed and her team made was that if relatives could maintain an inner sense of coherence, they were more likely to be involved in the care of the patient in a meaningful way, and therefore the patient was more likely to experience an appropriate death.

It makes sense that being involved 'in the light' would be preferable for the family in terms of reducing anxiety, starting the tasks of grieving, using the time left with the dying relative fruitfully and experiencing the death of a relative more favourably. How these factors influence the nature of the patient's death cannot be assumed and needs exploring. A Family Conference could be used as an intervention to help relatives from *"the dark"* into *" the light"*, by opening up communication, providing information, engendering a trusting relationship with the staff, providing support and a forum for emotional expression for the patient and relatives.

In summary, the aims of a Family Conference in a Palliative Care setting is to provide information, open up communication, support the patient and relatives, and prepare them for what lies ahead.

What Value Does a Family Conference Have in Contributing Towards Good Quality End-Of-Life-Care?

Besides case reports [19], anecdotal reporting [46] and the writer's own experience, any statement regarding the value that Family Conferences have in the care of the dying has to be deduced theoretically, since it has not been tested.

Where families display patterns of restricted communication, the aim of any intervention would be to encourage open communication. One would deduce that by helping the role players to obtain useful information, and to recognise and acknowledge their feelings, that communication would be more open. Addressing the family's feelings of helplessness by empowering them to identify and make use of available resources, better communication and more meaningful interactions with one another could be achieved.[44] Good communication with the family will improve cooperation, awareness, and interactions amongst the role players.[45]

THE VALUE OF FAMILY CONFERENCES IN PALLIATIVE CARE

- Care based on actual, not assumed needs [19, 22, 23]
- Affirms role of family [19, 33]
- Opens communication within the family [23, 36]
- Encourages trust and confidence in the staff [19, 42]
- Reduces anxiety/ distress [19, 47]
- Affords an opportunity to evaluate the need for additional intervention [5, 6, 19, 23, 29]
- More meaningful involvement of relatives in care-giving [43]
- Creates a forum for shared decision-making [23]
- Encourages the family to start the tasks of preparing and grieving for the loss [36, 42]
- Empowerment of the family to solve problems [23]

This will release the energy within the family unit to attend to important tasks of grieving and preparation, and meaningful communication.[45]

The nature and quality of the involvement of the relatives in caring for the dying is more meaningful once they have adequate knowledge support and trust in the staff.[43] Their anxiety / distress is less if they have adequate information, but are also assured of the availability of assistance.[23, 36, 42, 47] The acknowledgement of the family as a unit of care is an affirming outcome of including the family in the process.[43] Empowering the family to examine and use their internal and external resources can lead to better problem solving abilities.[37] The Family Conference affords the team the chance to assess and then base the care plan on the stated needs of the patient and relatives, rather than on the assumed needs.[22]

The Family Conference leads to shared decision-making that is centred on what the patient and family require. Additionally it affords the team a chance to evaluate the family dynamics and offer additional support, therapy or other interventions if required.[5, 36, 42]

There is an increase in mutual understanding and support after Family Conferences, and the relationship between staff and family is characterized by trust and confidence in each other.[19, 36, 46]

The Family Conference can have value as an opportunity to teach junior staff about psychosocial care, thereby increasing the level of skill of future team members.[33] One of the most important values that such a conference can have is to help patients and relatives to find a reason to hope by encouraging realistic goals, and giving the patient and family a direction in which to move.[40] By our own admission Palliative Care focuses on living until the moment of death, and therefore it is appropriate to assist patients in viewing and approaching their living-with-cancer with hope.[7, 9] Hope is a word that is used thoughtlessly, and seems inappropriate in a Palliative Care setting, unless one defines that hope. Palliative Care does not encourage false hope for a cure, nor does it advocate a vague unrealistic hope, but emphasises hope for realistic achievable goals.[40] This hope would differ from person to person. A young mother might hope to live long enough to prepare her children for her impending death, a grandmother might hope to live to see the birth of an expected grandchild, another patient might hope to be pain free, or mobile, or to spend their last weeks at home.

Why is the Family Conference in Palliative Care so Scarcely Researched?

Perhaps this is linked to the bigger question of why research in Palliative Care is limited. The difficulties could be divided into four areas:

1. The main tasks of Palliative Care concern the patient and his/her comfort (see definition of Palliative Care p23). This would mean that the energy and time available to the doctors is focussed on the patient as first priority. Whilst this is not wrong, and not all doctors are suited to research, research-mindedness is an important characteristic in Palliative Care.[48] In other words to change or

justify current practise with *"I do this because of the evidence"* rather than with *" I do this because it is how I have been taught"*.

2. Research skills are lacking amongst Palliative Care practitioners.[1] Research activity in Palliative care has increased considerably during the past ten years. The surveys on Palliative Care research seem to indicate that the number of centres undertaking research is steadily increasing. These centres seem to be mostly in North America and Europe.[48] It would stand to reason that in countries where Palliative Care is more established, and recognised as a speciality, more research would be undertaken.

3. Palliative Care units tend to be small and not linked to academic institutions.[1] In South Africa, Hospices are very seldom found within large hospitals or academic institutions, and this might make research more difficult, but not impossible.

4. Practical and ethical considerations: [7, 26, 48]

- Defining an outcome – when measuring whether a particular practice contributes to quality of life or quality of dying, both the definition of quality of life as well as the measurement thereof is difficult.
- There is little consensus in the field of Palliative Care regarding definitions.
- Dying is a dynamic and complex process, making measuring and counting difficult.

- Dying, and each person's perceptions of what constitutes a good quality death differs, therefore it is difficult to generalize results.
- The procedures used to assess validity and reliability of data may be difficult in quality of life studies.
- As the patient's condition deteriorates, obtaining data becomes increasingly difficult (such as questionnaires).
- The topics of research touch on personal and highly emotional issues and the data collection might be experienced as intrusive, exploitative, or experienced as painful.
- Very often the results will not benefit the participants.
- Often research could be considered unethical because of the fragility of the population involved.
- Informed consent is difficult when there is a high percentage of cognitive decline in this population.
- Research could be viewed as unethical because of possible risk to the trust between doctor and patient, since the patient is highly reliant on the doctor.
- The population could be regarded as vulnerable because of the high incidence of depression, tiredness, cognitive deterioration and physical impairment.
- The field of Palliative Care is young, and there is a distinct lack of tested tools (in terms of questionnaires etc).
- The population is clinically unstable.

Specific problems pertaining to research on Family Conferences must include the issues of time. Usually with family-focused intervention one has time to evaluate outcome over a reasonable time span. This would be difficult to do with dying patients and their families since the relevant time span is usually six months or less.[16,49] This time is also dynamic and eventful, making measuring outcome more difficult. Much of the value of a Family Conference concerns the duration of the illness, but the long-term benefits for the family in terms of grieving have not been addressed. Perhaps an area of research could concern the longer-term outcome of the benefits of Family Conferences during the care of the dying.

Another difficult issue in terms of researching Family Conferences is that each individual and family enters the highly stressful situation of terminal illness with their own emotional and spiritual baggage and issues, which will dictate how they respond to the losses and difficulties of the process.[21] As many families as there are, as many different interventions will be required.[50]

Researching Family Conferences poses the risk of eliciting painful and raw emotions if the research is timed too soon after the death of a loved one.[26] On the other hand the freshness and validity of the results could be questioned if one waits too long.

DISCUSSION

To have the role of the family accepted and acknowledged is important to the patient, as well as to the family and influences the outcome of any process.[39] One way to engage and acknowledge the family is to hold a Family Conference.[5, 6, 11] The Family Conference is an intervention tool used in a variety of settings and the theory is based on a basic counselling model.[5, 6, 11, 36, 38]

Palliative Care is the active care of patient and family coping with incurable illness, addressing physical, psychosocial and spiritual aspects of care.[7, 9, 22] Palliative Care accepts death as normal and inevitable but focuses its attentions on living.[40] The debate regarding when Palliative Care should be introduced is most flippantly answered by 'when the patient needs it', but a more practical, better-researched answer is still awaited. Practically Palliative Care is the main focus of care during the last six months of a patient's life, often initiated by the patient's need for symptom control, or dictated by the medical insurance.[18, 19, 35, 49]

Family Conferences are recommended as part of Palliative Care practice, and used as such, but this is founded on expert opinion and practical issues, rather than on research.[22, 23]

Whether we should hold Family Conferences is partly addressed by whether they form part of good quality end of life care.

By consensus patient, relatives and staff agree that the elements of information, support and opportunity to express emotions form part of good quality end-of- life-care.[18, 23, 25, 26, 27, 28, 50] Family Conferences can provide for these needs and could therefore be considered as part of good end of life care. Whether they actually do provide for these needs must be tested still.

At what time Family Conferences should be held can be deduced from the transitional points in the illness trajectory, where research has shown the need for communication and support by patient and family to be greater than usual.[35, 44] This too needs to be tested.

How Family Conferences should be held can be based on counselling models and adapted to each individual family's situation and to a Palliative Care setting.[23, 36, 38, 42] The specific elements to be included in order for the conference to form part of good end-of-life-care, still requires investigation.

Family Conferences are held to provide for the patient and his/her family's needs for: information, support, opportunity to express emotions, and preparation for what lies ahead.[18, 19, 23, 36] Their aim from the point of view of the staff is to increase mutual understanding and gain cooperation of the family, and to assist them to become involved in the patient's care in a meaningful way.[41, 42, 43, 46]

The value that family meetings have is assumed from anecdotal reporting and deduction. The value stems mostly from the opening up of communication within the family and between staff and family, as well as the development of a relationship based on trust and confidence between staff and patient/ family.[19, 23, 35, 42] The theory is that by meeting the families' needs for communication, information and support, they will be empowered to cope with demands of coping with a terminal illness, and will also assist them to start the tasks of grieving.[36, 42]

Very little of what is practiced, aimed at or assumed in terms of the role and value of Family Conferences in Palliative Care has been tested by research. This could be due to the difficulties of conducting any research in the field of a Palliative Care. There are also difficulties related to the lack of time to evaluate the outcome of such a family intervention before the patient dies. The dynamic and complex process of dying and the very personal and painful nature of the topic could also play a role in explaining the scarcity of research in Family Conferences.

Whilst this Literature Review seems to support practice at 2 Military Hospital, the writer finds herself no nearer to empirical evidence with which to justify these practices. The Palliative Care Team holds Family Conferences with the best of intentions, but need to justify the practice with assumptions that require testing if we are to know what is the value of Family Conferences in the care of the dying.

RECOMMENDATIONS

The issue of communication is central to the topic of Family Conferences, and in a multicultural, multilingual society such as South Africa inter-cultural communication is an area of study that should not be neglected since there is the possibility of potential miscommunications. Besides language barriers, translator problems and misinterpretation of non-verbal messages, there is also the issue of differing worldviews and health beliefs.[51] Family Conferences are offered by South African Palliative Care Teams, assuming that because of the family-orientated culture of many of the different ethnic and language groups, there will be benefit to patient and family. This is not necessarily true. In the opinion of the writer how different cultural groups in South Africa experience Family Conferences requires research. The results of such research will allow us to create care plans, including Family Conferences, that are based on stated needs of patient and family rather than on assumed needs.

Whilst language and cultural differences may pose difficulties, what is known and accepted is that even within the same cultural group every person and their family experiences terminal illness and death differently, therefore their needs will differ. The task of Palliative Care Team remains to base the care offered on the actual needs of the patient and family, in order for the care to be effective.[22, 50]

Dr Teno and her team at Brown University School of Medicine, United States of America, has developed tools to measure end-of-life care which need to be used in actual projects to answer some of the questions regarding what is best possible practice in Palliative Care.[52] Specifically in terms of Family Conferences in Palliative Care, the timing, format, aim, role and value are largely untested and require formal validation.

CONCLUSION

There is a lack of empirical research validating the use of Family Conferences in the care of the dying. Whilst experts and practitioners recommend Family Conferences as an intervention to assist the patient and family in coping with the stressors of terminal illness, the benefit if any, to the patient and family have not been measured.[22, 23] The value that a Family Conference might have for all parties is deduced from anecdotal reporting and theory.[5, 6, 19, 22, 23, 29, 36, 43, 47]

To be able to base practice at 2 Military Hospital on outcome-based evidence, empirical research into various aspects of the Family Conference in Palliative Care is required. From the writer's perspective the area most urgently requiring research is to measure whether holding a Family Conference has a beneficial effect on the patient and family, and what that effect is. This could possibly be done by standardising the timing, format, circumstances of Family Conferences held at 2 Military Hospital, and then developing a questionnaire with input from the family therapists (Social work and Psychology). The questionnaire development would have to be preceded with an exercise to determine the areas of concern regarding the functioning of the family during terminal illness. This could be done with focus groups consisting of Inter-Professional team members, patients, and family members. A prospective study examining the possible benefits of a Family Conference on the functioning of a family during terminal illness might be able to make a contribution towards the understanding of the value of Family Conferences in the care of the dying.

The factors that would have to be taken into account during such a study is the diverse range of ethnic and cultural groups in South Africa. Certain cultural groups believe that it is unacceptable to speak of negative facts, such as dying, since speaking of such things will make them happen. The family holding such a belief would probably experience a Family Conference negatively, since one of the aims is to prepare the family for future events. Whilst information-giving and support should be adapted to the needs of each different family, it would probably be quite difficult to prepare a family for an event that they are denying is going to happen, or if they are accepting the situation, will not talk about the facts.

The research into the use of Family Conferences that is required in order for Palliative Care to be based on empirical evidence, is likely to be challenging.

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