Family meetings—a qualitative exploration of improving care planning with older people and their families

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Abstract

Objective: To explore the opinions of participants in family meetings to improve the quality of this important rehabilitation tool.

Design: Qualitative exploration of opinions and experience from staff, patients and families.

Setting: Tertiary teaching geriatric rehabilitation hospital.

Participants: Staff, families and patients who had recently participated in family meetings.

Methods: Focus groups, written surveys and individual semi-structured interviews.

Results: Three main themes were identified in the staff focus groups—preparation, staff skills and aftermath. Opinions from family members revealed a high level of satisfaction. The patient interviews revealed a worrying lack of informed consent and lack of clarity of the purpose. All three groups identified an unclear agenda as the underlying reason for unsatisfactory meetings. An unfavourable outcome decision (such as placement in institutional care) also influenced patient opinions on the process. The majority of patients found the family meeting to be helpful.

Conclusions: Family meetings are much appreciated by patients and their families. A model of the family meeting process is proposed to account for our research findings and as a means to improve meetings. Adequate preparation and consent, and skilled facilitation may improve the effectiveness of family meetings while maintaining the patient's sense of autonomy.

Keywords: family caregivers, group meetings, negotiating care, qualitative research, aged, discharge planning, patient participation

Introduction

Family meetings help plan interventions and set goals so that an older person, family members and the multidisciplinary team are all striving for the same outcomes. Despite this importance, there has been surprisingly little research into the processes around such meetings [1–4].

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 their care outside the hospital’ [5]. They provide a rare opportunity for family members and patients to receive the same information at the same time [6]. Family meetings have most commonly been studied within intensive care, paediatrics, palliative care and primary care settings [5, 7–11]. Within a rehabilitation setting, one study documented the questions most asked by patients and support groups [1] and found most questions related to medical issues or to discharge planning.

High levels of family support are associated with progressive improvement in functional and psychosocial status in post-stroke patients [12]. Treating the patient in
the context of their family is increasingly recognized as vital to the long-term outcomes of the patient [12–15]. Consumers of health services continue to ask for improved communication with their health care providers, and ask to be informed and empowered to make decisions regarding their health care [10, 11, 16–18]. Used effectively, the family meeting could therefore be a powerful means to achieve these goals.

This study was stimulated by the observation that, although family meetings are often regarded as important and worthwhile, many staff members are anxious about them and about ways to ensure they run well.

The purpose of this exploratory study is to describe the experiences and opinions of participants in family meetings and to provide recommendations for participating staff to improve the quality of this aspect of inpatient rehabilitation.

Methods

This study used qualitative approaches to explore the subjective experiences of three groups of participants in family meetings: staff, patients and family members. For ethical and logistic reasons different methods of data collection were used for each set of participants—an open focus group interview with staff members, semi-structured one-to-one interviews with patients, and a written survey of family members. The setting was an urban rehabilitation hospital, providing inpatient assessment, treatment and rehabilitation services for older people.

Discussions with staff members occurred within five focus groups over six months. Each group comprised 3–8 people from the same discipline: consultant geriatricians, medical registrars, social workers, nurses and service coordinators. Each group of professionals was interviewed separately for 30–60 minutes in conference rooms within the hospital. Open-ended questions were used, exploring their experiences and descriptions of ‘good’ and ‘bad’ family meetings. The sessions were audio taped and transcribed. Initial thematic analysis was undertaken independently by each of two researchers followed by discussion and agreement on differences. The themes were then presented to all hospital staff in a meeting convened for staff participant feedback.

Semi-structured individual patient interviews were conducted with 22 patients who had had a family meeting within the previous 48 hours. Patients were selected from six wards. Each interview was conducted within the patient’s own ward, without family present, and lasted approximately 20 minutes. Notes were taken and three of the researchers reviewed these for emergent themes.

The written survey of family members aimed to distribute questionnaires to a convenience sample of 25 consecutive families, asking if the information was conveyed in a satisfactory manner and was sufficient, and if a copy of the family meeting form was provided. There was also space for free text comments. Questionnaires were returned by mail.

The staff focus groups, family questionnaires, and patient interviews were regarded as quality assurance activities, so formal ethics approval was not required, but all participants gave informed consent to the study and confidentiality was maintained.

Results

Staff focus groups

Three themes were developed from the staff focus groups: (i) preparation; (ii) staff skills; (iii) aftermath.

Staff theme one: preparation

This theme included discussion around staff preparation, preparing the patient and family, obtaining consent and ensuring that the key participants were present. However, there was disagreement as to how better preparation might be achieved:

‘Staff when arranging meetings may fail to explain the nature of the meeting, so people don’t know what to expect. They may just tell people the meeting is on, then the patient and family get very stressed’—social worker.

‘I’ve talked to the nurse, the social worker, the registrar, and I’ve had three completely different stories’—social worker.

Staff particularly focused on the ‘pre-meeting meeting’—defined by one as:

‘Right before the meeting we get together and everyone says their piece. Sometimes if that doesn’t happen, everything comes unglued’—social worker.

The duration of the meeting was a popular topic:

‘The first rule of family meetings is that they always expand to fill the time available, even though the business has been transacted in the first five minutes’—consultant.

‘I go there for two hours and come back frustrated because nothing is done’—registrar.

This theme also included clarification of the aim of the meeting, which can differ between patients, vary over time, or even evolve during the meeting. Staff members may have different aims, depending on professional perspective.

‘There’s no point seeing them (in a family meeting) if they’re in a bit of heart failure, and you’re not quite sure of the cause’—registrar.

‘I (attend) in case something blows . . . in case I need to pick up the pieces afterwards’—social worker.

Staff may not perceive the aims of other participants, which may include establishing rapport, communicating (both giving and receiving information), observing family dynamics, obtaining a consensus on management, and discharge planning.

Staff theme two: staff skills

The second theme included discussions around the most appropriate person to facilitate the meeting. In our institution this is usually the doctor, and staff explored this feature of hospital culture, acknowledging that others may have greater skills. Doctors have variable training, experience and skills.

‘The registrars (may) just fly blind . . . one of my biggest concerns is that there’s no role-modelling for them’—social worker.
Staff theme three: aftermath

Several staff commented on patient and family reactions after the meeting, especially when these were perceived as negative.

‘I’ve seen patients who have just hit the decks the next day . . . . they just crash’—nurse.

The patient or family might be more able to express their views after the meeting in the informal setting:

‘(the patient) is so different, is so much more relaxed’—service co-ordinator.

‘The husband just sat there and said he didn’t want his wife to come home . . . . then when he was left with me (after the meeting) . . . . he said he was going in for chest surgery in two weeks’—social worker.

Staff commented on the need to check back with participants:

‘I think it’s really important afterwards, that there aren’t any unanswered questions, or that the family or the patient haven’t misinterpreted what’s been said’—nurse.

Preparation and skill on the part of staff were suggested as ways to ensure a positive experience.

Patient interviews

Of the twenty-two interviews intended, six did not proceed largely because of unstable health status.

The most striking result from the patient interviews was the lack of adequate consent to participate in the family meeting. Six of 16 (37.5%) reported they had not been informed the meeting was taking place; three stated they had not wanted a family meeting. Twelve (75%) reported they had not been asked who they would like to be present.

This lack of adequate consent is supported by a previous audit of clinical notes at our institution, which found that verbal consent to participate in family meetings was documented in the clinical notes in only 28% of cases.

‘I was told it was on . . . . we just get told to go . . . . it was very sudden’—patient.

‘I talked to different patients, they all had one and it was just my turn’—patient.

‘My son took it on himself, I didn’t know a thing about it, he’s not my guardian, my other son is’—patient.

The patients identified a diversity of aims for the meeting: resolving inconsistencies, updating, educating and informing, reviewing care options. When asked who should run the meeting, six patients answered that the doctor should, six were uncertain, two suggested combinations of staff, and one believed the nurse should. Five of the 15 (33%) who attended their meeting had hearing difficulties, with three reporting being unable to hear. Five (31%) reported that they did not consider they had the opportunity to get their ideas across. Despite this, 12 (75%) were comfortable with the outcome of the meeting. Discomfort tended to correlate with a decision to move into care. Of the 11 patients who mentioned discharge destination, the nine who were returning home felt positive about the meeting, whereas the two who were moving into care felt negative.

Interestingly, several issues that concerned staff in the focus groups were not of concern to the patients. These included the physical properties of the room, the use of jargon, and staff coming and going during the meeting.

Family questionnaire

Of the 25 families intended to receive surveys, four were unable to be contacted before discharge of the patient, leaving 21 sampled families of which 13 were subsequently returned (61%). No attempt was made to follow up non-returned surveys.

All respondents stated that sufficient information had been conveyed in the meeting, and that it had been conveyed in a satisfactory manner. They appreciated the time put aside to discuss matters with the health care team. Positive comments were received.

‘All the information was given in a caring way. We were impressed at how the information was given, very positively to my confused father, and how he was made to feel comfortable and able to contribute’—family member.

However, only 54% reported that they had received a copy of the written record of the meeting, despite this being hospital policy.

A model for family meetings

Our results suggest that unsatisfactory family meetings occur as an isolated event rather than within an overall process. We therefore put forward a process or model for family meetings in Figure 1. We propose that meetings that run smoothly do so when agendas have been aligned between the patient, the family and the staff. This requires conveying and gathering information with the patient, adjusting expectations of all parties, and resolving any differences. The fourth stage is one of review, in which the team checks back with the participants and each other, to debrief and identify any unmet needs. This cycle can continue several times during a patient’s rehabilitation programme. Most family meetings occur at the resolve phase of the cycle but could be at any of the other phases. If the meeting is to resolve issues, then it will run more smoothly if the research and adjust phases have already been completed. It is possible the entire cycle could be completed in one meeting. It can be destabi-
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lizing if the patient and staff are not clear where the meeting fits within the cycle.

Discussion

Family meetings are important events in a patient’s stay and in a staff member’s work. All three parties identified them as tools where important decisions are made and, as such, meetings have the potential to contribute to favourable or unfavourable outcomes. It is reassuring that the three qualitative methods used, from the perspectives of three participating groups, have resulted in a number of converging themes.

Meetings that are unsatisfying are those where the participants have entered directly into the family meeting without first having clarified its purpose. Normally meetings are to resolve issues, which require prior research and adjustment. We have found the development of this model to be helpful in running family meetings and hope that this might provide greater clarity for other practitioners also. The particular aspects we have found useful are to know in which phase of the cycle the actual meeting fits and to know what needs to have happened before, and after, the meeting to make it run smoothly.

Another specific issue arising from this research relates to a worrying lack of informed consent by patients, with a tendency for staff (and perhaps families) to focus on their own aims and agendas. The lack of attention to patients’ hearing reflects and compounds this attitude [19]. Lack of informed consent is of particular concern in the rehabilitation setting, which aspires to an underlying philosophy of empowering the patient. This loss of the patient’s autonomy has been noted elsewhere [20–22]. A survey of social workers’ perceptions of family meetings noted that ‘these meetings were less often set up to provide information to the patients . . . and more frequently helped the family obtain information to make decisions’ [5]. We believe this is consistent with a lack of clarity of the meetings’ purpose for all parties. While the staff may believe they understand the purpose, this may not be shared by the patient or, indeed, by other staff members. This is best illustrated by a medical registrar’s comment that there was no need for a meeting as he was not sure of the cause of the medical problems.

It is not surprising that family meetings can be stressful for staff. Disagreement between family and hospital staff has been reported in 13 of 26 (50%) family meetings [5]. Abramsom describes disagreement as ‘a normative outgrowth of the complexity of family tasks in discharge planning’ [21]. Physician abilities in the areas of communication, decision-making and building relationships correlate directly with patient satisfaction [9].

The major strength of this study is the complementary nature of the three sources of information and the use of purposive sampling to ensure good representation of patients and staff members. The main limitation of this study relates to the low response rate from families. It is quite possible that dissatisfied families may not have responded. Patient interviews were conducted with written notes but no audio recording and transcription. These are areas that could be expanded in subsequent research.

We suggest the following practical implications arising from this study:

• There should be overt discussions between staff members and the patient to clarify the meeting’s purpose.
• The phase of the cycle in which the meeting occurs, and the phases needed to be completed before the meeting, should be identified.
• There should be genuine and documented informed consent from the patient.
• There should be good opportunities and support for the patient to express their own views during the meeting. This will include paying attention to the patient’s hearing.

The purpose of this exploratory study was to derive a practical guideline for staff and patients. Evaluation of this and questions around power, patient autonomy, and decision-making are worthy of further work. We have found that patient autonomy is less than ideal and highlighted staff concerns around preparation, skills and training. Despite this, patients and families expressed high levels of satisfaction with family meetings, which further reinforces the importance of exploring this area.

Key points

• Family meetings are part of a cyclical process of researching then adjusting agendas followed by resolving differences and reviewing outcomes.
Features of successful family meetings include:
Clarity regarding which phase of the cycle the meeting fits.
Genuine and documented informed consent.
Particular support for patient autonomy, including hearing.
Accepting that differing agendas are a normal part of the process.

References


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