

Family Meetings- an exploratory study of the views and experiences of older patients, family members and the multidisciplinary team in a hospital setting.

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ABSTRACT

Family meetings are an increasingly common decision-making forum in the hospital setting but there is limited research into the process and experience of such meetings. We carried out a pilot study to explore patient and family members experiences of family meetings.

This study explored the experiences of participants in family meetings in a clinical setting using an ethnographic approach with a convenience sample of ten family meetings with inpatients of a Department of Geriatric Medicine. A mixed method study design was adopted which included participant observations of family meetings, questionnaires and focus groups with the multidisciplinary team (MDT). Results showed some fundamental differences in opinions from the MDT about the purpose and outcomes of family meetings. Participation levels of older people varied considerably: those with higher levels of cognitive impairment had noticeably lower levels of participation. Participation levels of family members was noted to be much higher. All older people who attended, and eight of the families believed they had been included in the decision making process. Two families reported that final decisions had already been made by the MDT in advance of the meeting and, although dissatisfied with the outcome, still felt that the meeting process had been useful. This study raises questions about the inclusive nature of family meetings and whether decisions are really made in partnership. The divergence in viewpoints from the MDT about the purpose of these meetings is consistent with experiences of the older person and their family and this is informing our further research into family meetings.

Introduction

This pilot study has been conducted within the framework of the 'Care and Connect' project. The Care and Connect Project is an innovative academic, practice partnership which was established in October 2007. It is a joint initiative between the Adelaide and Meath Hospital, Tallaght and the School of Social Work and Social Policy, Trinity College Dublin. Its aim is to promote best practices in person-centred care planning for older people and to promote partnership in decision making between older people, families

and health care professionals and to gain a deeper understanding of this process. The Care and Connect Project aims to carry out exploratory research which examines how communication and the role of healthcare professionals within family meetings impacts on the participation levels of older people.

Literature Review

A family meeting '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 care outside the hospital' (Hansen, 1998). Health Care Professionals have different understandings of what constitutes a family meeting. This is reflected within the literature by the number of different terms for this process; family meetings (Griffith et al. 2004), family conferences (Hansen et al., 1998), discharge planning conferences (Efrainsson et al., 2003) and more recently care planning meeting (Popejoy, 2005; Hedberg et al., 2008). The variety of terms which exist to describe this forum reflect the number of functions this process can have; information sharing, medical updates, explaining medical interventions, rehabilitation planning, discharge planning, discussing home supports, collaboration and decision making. The family meetings process requires multi-disciplinary collaboration between the professional care providers, patients and their relatives and they are undoubtedly an integral part of multidisciplinary teamwork which may greatly influence and shape a patient's care and treatment during their hospital stay. For this reason it is an extremely important and significant event for the patient, their family and the healthcare professionals involved in their care.

Such a myriad of terms and differing objectives suggests that there is a need for clarification about the nature and purpose of this small group process and how older people as patients and their families experience this phenomenon. Family meetings are regularly conducted in the hospital setting. However, the published literature offers limited insight into the meetings process as created by the multi-disciplinary team and the level of patient participation in this process remains somewhat unclear (Froenck, 2005). Although this forum is intended to encourage the active participation and empowerment of older people and their families in decision making, doubts exist as to whether they effectively carry out this role (Efrainsson, 2004).

The promotion of patient participation has stemmed from the belief that patients have a right and a responsibility to be involved in their health care (World Health Organization 1978; Audit Commission, 1993). Approaches to care that attempt to understand the patient in a broader construct than just the individual are receiving increasing emphasis throughout the entire healthcare system (Logue, 2003). One of the main tenets of health care philosophy is that of holistic care and an acknowledgement that family involvement is appropriate and to be encouraged (Archbold & Stewart, 1996; Tilse, 1997). For older adults in healthcare settings to benefit from constructive involvement of their family members, healthcare professionals need a fuller understanding of the issues surrounding family presence in the healthcare environment

(Haesler et al.,2006). In the Irish context, there are indications that there is a need for special efforts to ensure involvement of the patient and family and to consider carefully the patients wishes. ('Quality and Fairness, A Health System for you', DOHC, 2001). Reports of the patient having lower levels of influence over decisions in comparison with family members and health care professionals, raises the possibility that patients may be left out of the decision-making process (Abramson, 1998). The structure of family meetings may also not always accommodate the needs of the older adult (Popejoy, 2005) and this issue requires further examination.

Hedberg et al., (2007, 2008) have completed two studies that focus on communication with stroke patients and their families during care planning meetings with the multi-disciplinary team. They argue that healthcare professionals have a significant role to play in facilitating and enabling active participation of patients. It would appear from the literature to date however, that evidence based knowledge on how to carry out such conferences is limited and Asplund et al.,(2000) point out that few studies focus on the direct experience of patients and/or relatives.

This research study was stimulated by the observation that although family meetings occur on a regular basis in the hospital setting, there is an incomplete understanding of whether this process and the language used and behaviours exhibited provides a climate that enables the active participation of older people and their family members. This pilot study aims to explore the subjective views and experiences of family meetings from the perspective of older patients, family members and the MDT. It is anticipated that recommendations to improve the quality and experience of the family meetings process will be developed from the study findings, and that they will also inform the longer term research focus for the Care and Connect project.

As the pilot study was part of a quality improvement initiative, formal ethics approval was not sought however informed consent/consent by proxy(for those patients assessed as being 'without capacity') was obtained from patients, family members and the multidisciplinary team involved. A mixed method study design was adopted which involved conducting participant observations of a convenience sample of 10 family meetings from the Department of Geriatric Medicine within the hospital. Participant observations are best suited to research projects which emphasize the importance of human beings, interpretations and interactions(Jorgenson,1989).The participant observations focused on the language and behaviours of the patient, family members and members of the multidisciplinary team present at the meeting. A data recording sheet was designed for purposes of the study and drew on the researcher's practice experience, participatory observation and group dynamic theory (Toseland and Rivan,1984: Jorgenson,1981). The data recording sheet included examination of informal processes; e.g. body language, eye contact, seating arrangements, punctuality. The data recording sheet also examined the use of jargon within the meeting, processes and interactions, information shared or given, decisions made and any other observations which the researcher felt was of interest were noted. The observer adopted an 'insider' researcher position (Reed and Proctor, 2005) i.e. the observer was a member of the wider multidisciplinary team conducting research into their own

workplace. Advantages of the insider role include familiarity with the situation and an in-depth understanding of the issues and context. The insider position also contributes to increased credibility with participants as they have an established role on the team and an increased commitment to the study and to sustain change. Disadvantages of this position include familiarity clouding understanding, conflicting commitments and participants feeling threatened and therefore reluctant to disclose information. As a social worker who facilitates family meetings, the observer would have preconceived ideas formed by their own experiences which could impede objectivity but which may have also enhanced enquiry. It is accepted in the literature that the emotional response to a group will not be objective, but it may enrich observational analysis, and that bias in data collection and analysis is critical to the quality of the work (Fronek,2005).

Questionnaires were administered to patients and their family members in order to gain insight into their subjective experiences during family meetings and where practical, this occurred in a semi-structured interview format. Where this was not possible, questionnaires were administered and returned by post. Questionnaires explored areas including previous experience of family meetings, understanding around the purpose of the family meeting, was consent sought about who should be invited to the meeting, decision making and freedom to express opinions/ask questions during the meeting.

Questionnaires were also administered to the multidisciplinary team(MDT) which covered similar themes to the patient/family member questionnaire but also included questions relating to pre-meeting preparation by the team and meeting facilitation and minute taking. Focus Groups were also held with the MDT and these occurred with between 1-4 people from the same discipline. It was decided to meet with members of each discipline separately in the hope that it would encourage openness and honesty in discussions relating to the role of MDT within family meetings. Focus groups were held with Consultants, Physiotherapists, Occupational Therapists, Social Workers, Speech and Language Therapists, Dieticians and Nurses. Open-ended questions were used to explore 8 key areas some of which overlapped with themes covered in the questionnaires in order to obtain more detailed information where possible.

Data Analysis

Information on the data recording sheets, questionnaires and notes from the focus groups were read in depth several times to gain an in-depth understanding of the information gathered; pattern codes were then developed (Miles and Huberman,1994). Data was then grouped for identifiable similarities and trends and convergent themes were noted and developed.

Findings

Participant Observation profiles

Participant observations were completed of a convenience sample of 10 family meetings. The family meetings were held in respect of ten inpatients of the hospital who were all >65, seven were male and 3 were female. All were inpatients within the

Department of Geriatric Medicine; five were under the care of the Stroke Service and five were under the care of General Medicine. Seven were assessed as having some level of cognitive impairment and four out of the seven were assessed as being 'without capacity' . These four did not attend their family meeting as well as another patient who was medically unwell on the day of their meeting and therefore did not attend. On average four family members attended each family meeting (ranging from two to seven family members). Additionally, on average five members of the MDT attended each family meeting (ranging from 3-6 attendees). At every meeting, a medical consultant or registrar was in attendance and a social worker. Attendance of other members of the MDT was determined by the purpose of the family meeting in question.

Informal Processes

Consistently good eye contact was observed between members of the MDT and family members. It was observed however that eye contact was often poor with patients, particularly those with a cognitive impairment, and this was the case for both family members and the MDT. It was noted that circular seating arrangements were in place for all meetings which the researcher considered inclusive nonetheless, demarcation did occur as the patient and their family members tended to sit on one side of the circle and the MDT sat on the other side. Punctuality of staff was an issue in a third of the meetings observed where the MDT arrived late resulting in the patient and family members being left waiting. The researcher observed that body language was generally open for all meeting attendees and that medical jargon was seldom used and on occasions when it was used, an explanation of its meaning was given.

Information Giving and Decision Making Processes

The purpose of nine of the meetings observed related to information sharing and discharge planning, the tenth meeting was convened in order to make a decision about a medical intervention. The Social Worker facilitated eight of the meetings and the medical Consultant facilitated two; there was no appointed minute taker at any of the meetings and it was observed that each professional tended to take their own notes during the meeting. Each family meeting lasted on average seventy-five minutes with meeting times varying from thirty minutes to two hours. Meetings followed a general structure of an opening phase with introductions, a medical update with reports from the multidisciplinary team, a negotiation phase including questions from the patient and their family members, decision making where appropriate and closure.

Outcome of Family Meetings

In almost half of all meetings, no final decisions were reached (SEE TABLE 1).

Diagram of Outcomes of Meetings

FINAL DECISIONS REACHED	NO FINAL DECISION REACHED
2 X discharge to home with Home Care Package	2 X patient to continue with rehabilitation programme. -Follow up meeting to be held -Time frame specified (3 weeks)
3 x Older patient to be listed for Long Term Care placement (Family made decision as older patient 'without capacity')	1 x information provided Family to consider consenting to artificial feeding of older patient (patient 'without capacity')
1 x Home Visit to be completed with patient prior to discharge to home.	1 x information given -Patient and family to discuss options -Patient deemed to have borderline capacity; second opinion to be sought re; patients capacity -Time frame specified.

Participation of Older Person and Family Members

Of the five patients who attended their family meeting, all were observed to participate in the meeting process to varying degrees; family members were often surprised and somewhat taken aback that their older relative with a cognitive impairment was in attendance at the meeting. It was noted that the older people with higher levels of cognitive impairment had poorer participation levels meanwhile, family members were observed to have much higher participation levels than patients. Patients who had a cognitive impairment and who were in attendance at their meeting were observed to be 'talked over' with usage of the grammatical third person by both family members and the MDT. The researcher noted that in only one of the family meetings were the MDT observed to be overtly checking the patients understanding and paraphrasing what had been discussed.

Questionnaires

Each family meeting was the first for each participant and their family;. ONE family reported being unclear about the purpose of the family meeting. Informed consent was sought from all patients about who they would like to attend their family meeting; those without capacity were not consulted. All patients who attended their family meeting believed they had been included in the decision making process. Meanwhile, two of the families surveyed reported that they believed that final decisions had already been made by the medical Consultant and MDT prior to the meeting; although these families were dissatisfied with the decisions reached in the meeting, they still felt that the meeting process had been useful. The other eight families reported that they believed

that they had been actively involved in the decision making process during the meeting. All the patients and family members surveyed felt that they had been given adequate opportunities to ask questions and express their opinions during the meeting.

Focus Groups

Theme 1: Descriptions of 'good' and 'bad' family meetings

Good family meetings were described by the MDT as those where the purpose of the meeting was clear from the outset. A successful meeting was one where pre-meeting preparation had taken place and goals were set. The MDT highlighted the need for good time management during the family meeting and stressed the importance of decisions being made. Bad family meetings were described as being characterized by poor pre-meeting preparation and in particular, MDT members not anticipating questions and issues that might be brought up by the patient or their family. It was also suggested that poor facilitation skills could contribute to a bad meetings experience. Finally, the focus groups communicated that meetings were often a distressing experience for all attendees if the patient/family were not adequately prepared for information provided during the meeting.

Theme 2 : Pre-meeting preparation

It was generally felt that except in very complex cases, pre-meeting preparation should occur at the weekly multidisciplinary case conference. Social Workers were the only professional group who expressed a desire to have a multidisciplinary planning meeting prior to all family meetings; all the other professions did not feel this was time effective given the time commitments of the average family meeting. It was felt to be crucial that the expectations of the patient and family members were clarified before the meeting took place and that this would contribute to a positive and productive meeting for all. It was suggested that it would be beneficial to develop a patient information leaflet explaining 'What is a family meeting?' and that this could be given to patients and their families prior to the meeting taking place and would form part of the meeting preparation process. It was acknowledged that this tool could prove particularly useful for those patients with a cognitive impairment who may have short term memory problems and could have difficult retaining verbal information.

Theme 3: Seating, meeting time, punctuality and venue

The majority of focus groups participants expressed satisfaction about the choice of the venue for family meetings as the Department of Geriatric Medicine had two meeting rooms that could generally be accessed for family meetings. It was also felt that seating arrangements within meetings were acceptable. However it was acknowledged that for older patients with hearing difficulties, it would be good practice for the person speaking to rotate so they were always sitting beside the patient.

Punctuality was reported to be a key issue relating to family meetings. MDT members who arrived late contributed to anxiety levels of all attendees; this was viewed as disrespectful. It was also noted that when members of MDT arrived late to a family meeting, it served to reiterate the power imbalances present by potentially making patients and families feel that the MDT's time was more valuable than patient/family time.

Theme 4: Facilitation and Minute Taking

It was recognized that the facilitator of family meetings needs to be highly skilled and have good mediation experience and skills in order to competently facilitate family meetings as issues of conflict and distress can often arise. In order to standardize family meetings and to ensure that time is used efficiently it was suggested that meetings should strive to have a start and end time. Discussion took place within the focus groups around whether there was a need for a minute taker to be appointed and formal minutes taken; concerns were expressed about the amount of time that would be required to take minutes, type them up and get agreement from all meeting attendees on the content of the minutes so it was proposed that a minutes template should be developed.

Theme 5: Participation of Older Person and Family Members

It was recommended that older patients with a cognitive impairment should routinely attend family meetings unless it is likely to cause them distress and the importance of pre-assessment in relation to this was noted. There was a general consensus that the participation levels of the older patient could be boosted if pre-meeting preparation was improved. It was again acknowledged that the provision of written information in the form of a patient information leaflet could potentially enhance participation levels, particularly those of the older patient. The MDT appeared to have insight into the fact that grammatical use of the third person did occur as they reflected that this practice as well as 'talking over' the older patient greatly inhibited participation.

Theme 6: Decision Making Process

Fundamental differences were evident in how the MDT viewed the decision making process within family meetings. Some indicated that if adequate pre-meeting preparation took place, the outcome of the meeting should in a sense be pre-determined. Others were of the opinion that this defeated the purpose of the family meeting as the decision making should be a participatory process which involved the patient, family members and the MDT in a joint decision making exercise. This theme also included discussion around the need for the purpose and outcome of the meeting to be clear to all attendees if decisions are to be made and again this was framed within the context of pre-meeting preparation. There was a recognition that particular challenges were faced when decision making related to medical/legal matters e.g. 'risky discharges' or the decision to begin artificial feeding of a patient as these were inherently ethically difficult and often the source of tension and conflict.

Theme 7: Aftermath of the Meeting-need for debriefing?

Current practice within the MDT is that the Social Worker usually provides debriefing to the patient and family as necessary and it was felt that this worked very well however, the Social Workers highlighted that it could be very time intensive. Members of the MDT reported that they usually provided informal debriefing to each other and it was not deemed necessary to formalize this practice.

Theme 8: Other suggestions for improvements.

It was proposed that an agenda should be agreed with the older patient and their family at the beginning of the meeting and that the older patient should also be provided with an opportunity to speak at the start. It was considered that this could improve

participation levels and give the older patient a greater sense of control over the meeting process. It was also suggested that it might be of benefit if the older patient was given an opportunity to meet with the MDT as a group without their family members being present. Finally, it was recommended that further attention should be given towards examining the low participation levels of older patients with a cognitive impairment and efforts should be made to improve current practices.

Discussion.

Family meetings are an important information sharing and planning event. However our study's findings show how final decisions are not always reached. There are several valuable clinical and research implications that arise from this pilot study. It is encouraging that older patients and family members reported being able to express their views, even if they differed from those of the MDT. This pilot study has also shown the clinical feasibility of the family meetings process as a tool for decision making as patients and families found the meetings process to be a positive experience even though they were not always satisfied with the outcome of the meeting. There were, however, fundamental differences in opinions from the MDT about what the purpose and outcomes of family meetings are and should be. Some believed that they should purely be an information sharing forum where patients and families were then given time to make an informed decision. Other members of the MDT reported that family meetings should be a forum where collaboration and shared decision making occurs. Finally, some of the MDT considered the meetings as a time to consult with patients and families on outcomes that had been largely achieved /decided. This divergence in viewpoints is consistent with patient and family members experiences and it would appear that there is a need for further exploration and consensus on this issue.

Findings relating to the importance of pre-meeting preparation and facilitation skills reflect those of Griffith et al (2004) in their study of family meetings. The development of an information leaflet for patients and families explaining what the meeting process involves, routinely clarifying their expectations, and setting an agenda for the meeting may result in more satisfying outcomes for all.

“Involvement” is often taken to mean “patient centeredness”, which doesn't necessarily imply active participation.(Cahill,1996; Elwyn et al.,2000). Observations of poor eye contact, use of the grammatical third person and poor levels of participation from older patients with higher levels of cognitive impairment raises questions about the inclusive nature of meetings and whether decisions are really made in partnership with patients? Efrainsson (2006) points out that there is a discrepancy between the ideological intention and the actual realisation of discharge planning conferences and alludes to the ‘tokenism’ of patient participation within the family meetings process(Brownlea,1987). Hedberg et al.,(2007) raised similar concerns in their study which examined nurses as moderators of communication in care planning meetings with

stroke patients. They observed the nurses talking *about* rather than *to* the patient and concluded that family members were seen as more important speech partners than the patient. It is therefore important to ask do we, as health care professionals, feel more accountable to family members and why is there an intentional/unintentional focus on them within the family meetings process? Perhaps the term 'family meeting' is a misnomer or paradox in this setting and meetings should be more appropriately named to reflect a patient focus and the true purpose of the meeting? The notion of participation and choice may need to be redefined for those older people with 'borderline' capacity issues and the evidence from this study would suggest that there is a need for development of guidelines which would promote the active participation of this group in decision-making. These findings indicate that there is a need for further research into how the language and behaviours of healthcare professionals potentially impedes patient participation through informal processes and poor communication. In addition, there appears to be a need to develop an education programme for healthcare professionals which would focus on strategies to increase patient participation levels, particularly those with a cognitive impairment.

Limitations.

The main limitation of this study is the low attendance of patients at the family meetings which limited observations of patient participation and their views and experiences and makes generalisations difficult. It must also be recognised that the observer has preconceived ideas and inherent bias about how family meetings should be conducted and facilitated as a result of being a practitioner in the setting and this may have influenced data collected and recorded. Data collection and data analysis would have also been greatly enriched by the use of audio or visual recording of the meetings and the researcher would strive to incorporate these methods of data collection in future studies. A major strength of the study is the complementary nature of the three sources of information and use of purposive sampling to ensure good representation of family members and MDT.

Conclusions

The findings from this pilot study show that the family meetings forum is a significant event for older patients, their family members and the multidisciplinary team involved. The low participation rates of cognitively impaired older patients is a worrying discovery given their vulnerability however it does add weight to evidence already in the literature that the voice of the older patient may get lost within the meetings process. This study has produced many insights which will be used to improve the family meetings process. A follow-up study is planned which will further examine the relationship between language and behaviours of the MDT and the participation levels of older patients.

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