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A FAMILY MEETING ADDRESSING SPIRITUAL NEEDS IN A PALLIATIVE CARE SETTING: SOME PRACTICAL IMPLICATIONS

(Study undertaken at the University of Adelaide)



Background to the Study

- Holistic care of palliative patients (including spiritual and psychosocial care) is widely accepted
 - as important
 - as a multidisciplinary task.
 - as a key area for research
- Spirituality defined “as the web of relationships that gives coherence to our lives”¹. Includes relationships with places, things, ourselves, significant others, and with a power beyond ourselves. May or may not include religion.



What is Important in the Implementation of Spiritual Care & Psychosocial Care?

- Self-awareness of staff^{2,3}.
- The ability to really listen and to create opportunities for story telling⁴.
- Opportunity and ability for referral to staff with specialised knowledge^{5,6}.



Why Work with the Whole Family?

- Families are systems – a part impacts on the whole⁷.
- Reduced risk of complicated grief⁸.
- Increased ability to adapt to change⁹.
- Families differ – one process does not fit all¹⁰



Murphy's Model: Five Parts

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

(Murphy 1999)



The Key Roles

- Story Teller:
 - The one whose turn it is to speak
 - Only they may speak at that time.
- Witness:
 - Listens and absorbs
 - May not judge or interrupt.
- Guide/Facilitator:
 - Gives permission for the story-teller to speak
 - supports, encourages and prompts.



Recruiting

- Drawn from families registered with 2 metropolitan palliative care services
- 3 categories of stakeholders:
 - patients
 - family members as chosen by patients
 - staff involved in patient care.
- Criterion sampling
- Recruited 12 families (47 participants) and 14 staff



Study Process

- Hermeneutic Phenomenology utilising Ricoeur's Theory of Interpretation^{11,12}
- Implementing the family meeting
- Individual in-depth interviews with patients and family members who participated
- Individual semi-structured interviews with consenting staff involved in patient care
- Transcribing of interviews
- Data analysis

Results: Patients and Family Members

Who would benefit?

Everyone	Special circumstances	Not for all
<ul style="list-style-type: none">• offer to everyone• generally beneficial• patients free to choose• value even if intense• would need guidelines• cannot measure the value of it	<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	<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



Quotes

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)



Promoting the meeting

General Comments	Specific Means
<ul style="list-style-type: none">• clear purpose• simple clear information sheet• emphasize not necessarily religious• coping/family functioning• different name would be better	<ul style="list-style-type: none">• specific brochures at all service providers• include with usual palliative care brochure• word of mouth• personal promotion by staff



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).



Results: Staff Members

A good thing

General Positives	There is a need
<ul style="list-style-type: none">• powerful• essential• brilliant• valuable• beneficial• I'd want it• will get attention.	<ul style="list-style-type: none">• need to talk• lack of counselling• lack of spiritual support• difficult to know most• effective ways for families



Quotes

It would be fantastic, absolutely fantastic. Look at our aging population, 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).

I think there's a huge need for putting something like that in place for families coming to terms with their loved one dying and the patient themselves. I don't think there is anywhere enough spiritual support for families and dying patients (S2para.21).



Practical Barriers

Funding	Staff time/numbers	Other barriers
<ul style="list-style-type: none">• lack of availability• other areas given priority	<ul style="list-style-type: none">• time intensive• shortage of suitable staff	<ul style="list-style-type: none">• language issues• cultural issues• would it work with interpreters?



Quotes

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 physical/material, it's easier to deal with that, because the emotional and the spiritual is sort of....its demanding and less definable

(S13para61)



Staff qualities

Those needed	Generalist vs specialist
<ul style="list-style-type: none">• adaptability• aware of own spirituality• ability to build rapport• specialist field• most staff currently ill-equipped	<ul style="list-style-type: none">• prioritizing tasks• immediacy of need• protecting own discipline• too many faces• lack of awareness of skills needed



Quotes

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).

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 incorporation

Promoting the meeting	Participation	Other
<ul style="list-style-type: none">• telling patients personally about meeting• make it a normal thing in the system	<ul style="list-style-type: none">• need a way of knowing who to offer it to• number and timing of meetings	<ul style="list-style-type: none">• coordinate with other services• provide staff training• start a trail period in hospice



Quotes

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).

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).



Limitations

- Relatively small number of participants
- More work to establish applicability to other age groups, ethnic and religious backgrounds
- Patients self selected – some family dynamics would make it extremely unlikely that these families would participate
- A more precise method for determining who would most benefit



General Conclusions

- Beneficial and ideally offered as a normal part of services
- Current staffing and funding levels do not give high priority to psycho-social and spiritual care hence determining who would benefit most would be important
- Appropriately trained staff needed
- Promotion that makes clear the broad nature of the possibilities within this model.



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