
ORIGINAL ARTICLES

Meeting the family: Measuring effectiveness of family meetings in a specialist inpatient palliative care unit

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(RECEIVED December 28, 2010; ACCEPTED April 9, 2011)

ABSTRACT

Objective: The World Health Organization (WHO) definition of palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness . . .” recognizes the importance of family members in this setting. In practice, family meetings account for a significant amount of the weekly workload in a specialist inpatient palliative care unit. Despite this, there is little empirical evidence to support the benefits of family meetings from the perspective of family members.

Method: A prospective study over 6 months, invited a designated family member to complete a self-report instrument (SRI) and the Family Inventory of Needs (FIN) questionnaire prior to, immediately following, and 48 hours after a planned family meeting attended by several members of the multidisciplinary team.

Results: Thirty-one designated family members completed the study. The SRIs completed prior to a family meeting identified particular areas of concern and worry for family members, and also helped to generate an agenda based on the family's particular needs. The pre-meeting FIN identified areas of patient care of greatest importance to each family member, and asked them to rate whether particular care needs were presently met or unmet, in their opinion, by the healthcare team caring for the patient. Following the family meeting, repeat SRIs showed an overall reduction in concerns and increased confidence in dealing with those issues raised. Post-family meeting FIN scores confirmed a greater number of met care needs compared with pre-meeting scores, all of which were sustained over time.

Significance of results: This study confirms the value of planned multidisciplinary family meetings for patients in specialist inpatient palliative care units. It identifies the often unmet needs of family members and the sustained benefits associated with formal family meetings.

KEYWORDS: Family meeting, Palliative care, Specialist inpatient unit, Effectiveness

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INTRODUCTION

No universally agreed definition exists for what constitutes a family meeting, but perhaps Hansen

summarizes its key components best by suggesting it to be “a meeting which involves a number of family members, the patient and hospital personnel in discussions concerning the patient’s illness, treatment and plans for their discharge or their care outside the hospital” (Hansen et al., 1998). The World Health Organization recognizes the importance of family in its definition of palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness . . .” (WHO, 2002). Clinical experience bears this out and suggests that family meetings represent a potentially powerful clinical tool in facilitating communication between healthcare professionals and families. Such meetings enable patients, family members, and healthcare providers to discuss current medical issues, prognosis, goals of care and place of care (Cohen Fineberg, 2005). This is particularly important in the palliative care setting, where patient preference to die at home often means that family members provide much of a patient’s end-of-life care. Where families are more involved in the day-to-day care of a patient, they may also have a role in decision making regarding goals of care and ultimate place of care. Family members are, therefore, often recognized as members of the multidisciplinary team themselves (Christ & Blacker, 2005).

Despite their perceived value in palliative care settings, there is a dearth of published data to support the effectiveness of family meetings. Much of the published work focuses on communication techniques rather than broadly assessing the effectiveness of family meetings as an intervention (Dumont & Kissane, 2009; Gueguen et al., 2009). Others have reflected upon the characteristics of family meetings in terms of patient demographics and information discussed at meetings (Yennurajalingam et al., 2008). Furthermore, a significant amount of data is extrapolated from psychiatry or intensive care settings rather than directly from patients in hospice or palliative care settings (Curtis & White, 2008; Hudson et al., 2008). To date, only one study has measured the effectiveness of family meetings in a palliative care setting (Hudson et al., 2009).

Prior to this study, we conducted an audit of our practice of conducting and recording family meetings in our inpatient hospice unit. Our findings revealed a poor level of documentation regarding both the individuals attending the meetings and the issues discussed (Hannon et al., 2010).

The aim of this study was to prospectively assess the effectiveness of family meetings in an inpatient specialist palliative care unit.

METHOD

Research Subjects

Prospective Study Participants

Patients admitted to the inpatient unit of Our Lady’s Hospice, Harold’s Cross, (Dublin, Ireland) from December 2009 to May 2010 were recruited. Patients were included if they were ≥ 18 years of age, spoke English as their first language, had a primary diagnosis of cancer, and had capacity to give informed consent. Patients were excluded if they were actively dying on admission to the unit (in such cases an urgent family meeting may have been necessary), or if they declined a family meeting following discussion with a member of the multidisciplinary team. The exclusion criteria also included a primary diagnosis of a non-malignant condition, and the need for a translator or interpreter to aid communication with either the patient or family member(s).

Data Collection

Routine Practice

On average, there are 400 patient admissions per annum to our 36-bed hospice inpatient unit. Approximately 75% of patients are admitted for terminal care and die on the inpatient unit, with the remainder being admitted for periods of symptom control, respite, or rehabilitation. Family meetings account for a significant amount of the clinical workload, with up to four meetings offered per week on each of two 18-bed wards. The meetings are primarily organized and chaired by the medical social worker and attended by at least one member of the medical team; a nurse; and representatives from physiotherapy, occupational therapy, and/or chaplaincy, where relevant. The number of healthcare professionals at such meetings is sometimes proportionately reduced to avoid intimidating the patient and the patient’s family. Meetings last between 40 and 60 minutes each on average, and offer family members an opportunity to meet with several key members of the multidisciplinary team simultaneously. Most family meetings serve to provide a medical update, to discuss potential discharge plans where feasible, to sensitively discuss prognosis, and to give an opportunity to open lines of communication among family members themselves. Family meetings are also used as an opportunity to identify potentially vulnerable family members or families who may require additional bereavement aftercare support.

Study Protocol

Once a patient was deemed eligible and written consent was obtained, the patient’s designated next-of-

kin (as per their admission documentation) was approached. Written consent was also obtained from this family member. Baseline demographic data were collected on both the patient and designated family member. The meetings were scheduled by and chaired by a medical social worker. A physician consultant and/or a specialist registrar in palliative medicine and a member of nursing staff were present at each meeting. Where relevant, a physiotherapist, occupational therapist, and/or chaplain were invited to attend.

A standardized approach was used for data collection: for each patient, a single designated family member was invited to complete both a standardized self-report instrument (SRI) and a Family Inventory of Needs (FIN) tool prior to the family meeting (T0), immediately after the meeting (T1) and 48 hours after the meeting (T2).

SRI

The self-report instrument was devised by and utilized by Hudson et al. (2008). Based on four leading questions, it was used to identify key concern(s) for family members prior to the meeting (T0), thus forming an agenda, via a free-text component. It also included a numerical rating of how worried family members were about these concerns, how often these concerns arose, and how much the problem interfered with their lives on a scale of 1 to 10 (where 1 represents “not at all” and 10 “all the time”). Family members were also asked to rate how confident they felt in dealing with this concern, again on a numerical scale of 1 to 10, (where 1 represented “not at all” and 10 “all the time”). Immediately following the family meeting (T1) and 48 hours later (T2), a modified version of the self-report instrument was completed by family members. It reminded the family member of their identified concern(s) pre-meeting and repeated the four original questions, which

were again scored numerically 1 to 10, reflecting the perceived usefulness of the meeting.

FIN

The FIN is a 20-item questionnaire that has been shown to be a reliable and valid tool in assessing the importance and fulfilment of care needs of family members of advanced cancer patients. It has two subscales, each designed to quantify a separate concept; “Importance of Family Care Needs” and “Fulfilment of Care Needs”. “Importance of Family Care Needs” is defined as the family member’s perception of the significance of requirements for care as provided by healthcare professionals. Each of the 20 statements is rated on a continuum from unimportant to extremely important, which is reflected by a numerical score on a 0–10 scale, where the 0 and 10 anchors indicate the perception of an unimportant and a very important care need, respectively.

The second subscale, the Fulfilment of Care Needs subscale, uses the same 20 statements as the Importance of Family Care Needs subscale. This subscale has been defined as the judgement made by individual family members regarding whether their perceived needs have been satisfied by healthcare professionals. Rather than lying on a continuum, this is considered a dichotomous concept and is scored as being either “met” or “unmet” at each of the time intervals (T0, 1, 2), (Kristjanson et al., 1995).

Data Analysis

Based on Hudson et al.’s (2009) previous study, which utilized the same assessment tools, we estimated that a sample size of 30 participants would be necessary to achieve 80% power with an α level of 0.05. Descriptive analyses are presented as proportions, means, and standard deviations (SD). Paired *t* tests were used to make comparisons between pre and

Table 1. Self-report instrument (SRI) results at T0 (pre-meeting) and T1 (post-meeting)

Question ^a	Mean SRI item scores \pm SD		Mean differences (95% CIs)	<i>p</i> value ^b
	Pre-meeting (T0)	Post-meeting (T1)		
Q1	8.7 \pm 1.7	5.3 \pm 2.3	3.4 (2.4 to 4.3)	<0.001
Q2	8.3 \pm 2.4	5.8 \pm 2.5	2.3 (1.5 to 3.0)	<0.001
Q3	7.2 \pm 2.5	5.8 \pm 2.5	1.3 (0.3 to 2.2)	<0.01
Q4	5.6 \pm 2.3	7.6 \pm 1.9	2.0 (–1.0 to –2.9)	<0.01

^a**Q1:** How upset or worried are you about these concerns?

Q2: How often do these concerns arise?

Q3: How much are these concerns interfering with your life?

Q4: How confident do you feel in dealing with these concerns?

^bUsing paired *t* test and Bonferroni correction (adjusted significance: $p < 0.0125$)

SD, standard deviation; CI, confidence interval

post-measures. Fisher exact test was used to compare FIN pre- and post-measures. Graph Pad Prism (Version 4.00) was used for statistical analysis. Because a number of univariate analyses were performed, and to reduce the risk of a Type 1 error, a Bonferroni correction was used for the data analysis shown in Table 1. The conventional significance level was adjusted from 0.05 to 0.0125, meaning that any p values < 0.0125 were considered significant.

Ethical Considerations

This research was approved by our local Research Ethics Committee, based at St. Vincent's University Hospital, Dublin. Written informed consent was obtained from each patient and designated family member after explaining the purpose of the research, the voluntary nature of the participation, the respect for privacy in the handling of data, and the other research protocols. Additional support from the multidisciplinary team was offered to any participants who became distressed as a result of any issues raised during the course of a family meeting.

RESULTS

We recruited 31 participants over the study period (from December 2009 to May 2010), of whom 28 completed data across all three timescales (T0, T1, T2). In two instances, the patient deteriorated and died before data collection was complete, and in one case we were unable to contact the designated family member following the family meeting within the allotted time scale for data collection. All 31 participants were included in data analysis.

Demographic Data

Demographic data relating to patients and their respective designated family member participants are summarized in Table 2. Of the 31 patients who consented to the study, 14 (45.2%) were male. Eighteen (58.1%) were married, nine were widowed (29.0%), three (9.7%) separated or divorced, and one (3.2%) single. In the majority of cases the participating family member was either a spouse (35.5%) or adult child (48.4%). Table 2 also shows patient outcomes at the end of the study period. Nineteen (61.3%) patients died in the hospice during the study period, seven (22.6%) had been discharged home and were being attended to by the community palliative care team, and five (16.1%) patients remained inpatients at the end of the study period.

Table 2. Patient and participant data

Patient and participant data	$N = 31$ (%)
Patient cancer diagnosis	
Breast	04 (12.9)
Colorectal	03 (09.7)
Lung	06 (19.3)
Prostate	04 (12.9)
Upper GI	06 (19.4)
Brain	03 (10)
Other	05 (16.1)
Marital Status	
Married	18 (58.1)
Single	01 (03.2)
Separated/divorced	03 (09.7)
Widowed	09 (29.0)
Participant relationship to patient	
Husband	07 (22.6)
Wife	04 (12.9)
Daughter	13 (42)
Son	04 (13)
Sibling	02 (06.5)
Other	01 (03.2)
Patient Outcome	
Death during hospice admission	19 (61.3)
Discharge home	07 (22.6)
Remains inpatient	16.13 (5)

SRI Results

The most common concerns identified by family members in the SRI were related to the patient's current medical status, prescribed medications, anxieties regarding the expected trajectory of illness and prognosis, and fears for the psychological well-being of the patient.

The results of the four numerical rating scales in the SRI are shown in Table 1. Paired t tests were performed comparing scores before and immediately after the family meeting (at T0 and T1) and immediately after and 48 hours after the meeting (T1 and T2). There was no statistically significant difference between scores at T1 and T2; therefore, Table 1 shows the T0 and T1 t test results only. The 95% Confidence Intervals in Table 1 represent the difference in scores pre- and post- family meeting.

Item one on the self-report instrument asked participants to rank on a numerical scale their current level of upset or worry. At T1, the mean difference in score was 3.4 lower than at T0, (95% confidence interval 2.4–4.3, p value < 0.0001). In terms of the frequency with which concerns arose, mean scores fell by 2.3, (95% confidence interval 1.5–3.0, p value < 0.0001). How much these concerns were interfering with participants' lives also fell by a mean score of 1.3, (95% confidence interval 0.3–2.2, p value < 0.01). Participants generally felt more

confident in dealing with their concerns following the meeting, with scores increasing by a mean of 2.0, (95% confidence interval $-1.0-2.9$, p value <0.001).

FIN Results

The two FIN questionnaire subscales were scored separately. In terms of the Importance of Family Care Needs, participants tended to score items divergently as either very important indeed (i.e., 10) or not important at all (0). The areas of lesser importance related to expected outcomes of the illness and to providing support for participants themselves. These included the need to feel there was hope (Item 9), the need to know the probable outcome of the patient's illness (Item 13) and the need to have someone concerned with the participant's own health (Item 19). Following the family meeting at T1 and on review at T2, there was no statistically significant change in scores on the Importance of Family Care Needs subscale. Family members consistently reported the same items on the scale as very important or not important at all, irrespective of discussion at the meeting. Results in Table 3, therefore, refer only to the Fulfilment of Care Needs subscale.

For the second subscale, the Fulfilment of Care Needs Subscales, any item scored at zero on the Importance of Family Care Needs Subscales was not included in this part of the questionnaire as it was deemed unimportant and therefore not necessitating

further discussion. There was no statistically significant difference in scores between T1 and T2. T0 and T1 scores are shown in Table 3. Scores reflect the number of participants who identified each individual item as "met" at T0 and T1, as a percentage of the number who scored it as important. In all cases, participants scored a greater number of items "met" following the family meeting. Areas of greatest improvement were seen in answering questions honestly (item 1) and offering information regarding prognosis (item 2). Participants felt they had a greater understanding regarding patient's current care (items 5 and 6), as well as having a greater awareness of what to expect in the future, in terms of symptoms and estimated time frames or prognosis (items 11 and 12). Participants felt they had more information regarding caring for the patient at home (item 16) and were more aware of available supports (item 20).

DISCUSSION

In view of the limited data supporting the effectiveness of family meetings, coupled with the significant time spent facilitating family meetings in our inpatient palliative care unit, we conducted a study exploring the benefits of such meetings from the perspective of family members. Our study demonstrates that family meetings are an effective means of communicating with family members in this

Table 3. Family Inventory of Needs (FIN) results

Family Inventory of Needs (FIN)	"Met" at T0 (%) ^a	"Met" at T1 (%) ^b	p values Fisher exact test
1. Have my questions answered honestly	17 (54.8)	28 (100)	<0.0001
2. Know specific facts re: prognosis	8 (25.8)	24 (88.9)	<0.0001
3. Feel professionals care about patient	28 (93.3)	27 (100)	0.4925
4. Informed re: changes in patient's condition	18 (62)	27 (100)	0.0003
5. Know exactly what is being done for patient	16 (53.3)	27 (100)	<0.0001
6. Know what treatment patient receiving	15 (48.4)	27 (100)	<0.0001
7. Explanations given in understandable terms	23 (74.2)	27 (100)	0.0053
8. Told about changes in treatment plans	17 (58.6)	27 (100)	0.0001
9. Feel there is hope	13 (65)	19 (95)	0.0436
10. Assured patient receiving best possible care	24 (85.7)	26 (100)	0.1120
11. Know symptoms disease/treatment can cause	6 (20.1)	26 (100)	<0.0001
12. Know when to expect symptoms to occur	3 (11)	23 (92)	<0.0001
13. Know probable outcome of illness	11 (55)	20 (100)	0.0012
14. Know why things being done for patient	16 (57.1)	26 (100)	0.0001
15. Know names of healthcare professionals	26 (89.9)	26 (100)	0.2384
16. Have information re: what to do for patient at home	7 (25.9)	26 (100)	<0.0001
17. Feel accepted by healthcare professionals	28 (100)	27 (100)	–
18. Help with patients care	19 (79.2)	24 (100)	0.0496
19. Have someone be concerned with my health	9 (56.3)	16 (100)	0.0068
20. Be told about people who can help with problems	10 (35.7)	26 (96.3)	<0.0001

^aIndicates item on FIN scored as "met" by family member prior to family meeting.

^bIndicates item on FIN scored as "met" by family member following family meeting.

setting. The level of family members' concerns and worries decreased following the meeting, and these improvements were sustained over a 48-hour period. Family members reported increased confidence levels in dealing with these concerns following a family meeting, which was also sustained over time.

This study provides further evidence that family members of cancer patients have unmet information needs, particularly in relation to medical updates, prognosis estimation, and discharge planning. Our intervention, however, demonstrates that structured family meetings can offer an effective and valuable means of information sharing. These results were independent of the patient's overall outcome, with family members benefiting from meetings even in situations in which discharge home was not achieved.

Historically, family meetings were often conducted in emergency situations or in an ad hoc fashion, rarely planned in advance, and seldom formed part of a patient's overall care plan while in hospital. Despite the long-held recognition of family members as an integral part of patient care at the end of life, few studies have yet to assess the manner in which we communicate with families, or, indeed, what tools are used. The results of our study compare favorably with those of Hudson et al. (2008), where the same data collection tools were utilized. In terms of the SRI, our results showed statistically significant improvements in scores across all domains. The FIN (Fulfilment of Care Needs Subscale) results were similarly impressive, with dramatic improvements in meeting the care needs of family members in most areas assessed. This adds further weight to the arguments supporting involving family members in discussions with members of the multidisciplinary team to optimize patient care planning. Furthermore, family meetings offer family members an opportunity to access personal support, and for multidisciplinary team members to identify family members who may require additional support. Hudson et al.'s recently published systematic review of instruments used to support family caregivers, and Aoun et al.'s reliability testing of a tool measuring family carer satisfaction with palliative care services, demonstrate the growing interest in offering structured assistance to family members, and the evolving areas for further research (Aoun et al., 2010; Hudson et al., 2010).

Our study has a number of limitations. First, data collection was performed by the same personnel conducting the family meetings, and this may have introduced a positive response bias. Second, not all patients admitted to the inpatient unit are routinely offered a family meeting, mainly because of the time constraints associated with conducting frequent meetings. This may result in a selection bias. Third, our study was

wholly quantitative and was not designed to capture qualitative data to support our results. A further study with qualitative elements and independent data collectors may add further weight to the benefits of family meetings as demonstrated in this study. Fourth, the psychosocial needs of family members are incompletely captured by the tools employed in this study, and could form the basis of further studies. Finally, the benefits of family meetings specifically from a multidisciplinary team perspective, were not formally evaluated in this study.

An unexpected outcome of the study was the value of the SRI in setting an individualized agenda for each family meeting. This allowed the multidisciplinary team to tailor meetings based on the particular needs of each family, as outlined in the completed instrument prior to each meeting (at T0). Although not directly measured, this appeared to be associated with greater levels of satisfaction among the attending members of the multidisciplinary team as well as family members. It may also have positive implications in terms of time spent conducting individual family meetings, given that time constraints are regularly identified as barriers to greater numbers of family meetings. Future studies exploring the satisfaction levels among members of the multidisciplinary team following family meetings would be useful. It may also be interesting to explore whether routinely offering a family meeting, planned soon after admission, with a well-defined agenda, actually has an efficiency advantage and reduces the need for, and frequency of, informal discussions with family members on the ward.

CONCLUSIONS

This study adds further weight to the previously published data supporting the benefits of conducting family meetings in inpatient palliative care units. The use of a self-report instrument in conjunction with a validated tool such as the FIN, affords the opportunity to objectively assess the effectiveness of family meetings. Further studies are required; these should include a qualitative component to address the effectiveness of family meetings from the perspective of both family members and members of the multidisciplinary team. To fully address the holistic care needs of patients, and thereby fulfill the true definition of palliative care in practice, ongoing involvement of family and the assessment of family members' needs are fundamental requirements.

REFERENCES

- Aoun, S., Bird, S., Kristjanson, L.J., et al. (2010). Reliability testing of the FAMCARE-2 scale: measuring

- family carer satisfaction with palliative care. *Palliative Medicine*, 24, 674–681.
- Christ, G.H. & Blacker, S. (2005). Improving interdisciplinary communication skills with families. *Journal of Palliative Medicine*, 8, 855–856.
- Cohen Fineberg, I. (2005). Preparing professionals for family conferences in palliative care: evaluation results of an interdisciplinary approach. *Journal of Palliative Medicine*, 8, 857–865.
- Curtis, J.R. & White, D.B. (2008). Practical guidance for evidence-based ICU family conferences. *Chest*, 134, 835–843.
- Dumont, I. & Kissane, D. (2009). Techniques for framing questions in conducting family meetings in palliative care. *Palliative and Supportive Care*, 7, 163–170.
- Gueguen, J.A., Bylund, C.L., Brown, R.F., et al. (2009). Conducting family meetings in palliative care: Themes, techniques, and preliminary evaluation of a communication skills module. *Palliative and Supportive Care*, 7, 171–179.
- Hannon, B., O'Reilly, V., Bennett, K., et al. (2010). Family meetings in a specialist palliative care unit: Are they effective? EAPC 2010 Abstracts: Oral, Plenaries and Invited Lectures. *Palliative Medicine*, 24, S5–S239.
- Hansen, P., Cornish, P. & Kayser, K. (1998). Family conferences as forums for decision making in hospital settings. *Social Work Health Care*, 27, 57–74.
- Hudson, P., Quinn, K., O'Hanlon, B., et al. (2008). Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *BMC Palliative Care*, 7, 12.
- Hudson, P., Thomas, T., Quinn, K., et al. (2009). Family meetings in palliative care: Are they effective? *Palliative Medicine*, 23, 150–157.
- Hudson, P.L., Trauer, T., Graham, S., et al. (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*, 24, 656–668.
- Kristjanson, L.J., Atwood, J. & Degner, L.F. (1995). Validity and reliability of the Family Inventory of Needs (FIN): Measuring the care needs of families of advanced cancer patients. *Journal of Nursing Measurement*, 3, 109–126.
- WHO. (2002). *National Cancer Control Programmes: Policies and Managerial Guidelines*, 2nd ed. Geneva: World Health Organization.
- Yennurajalingam, S., Dev, R., Lockey, M., et al. (2008). Characteristics of family conferences in a palliative care unit at a comprehensive cancer center. *Journal of Palliative Medicine*, 11, 1208–1211.