

A Family Meeting Addressing Spiritual Needs in a Palliative Care Setting: Some Practical Implications

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ABSTRACT

Purpose

The Purpose of this study was to evaluate the use of a family meeting model to address the spiritual needs of palliative patients and their family members in the context of regular palliative care service.

Approach

This qualitative study was informed by an interpretivist approach and underpinned by Hermeneutic Phenomenology. The family meeting model utilised was developed by Murphy and incorporates a broad understanding of spirituality, acknowledging that religious practice may or may not be a part of spiritual expression.

Setting

The study was conducted in two metropolitan palliative care services in southern Australia both of which provided hospital, hospice and outreach home care services.

Participants

Participants included 12 palliative care patients, 35 family members and 14 palliative care staff from a variety of disciplines. Participating staff had all referred patients to the study and had been involved in their care.

Methods

Twelve family meetings, utilizing Murphy's family meeting model, were facilitated, by the chief researcher. Following the family meeting (usually within two days) individual in-depth interviews were conducted with consenting participants, both patients and family members. Following transcription of interview texts Ricoeur's theory of interpretation was utilized for the analysis of data. Staff members were invited to participate in semi-structured interviews.

Findings

All categories of stakeholder considered that ideally this type of family meeting intervention should be offered within regular palliative care services. Patients, family members and staff experienced and observed benefits from participation. It was recognised that specific skills were needed to facilitate such meetings and that not all staff would have these required skills. Barriers to the implementation of this model including funding priorities, staff time and possible language and cultural issues were identified.

Conclusion

It was concluded that this type of family meeting is potentially a very useful intervention in a setting which promotes holistic care of patients and their family members, including attention to their spiritual care. Work to overcome barriers to implementation such as time and cost issues would need further investigation.

INTRODUCTION

The spiritual care of palliative patients and their families has increasingly been recognised as both an important and a multi-disciplinary task within the palliative care system (Milligan, 2004; Wesley, Tunney, & Duncan, 2004). Williams, Cobb, Shiels and Taylor (2006) concluded that the "fundamental importance of spirituality at end-of-life" (p.407) had been confirmed and a negative correlation between spiritual well-being and anxiety and depression has been identified (McCoubrie & Davies, 2006).

The increasing interest in spiritual care has generated a number of attempts to offer models of care, most of which focus on the patient. Some have attempted to integrate this into the general care of the patient (Friedemann, Mouch, & Racey, 2002), others prescribe a one method for all approach (Hunt, Cobb, Keeley, & Ahmedzai, 2003) and others again offer an intervention to be selectively used to facilitate spiritual care (Chochinov et al., 2005; Chochinov et al., 2006; Murphy, 1999).

This paper reports on the outcomes of investigating the implementation of Murphy's (1999) family meeting model within regular palliative care service. As such they are a part of a larger study that implemented the model and investigated its suitability as specifically focus on the practical implications of including Murphy's model. The personal outcomes of the meetings will be reported in a separate paper.

LITERATURE REVIEW

One of the biggest challenges in the provision of spiritual care has been a lack of clarity about what spirituality means and how it relates to or differs from religion. Spirituality, as defined in this study, is described 'as the web of relationships that gives coherence to our lives. Religious belief may or may not be a part of that web' (Rumbold, 2003 p.12). This web of relationships has been further described to involve relationships with places, things, ourselves, significant others and with a power beyond ourselves (Lartey, 1997).

There is increasing evidence that considering the family as the unit of care, rather than just the patient, has better outcomes for both patients and family members (Cohen et al., 2006; Kissane & Bloch, 2002; Northouse, 2005; Tanyi, 2006; 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 has an impact on other parts of the system and requires the negotiation of a new balance within the system (Hoffman, 1981; Kemp, 1995).

Murphy's (1999) family meeting model is designed to facilitate the holistic care of the whole family unit, including spiritual care, as it has been defined in this study. Murphy describes the family meeting as being in many ways a sacred event, a time for making peace, discharging old resentments, giving thanks and saying goodbye. 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. He has developed a five-part paradigm to guide families through this process which includes; the story of their illness, worries and fears, bringing the memories out from the shadows, the family speaks and the blessing or closing. The main features of this model are explained in more detail in Table 1.

A number of qualities have been identified as important attributes for staff in the provision of spiritual care. These include: self-awareness of their own spirituality and feelings about death, being comfortable with silence, the ability to attend to their own spiritual needs (Govier, 2000; Jackson, 2004; Stanworth, 2004) and the ability to really listen (Narayanasamy, 2004). This ability to listen may well extend to creating the time and opportunity for the patients and families to tell their story, this being very important in the expression and resolution of spiritual needs (Kleinman, 1989; LeFavi & Wessels, 2003; Murphy, 1999). Any proposed model which may facilitate spiritual care needs to take into account these qualities which staff would need in order to implement the model. It also means that the views of staff in relation to the suitability of an intervention for incorporation into regular services are important.

METHODS

Approach

An interpretivist approach puts the emphasis on interpreting experienced or observed phenomena, rather than on explaining in the sense applied in natural science (Crotty, 1998). One of the methodologies which arise from interpretivism is Hermeneutic Phenomenology. Hermeneutics is the “art and science of interpretation” (Ezzy, 2002) especially as it applies to text and phenomenology is the study of the essence of a phenomenon as it presents itself in lived experience in the world (Crotty, 1998). The hermeneutic circle (Heidegger, 1967) demonstrates the process of interpretation which involves constant movement from part to whole and back to part in order arrive at an understanding of the experience of the participants.

In depth unstructured interviews for patients and family members and semi-structured interviews for staff were conducted. These methods are consistent with the above methodology and in the case of palliative patients have been shown to be very appropriate (Silverman, 2000; K. E. Steinhauer et al., 2000).

The five main areas of consideration described by Rice and Ezzy (1999) as necessary to ensure rigor in qualitative studies, were applied to this study. These are described in more detail in Table 2. Approval to conduct the study was obtained from four separate Human Research Ethics Committees.

Participants

A total of 66 patients who met the selection criteria (Table 3) were referred by medical and nursing staff. Potential participants were then either introduced to the researcher by staff or approached by the researcher who discussed the study with them and obtained informed written consent. The mean age of the 12 patients (7 female, 5 male) who agreed to participate was 66.7 years.

Participating family members were invited by the patients. Thirty-five family members (68% female) attended meetings. Only family members over the age of 18 who were able to converse in English were invited to participate in subsequent interviews. Their mean age was 50.5 years and the number of participants at each meeting ranged from 2 to 11.

Staff members from the participating palliative services, who had been involved in the care of patients and family members and who had referred patients to the study were recruited for a semi-structured interview. All those approached (consultants 5, nurses 7, social worker/counsellor 2) agreed to participate.

Process

Family meetings were facilitated by the principal researcher (HT) who has a background in counselling and pastoral care. In preparation for the study she participated in training facilitated by Murphy. The meetings, which lasted from 1.5-2.0 hours, were conducted according to the model described by Murphy (1999) and took place in a location chosen by the patient (5 patients’ home, 1 relative’s home, 4 hospice, 2 hospital). Family meetings of this type were not a part of regular care provided by the participating services.

At the conclusion of the meeting each eligible person was invited to make an appointment with the researcher for a one on one in-depth unstructured interview to discuss their experience of the meeting. The average length of these interviews was 45 minutes. Each interview began with the question ‘Can you tell me about your experience of the family meeting?’ Prompt questions such as ‘Can you tell me more about that?’ or ‘What was that like for you?’ were utilised to provide more in depth information. Only data relating to the possible use of this model as part of regular palliative care service offerings is included in this paper.

Semi-structured interviews with participating staff (average length 1 hour) covered three main areas: how they selected patients for referral, their impressions of outcomes for participating patients and family members and their ideas about the suitability of this model for inclusion in regular palliative care services. Only the data relating to the last issue is discussed in this report.

Data Analysis

All interviews were audio recorded, transcribed and were analysed with the assistance of the software package QSR International NVivo 2.0 (2002). Ricoeur’s theory of interpretation (Geanellos, 2000; Ricoeur, 1981), which describes three levels of analysis, was utilized in the analysis of data in this study. These three levels of analysis are 1) what the text says 2) what it talks about – a naïve understanding 3) in depth understanding. The analysis process included reading and re-reading transcript texts, identifying and describing major themes as they emerged and the sub-themes, categories and sub-categories as they arose from the themes. For example a theme had two or more sub-themes which described particular aspects of this theme. A particular sub-theme may have had two or more categories which further described its nature.

Findings

As different types of interviews were involved, patient/family member data and staff data were analysed separately, but both revealed sub-themes relating to the applicability of this family meeting model to regular palliative care services. These data are detailed in Tables 4 and 5. The main ideas arising from the data are illustrated with direct quotations from interview transcript.

Patient and Family Member Data

Data arising from patient and family member interviews about the general applicability of the family meeting were coded to two categories entitled: ‘who would benefit’ and ‘promoting the meeting’.

Who Would Benefit: 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, although some recognised the importance of patient choice.

I think it is 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 to benefit. (F12Bpara.38)

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. (P5para.188)

A few participants considered that the opportunity should be offered to families with special circumstances such as those who had not experienced a family death before, situations where diagnosis is recent, and those families with poor communication.

I probably thought it was more helpful for people who don't know anything about that part, like death, or haven't experienced it before. (F5Hpara.4)

Sometimes the not nice ones (*family meetings*) would also be healing I imagine (F3Bpara.92)

A significant number of participants also recognised that this style of family meeting would not be beneficial for all and some specific situations were identified. These included: families where people are just unable to face the situation, where silence helps to maintain a sense that this is not happening, situations where people were afraid of what might come out during the meeting, some cultural situations and families that were too volatile.

I think it would be ideal if you could get families together to talk about things. As you have probably experienced, there's a lot who won't face it (F11Gpara.109).

I mean let's face it. Some families don't get on with each other (F6Apara.61).

You will probably have to consider languages and that because people's understanding might be a bit different – different cultures are different. They might think you are being invasive (P8para.54).

The consensus of opinion was that it would be beneficial to make a family meeting of this type generally available but that for a variety of reasons some families would be unlikely to take up the offer.

Promoting the Family Meeting: In the course of discussing the general applicability of the family meeting, a few participants made suggestion about how it might be promoted to palliative patients and their families. Some general comments included: a need for simple clear information – especially stressing that it was not religious in nature, emphasising coping and gaining insight into the family. These are illustrated in the following quotes.

I think it has to be put very simply to people – the kind of things that you're offering and the kind of things that they may get out of it, like just really simply 'this is what we talk about' (P8para.54).

A lot of them will say it sounds too religious based, although its not (F11Cpara.126).

Some specific ideas about promoting the meeting were also offered such as brochures explaining this type of meeting, available at all relevant agencies, and the importance of word of mouth promotion, especially by staff.

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 or whatever (P8para.66).

There are so many (*agencies*). If it was put to each one you'd be inundated within a week (F11Cpara.163).

Staff Data

As illustrated in Table 5 four categories of data were identified within the sub-theme 'inclusion in regular services' arising from staff data.

A Good Thing: Every one of the participating staff members indicated either that it was a good program or that they perceived a great need for it in the system. Some examples of their comments are shown below.

It would be fantastic, absolutely fantastic. 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 (S6para.116).

Well if I was dying I'd want it offered to me (S13para.64).

Practical Barriers: Staff members also identified the potential practical barriers to its implementation. Funding was seen as the biggest practical barrier, both general lack of funding in the health system and the conflict of priorities for available funding.

There's always the number one – money (S14para.66).

Yes but also I do 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. The broad cultural priorities of, for want of a better term, the physical material, it's easier to deal with that, because the emotional is sort of...its demanding and less definable (S9para.61&66).

Related to the issues of funding is staff time and numbers. With ever extending patient lists in palliative care services there is little time for interventions that are time intensive.

I think in the current system it (*spiritual care*) doesn't happen like it should. And even if you increase funding, it would be very difficult I think just in practicalities. It's difficult to organise, manage and if you do that with every patient, just pretty quickly you double people's time (S13para.54).

The possible barriers of language, interpreter and differing cultures were also raised as increasingly patients and their family members who do not speak English are registered with palliative care services.

Also we have non English speaking people so that will become a bit of a barrier. I'm not sure how good a family meeting could be – I wouldn't think it would be ideal going through an interpreter. It wouldn't actually be a very meaningful, thoughtful conversation using an interpreter both ways (S1para.31&33).

Staff Qualities: Participating staff members also commented on staff personal qualities which would be needed, in their view, to facilitate such meetings, about one third stating that staff were currently ill equipped for this task, which some considered to be a specialised field.

And sometimes being chronically nice, as we are at palliative care, we try to take on too many things and things for which we're ill equipped (S12para.40).

I guess I would be thinking of people with a social work background, grief and bereavement coordinators, people who have done courses in dealing with the issues that are likely to come up I guess. If there was a role for nursing also that would need to be specific nursing, not as part of a clinical role (S1para.17).

Not all agreed however, that this was a specialist task suggesting that either it needs to be facilitated by the person present in the moment or that many patients do not want to deal with so many different specialists.

It's a bit like the leader of the team is the one who's right there at the time. It's not necessarily the medical director or the nursing director or the social worker (S12para.50).

When you have that initial talk with them (*the patient*) they don't want anyone else involved at this stage. And so that is always a conflict (S13para.37).

Ideas for Incorporating it into the System: Consideration was given by some staff participants as to how this type of family meeting could be promoted if it were incorporated into regular services. Three particular issues were raised: 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.

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*) (S3para.81).

It was considered important that such a meeting be seen as 'normal' within the system.

So just rock in and 'Hi! Well we need to have a family meeting and this is just standard procedure, and let's get on with it.' I think that would be fantastic (S4para.32).

The issues of who to offer it to, how many meetings would be offered and the timing of those meetings in relation to illness trajectory were also considered important.

Because it is time consuming 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).

I guess that's the other issue – would it be five meetings or would it be open ended or would it be whatever was needed and could the staff that was to provide the service be able to accommodate the flexibility in what those people actually need (S1para.29).

Several other issues relevant to the process of incorporating this family meeting model into regular services were raised such as cultural differences and appropriateness, for example the degree to which truth in relation to death is acknowledged. The almost global value of story telling was however recognised.

I think the professionalism (*of interpreters*) is improving, but 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).

DISCUSSION

The view expressed by all participating staff members was that the type of family meeting reported would be good to offer patients and preferably as a 'normal' part of the service. Patient and family member participants supported this view, the general consensus of opinion among those who commented being, that it should be promoted as 'normal' and although voluntary, was recommended. This view is certainly consistent with those of experts such as Kissane and Bloch (2002) and Waldrop, Milch and Skretny (2005) whose work recognised the value of working with family units, rather than just the patient.

As reported, most staff however, indicated that due to current staffing and funding levels, and because the current medical model does not give high priority to psycho-social and spiritual care, decisions would have to be made about to whom the service would be offered. Kissane and Bloch (2002) also indicated that family interventions may not be for all as some particularly dysfunctional families may not have the skills to benefit from a family intervention. An appropriate screening tool to enable the identification of those families most likely to benefit from this intervention would probably be helpful in determining which

families would be offered this family meeting. The Family Relationship Index (Kissane & Bloch, 2002), which was found to be effective in identifying those families most likely to benefit from family therapy, in relation to bereavement outcomes, could be further investigated for its possible use in this context.

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 members of nine of the 12 participating families indicated an interest in having more than one meeting. Further work with Murphy's model would help determine the optimal number of family meetings needed for best outcomes, however, the results of this study suggest that this would vary considerably with individual patients and families.

Implications for promoting this type of family meeting within the regular care service were commented on by patient, family members and staff participants. The suggested method of promotion was, simple and clear information about the purpose of the meeting, making it clear that it was not necessarily religious in nature. This 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 print material about palliative care services and also personally promoted to patients by staff. This latter suggestion is supported by the higher rate in recruiting in the reported study for potential participants who were personally introduced to the researcher by a staff member compared to those who were referred only. It is also consistent with the findings of Steinhauser et al. (2006) that showed that a letter of personal recommendation by the physician resulted in higher recruitment rates.

The need for particular qualities in the successful facilitation of such family meetings, was recognised by some staff participants. These observations are not only consistent with the views of Murphy (1999) who developed this model and continues to provide workshops for the development of relevant qualities, but have also been identified by Sherman et al. (2005) and Steinhauser et al. (2006). 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 background, possess suitable personal attributes and are trained in the necessary skills that have been identified as making effective and safe facilitation possible for both participants and staff facilitators.

LIMITATIONS

The relatively small number of families (12) and staff members (14) participating in this study is a limiting factor. Further research is needed to investigate the applicability of the model to a broader range of families from the perspective of age and ethnic and religious background. A further limitation is that all patients self selected and it is possible that the nature of family relationships influenced their decision to participate. A more precise tool is needed for measuring benefits of the meeting and for determining which families would benefit most.

CONCLUSIONS

The outcomes of this study suggest that the ideal option would be to offer this type of family meeting opportunity to all patients registered 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. The challenges to

implementation include sufficient staff with time and suitable qualities and skills, language and cultural issues and funding priorities. Of course it could be argued that an intervention that may in the longer term reduce the need for individual therapy may 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 registration data collected, this intervention could be more easily be applied in the current health care system.

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Table 1: Key Features of the Murphy's Family Meeting Model

Aspect of Model	Main Features
The 5 Part Paradigm: 1. Story of the Journey	<ul style="list-style-type: none"> - Begins with the patient talking about the journey of illness as they experienced it. - It includes the things that are and have been important to them, have helped them to make sense of it. - It may also include the story of other important experiences and struggles of their life.
2. Worries and Fears	<ul style="list-style-type: none"> - The storyteller is encouraged to speak of their worries, fears and concerns about the illness and its outcomes for themselves and the family.
3. Speaking of Roots	<ul style="list-style-type: none"> - Speaking of family history, recent and not so recent. - Allowing the pains and the joys to be openly express
4. The Family Speaks	<ul style="list-style-type: none"> - Each person present has the opportunity to tell the story of their journey in relation to their loved one's illness - They speak of the history as they have experienced it - They have the opportunity to respond to what others have said.
5. The Closing or Blessing	<ul style="list-style-type: none"> - A way of bring the meeting to a close which is appropriate for the family. - It may be a ritual with religious connotations if the is appropriate - It may be an opportunity for each person present to say one thing that they value most about the person who is dying.
The 3 Main Roles: 1. The Storyteller	<ul style="list-style-type: none"> - The one who speaks – everyone takes a turn (1 at a time)
2. Witness(es)	<ul style="list-style-type: none"> - The ones who listen preferably without judgement or interpretation – everyone else who is present
3. The Facilitator or Guide	<ul style="list-style-type: none"> - One who is able to guide and move the meeting along with the use of probe questions if needed. For example 'Do you want to say more about that?' 'What was that like for you?'

Table 2: Application of Standards of Rigour

Type of Rigour	Application
Theoretical	The application of sound reasoning to the choice of methods which are consistent with both the theoretical underpinning of the study and the research questions being investigated.
Procedural	The careful documentation of all decisions and processes from the initial proposal to the final conclusions which includes an audit trail.
Interpretive	Interpretive rigour is achieved when an understanding is reached which is consistent with the views of the participants within the context of their world view. It is supported by direct quotes from the participants.
Evaluative	This involves giving full consideration to all ethical aspects of the study including informed consent and giving paramount concern to the well-being of the participants.
Rigorous Reflexivity	This takes into account the impact of the researcher on the intervention, data collection and data interpretation including their life experiences and personal philosophical stance and world views

Table 3: Patient Selection Criteria

<ul style="list-style-type: none"> - Patients considered by medical to staff to be able physically and mentally able to attend and participate in a family meeting - Those who were aware of the terminal nature of their illness - Those whose prognosis was less than six months - Over the age of 18

Table 4: Patient and Family Member Data – General Applicability of the Meeting

Category	Sub-Category	Main Ideas
<i>Who would benefit</i>	Everyone	<ul style="list-style-type: none"> - offer to everyone - generally beneficial - patients free to choose - value even if intense - would need guidelines - value cannot be measured
	Special circumstances	<ul style="list-style-type: none"> - those who haven't experienced death in the family - those with recent diagnosis - those with poor communication - families with difficulties
	Not for all	<ul style="list-style-type: none"> - some can't face it - some families too volatile - wouldn't suit some cultures - too hard on some patients
<i>Promoting the meeting</i>	General comments	<ul style="list-style-type: none"> - clear purpose - simple clear information sheet - emphasize non-religious/coping/family functioning - different name would be better
	Specific means of promotion	<ul style="list-style-type: none"> - specific brochures at all service providers - include with usual palliative care brochure - would of mouth - personal promotion by staff

Table 5: Staff Data – Inclusion in Regular Service

Category	Sub-category	Main Ideas
<i>A good thing</i>	General positives	powerful, essential, brilliant, valuable, useful, beneficial, I'd want it, will get attention.
	There is a need	<ul style="list-style-type: none"> - need to talk - lack of counselling - lack of spiritual support - difficult to know most - effective ways for families
<i>Practical barriers</i>	Funding	<ul style="list-style-type: none"> - lack of availability - other areas given priority
	Staff time/numbers	<ul style="list-style-type: none"> - time intensive - shortage of suitable staff
	Other barriers	<ul style="list-style-type: none"> - language issues - cultural issues - would it work with interpreters?
<i>Staff qualities</i>	Those needed	<ul style="list-style-type: none"> - adaptability - aware of own spirituality - ability to build rapport - specialist field - most staff currently ill-equipped
	Generalist versus specialist	<ul style="list-style-type: none"> - prioritizing tasks - immediacy of need - protecting own discipline - too many faces - lack of awareness of skills needed
<i>Ideas for incorporation</i>	Promoting the meeting	<ul style="list-style-type: none"> - telling patients personally about meeting - make it a normal thing in the system
	Participation	<ul style="list-style-type: none"> - need a way of knowing who to offer it to - number and timing of meetings
	Other	<ul style="list-style-type: none"> - coordinate with other services - provide staff training - start a trial period in hospice