

Title

Patient and family members' perceptions of family participation in care on acute care wards.

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ACKNOWLEDGEMENTS

The authors would like to thank all the nurses, patients and families at the participating hospital for their participation in the study as well as the nurse leaders who supported the study. Additionally, the lead author was a grateful recipient of an Australian Government Research Training Program Scholarship. The funder had no input into any phase of the project or publication decisions.

ABSTRACT

Background: Hospital leaders, policy makers, and healthcare professionals are realising the benefits of delivering care that promotes family participation because it is known to enhance the quality of care, and improve patient satisfaction.

Aim: The aim of this study was to explore, from the perspective of patients and family members within an adult acute-care ward: a) their beliefs and attitudes towards family participation in patient care; and b) staff behaviours that support or hinder family participation in patient care.

Design and methods: A naturalistic approach with an exploratory sequential design was used in a medical assessment and planning unit of a regional referral hospital in Australia. Purposeful maximum variation sampling was used to recruit patients, and family members who differed in age, ethnicity, relationship to patient, and gender. Observer-as-participant observation data and semi-structured interviews were undertaken. Following separate inductive content analysis, data were triangulated.

Results: Thirty-two patients and 26 family members were recruited. Thirty hours of observational data were gathered. Eighteen patients and 15 family members were interviewed. Analysis uncovered two contrasting categories: (1) disconnected communication, and (2) family influence quality.

Conclusion: The findings of our study demonstrated that most patients and families perceived staff communication as disconnected and inadequate, which constrained them from engaging in care processes or decision-making. However, when family felt empowered and participated in patient care the quality of healthcare was enhanced. Healthcare professionals can use these findings to make informed evidence based changes to the way they practice and communicate to ensure family participation in patient care is optimised in the acute care setting.

Key words: Acute-care, attitudes, collaboration, family, hospitalisation, medical units, mixed methods, nursing, patient and family centred care, and participation.

Introduction

Family participation in care is widely acknowledged as being important because they ensure patients are seen, heard and understood (1-3). Moreover, when family members participate in patient care there are positive patient and family outcomes including enhanced illness self-management, improved quality of life, and reduced incidence of readmission (4-8). Patient and family focused care is frequently cited as a dimension of high quality care in a range of international policies and programs (9-12). While family participation in care, sometimes termed collaboration, engagement, or involvement (2,13) is increasingly acknowledged as desirable in healthcare settings, the concept remains unclear within the adult acute care literature (14). Further, this lack of clarity regarding what represents meaningful participation from the perspective of patients and family members in this context has meant the uptake of practices that foster family involvement has been slow (11,15-16). Similarly, little is known about the barriers and facilitators to family participation in patient care within the adult hospital setting.

Background

The philosophy of patient and family centred care (PFCC) is globally being adopted by healthcare services because there is growing awareness to achieve the best outcomes, patients and families must be more actively engaged in decisions about their healthcare (17). Critical to this philosophy is the engagement of patients and families as full partners in healthcare (18,19). Healthcare partnerships, involvement in patient care, and shared decision-making are fundamental to the concepts of participation and collaboration (20). Engagement and involvement are synonyms for participation (13), and they occur through reciprocal relationships and dialogue (21).

For meaningful participation to occur a dialogue must first occur between patients, their family and the relevant healthcare professionals. Effective interpersonal communication has long been recognised as an essential component of best practice in healthcare (22), and aligns with a PFCC approach to share unbiased information with patients and their family in ways that are affirming and useful (17). Tailoring information to the individual patient or family member allows healthcare professionals to uncover knowledge deficits, health beliefs and establish from family members their preference for participation and decision-making.

Poor health literacy can impact on patients' and families' capacity to make informed decisions and participate in care processes (9). Health literacy is a significant problem internationally (23,24), and reflects an individual's capacity to access, understand, appraise and apply information to make effective decisions about healthcare (25). Consequently, patients and families are less likely to participate in care processes if they do not fully understand their plan of care (26). Further, the literature highlights the important role health professionals can play at improving health literacy levels (27,28) to enhance the safety and quality of healthcare (29). Low health literacy has repeatedly been linked to health consumers having difficulties comprehending, recalling and acting on health information provided by health professionals (30,31).

The attitudes of healthcare professionals, and the need to preserve patient autonomy have also been highlighted in the literature as hindering family participation in patient care (32,33). For example, when healthcare professionals hold paternalistic attitudes they are less likely to consider patient and family beliefs, values and care preferences, and meaningful participation does not occur (34). In the adult acute setting when compared to other healthcare staff, nurses are recognised as key facilitators of PFCC (35) because they have prolonged direct contact with

patients, and their families, (36,37). The ‘one size does not fit all when it comes to PFCC’ is an important concept (38,39) and nurses can tailor the PFCC approach to the patient/family context. However, models of nursing care for PFCC have largely been informed by research from clinically disparate settings such as, paediatrics (40,41), critical care (42), mental health (43), and primary care settings (44) which may not translate readily into the adult acute care context where patients potentially have capacity to advocate for themselves.

A developing body of research exploring PFCC within adult acute care wards provides some insight into how meaningful family participation or collaboration is enacted by nurses in this setting. For instance, bedside handover provides nurses with a structured mode of sharing information, and allows them to develop a trusting relationship with patients, and their family (3). Furthermore, participating in patient physical rehabilitation may also represent a collaborative care activity, where families can partner with healthcare professionals to support patient recovery (45,46), but further research is needed to understand the key features that characterise meaningful participation from the patient and family’ perspective within the acute care setting.

Patient and family consumer groups have adopted from the disability rights movement the phrase, ‘nothing about us without us’, because they strongly believe the importance of policies being informed by the individuals upon whom they impact (47). This style of inclusion is not readily evident in the design of PFCC policies with hospitals, and authors suggest that this extends further to the area of PFCC interventions where there is a critical lack of patients’ and families’ perspective (48). It is evident that the optimal approach to foster family participation in patient care within the adult acute care setting is still unclear (49). Therefore, to implement sustainable PFCC practices in hospitals, policy makers, and healthcare professionals must first

understand what patients and families see as representing meaningful participation or collaboration.

Limited studies have examined family participation in patient care within the adult acute care setting from the perspective of those most affected by the care delivered – patients, and their families. Further, the factors that are delaying the uptake of PFCC practices in the acute setting is unclear. To identify the barriers and facilitators linked to the family participation in the adult acute care setting, it is necessary to explore these issues with a focus on patients and families. We previously considered and explored nurses' perspectives in a parallel study (50). The aim of this study was to explore, from the perspective of patients and family members within an adult acute-care ward: 1) their beliefs and attitudes towards family participation in patient care; and 2) staff behaviours that support or hinder family participation in patient care.

Methods

Design

A naturalist approach guided the research design for this study (51,52). The study consisted of two sequential phases. Observer-as-participant observations were conducted in Phase 1 to understand the adult acute care context and analysis of Phase 1 data informed the questions used in the semi-structured interviews in Phase 2. The four core principles of PFCC are dignity and respect, information sharing, participation and collaboration (19, 53). These concepts provided the underlying conceptual foundation for this study and were used to understand patient and family perceptions of family participation in patient care within the acute care setting.

Setting

The study setting was a 28-bed medical assessment and planning unit (MAPU) located within a 324-bed regional referral hospital in Australia. The MAPU had formal visiting hours from 08:00h to 20:00h daily, and a patient average length of stay of 72 hours. The selection of this ward was guided by the results of a hospital-wide survey in which the MAPU nurses had the highest positive overall attitude towards involving family in nursing care. The attitudes of nurses toward the importance of families in nursing care were assessed by the Families Importance in Nursing Care (FINC-NA) survey instrument (54). The selection of this unit was considered optimum to answering the study aims, and reflected a unique case sampling approach (55,56).

Participants

Participants included patients and family members who were in the MAPU during the period of data collection. Inclusion criteria, in both phases required patient participants to be aged 18 years or older, who were able to provide informed consent, able to identify a family member who was in contact with them during their hospitalisation. Medically unstable or palliative care patients were excluded for humanitarian reasons so as not to add additional stress on the patient and/or their family. Likewise, in both phases, family members who were identified by consenting patients were invited to participate. In our study, a family member was defined as an individual who had a close and continuing relationship or formed part of the patient's pre-existing support system. Sample size was determined by data saturation.

Recruitment

The principle investigator (first author), to achieve purposeful maximum variation sample (57), liaised with the ward nurse in charge each shift to identify patients and family members who

differed in age, ethnicity, relationship to patient, and gender. Participants in the observation and interview groups differed.

Data Collection

Data collection occurred between June and August 2016. Demographic data were collected from all participants included: age, gender, highest level of education, while patients were asked if they live alone or with others, and family members were asked their relationship to the patient.

Phase One - Observational data

Observation of nurse interactions was informed by the literature (58), which emphasises the unique role that nurses perform in fostering patient-family participation in care. In this study, family participation and collaboration was defined as nursing care that was informed by the patient's and family's preferences, and expressed needs. The observer, an experienced acute care nurse (the first named author), using a field guide (Supplement 1), shadowed the participating nurse for a 2-hour period to observe for events where family partnering and/or collaboration in care may or may not have occurred. The timing of the two-hour periods varied across times and days of the week to increase the opportunity to observe how PFCC was broadly enacted. Digital recordings of observer thoughts were the primary means of documenting participant comments and or behaviour, and occurred at the end of each observed period. Written contact summaries, were also recorded directly after each observational period to ensure contemporaneous data collection (59). Analysis of observational data was conducted immediately following this phase of data collection to generate interview questions for Phase 2. The process of analysis is explained in detail within the data analysis section below.

Phase two - *Interview data*

Following completion of the data analysis of the Phase 1, observational component of the research, semi-structured interview questions were conducted. Interview questions were also designed to explore the domains of the Theoretical Domains Framework (TDF) (60) and identify staff behaviours that could hinder family participation in patient care. The TDF is founded on psychological and organisational theory that recognises healthcare professionals' behaviour change is key to improving the quality of patient care (61). Whenever possible interviews were conducted jointly with patient and their family to facilitate richer descriptions, and reveal what helped or hindered family participation in care processes. Interview schedules used with patient and family members are shown in Table 1. Prompts were also used to probe, clarify, and elicit meaning from participants. Interviews were conducted in a private area of the hospital, lasted for approximately 25 minutes, were digitally recorded and transcribed verbatim.

****insert table 1 here****

Data Analysis

Descriptive statistics were used to summarise the demographic data collected from patient and family participants. Transcriptions were checked for accuracy by re-listening to the tapes with comparisons to the transcripts. Qualitative data were stored and managed using the software program NVivo 11™ (QSR International Pty Ltd., Melbourne, Victoria). Data collection and analysis occurred simultaneously, and a code needed to appear at least three times across the data to be considered as holding important meaning (62,63). Data analysis of the transcripts and field

notes was conducted using the analytical framework described by Miles, Huberman and Saldana (64). The approach involved: (1) assigning codes to field notes and interview transcripts using the affective coding method to identify underlying value and belief systems (63); (2) sorting and sifting through these coded data to identify similar phrases, relationships between variables, patterns, themes, categories or distinct differences; (3) using a visual matrix to display data enabling cross case analysis for subthemes and themes to be generated; and (4) integrating themes and subthemes into higher level connections through seeking plausibility, clustering, noting patterns and making metaphors. Finally, following separate analysis, the observational and interview data were triangulated (65) to provide a comprehensive description and deeper understanding of family participation in patient care as it was perceived by participants within the adult acute-care ward.

Trustworthiness of the study

Trustworthiness was upheld using the qualitative strategies of credibility, transferability, dependability and confirmability (66). Credibility of the findings were obtained from the naturalistic setting (67), the purposeful sampling strategy and varied data collection methods. Transferability was addressed through clearly outlining the data collection process, providing key descriptive information regarding the participants and detailed information regarding the data analysis process. Further, dependability and confirmability were addressed by the researcher adopting the participant-observer role. An audit trail of the process was maintained for establishing confirmability of the results.

Ethical issues

Ethical approval to conduct this study was granted from both the hospital and health service district: HREC/16/QTDD/1, and university Human Research Ethics Committee: 2016/144. Informed consent was provided prior to participation in observations or interviews. Pseudonyms and participant codes were used to ensure anonymity.

Results

Thirty-two patients and 26 family members were recruited. The majority of patients were male, while family members were mostly female, and identified as the patient's spouse (Table 2). Thirty hours of observational data were gathered with observations conducted over 2-hour periods across all days of the week, and between the hours of 06:00 am and 22:00 pm. Eighteen patients and 15 family members were interviewed with interviews lasting approximately 30 minutes. Seven patient interviews were conducted jointly with family members.

The analysis uncovered two opposing categories: (1) disconnected communication; and (2) family influence quality. The first category contained four themes that revealed how communication practices hindered family participation in patient care. The second category contained three themes that highlighted the benefit family participation had on the quality of patient care (Figure 1). When quotes from the data have been provided below to illustrate the themes, "O" indicates that the quote has originated from an observation period, while "I" indicates the quote has originate from an interview.

****insert table 2 here****

****insert Figure 1 here****

Tables

Table 1. Interview schedules

Patient participants	Family participants
<ul style="list-style-type: none"> • What does family partnering in care mean to you? • Are there aspects of your care you don't want your family to do? • What helps your family to participate? • What hinders your family to participate? • How do you think you would feel if your family could not participate in your care? • How do you think the daily routine on the ward influenced your family's ability to become partners? 	<ul style="list-style-type: none"> • What does partnering in care mean to you? • Are there aspects of your care you don't want to do? • What helps you to participate in care? • What hinders you to participate in care? • What outcome(s) did you see occurring? • How did you think your relatives care would change after you were involved? • How do you think you would feel if you could not partner in their care?

Table 2. Demographic data of participants.

	Patients n = 32	Family n = 28
Age in years (mean, SD)	62.3 (\pm 17.3)	47.9 (\pm 19.5)
Gender (Male; n (%))	18 (56)	7 (25)
Highest level of Education		
Post graduate degree	1	1
Bachelor's degree	2	2
Associate certificate	2	3
High school certificate	17	14
Less than high school certificate	10	8
Lives with someone at home (patients only)		
Patient lives alone	9	-
Relationship (family only)		
Spouse	-	15
Adult relative (i.e. son, daughter, brother, sister)	-	12
Significant other (i.e. non paid carer)	-	1

* SD = standard deviation

Figure

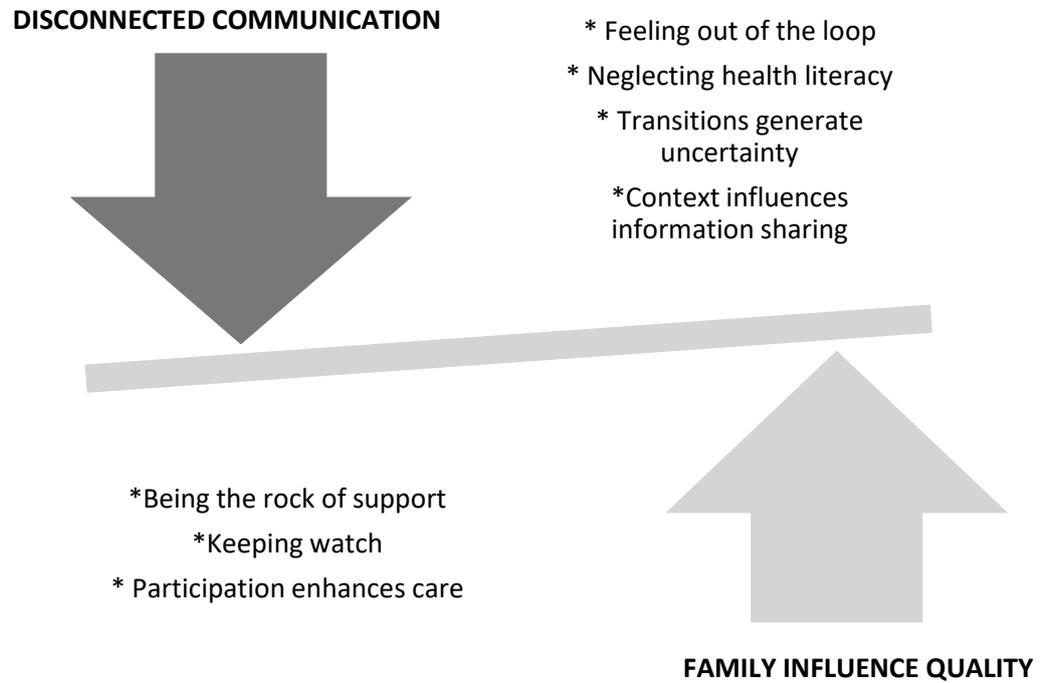


Figure 1. Categories and themes from patient and family members' observations and interviews

Disconnected communication

Four themes emerged from the triangulated data within the first category and included: feeling out of the loop, neglecting health literacy, transitions generate uncertainty, and context influences information sharing. These themes revealed how fragmented, and inapt communication was a barrier to family participation in patient care within the adult acute care setting.

Feeling out of the loop

Patients and family members were confused, and frustrated because they felt excluded from key information or were not kept up-to-date on the plan of care. Interviews revealed, that patients wanted their family to know the plan of care because it alleviated their uncertainty, and provide reassurance that, should they lose capacity to speak for themselves, their family would be well informed to act on their behalf. For example, *“If they [family] are really well informed on what’s going on for me, then I feel less stressed because I know that, **they’re across it, and they’re not worrying so much.** If I was to lapse into a coma or whatever else, then **they can make the right decision** because they know what’s going on”* (P2-I).

Interviews also revealed that the majority of families believed staff missed opportunities to share information with them, or explain care processes. For example, a patient’s daughter was reflecting on her family’s hospital experience and stated, *“They see that we’re here, and they [staff] could let us know about stuff, but **they don’t say anything to us.** There needs to be quite a bit **more communication between the nurses, doctors and the family** for the people that are in here in their care. Every time we come up here, it’s **not a single person who comes and says,***

oh, just step out here and we'd like to [give] information to you - just a little bit more about what's going on [would be good]" (F15 -I).

Neglecting health literacy

Almost half of the participating family members highlighted that staff did not check if the information they shared was understood or meaningful to them. For example, during an interview with the daughter of a patient, she disclosed that both she and her mother were deaf but able to lip read. She recounted her frustration [clearly indicated by her tone of voice] because medical staff did not accommodate this need and were, “... **not making eye contact and we had no idea what was going on. We were confused and the doctor didn't relate anything back to us, just checked her [vital signs] and walked out.**” (F11-I). Further, most patients felt staff overestimated their capacity to receive, understand and relay information accurately to their family. Consequently, patients were concerned that their family members may become distressed if they relied solely on them for information and updates. For example, one patient said: “*A lot of times the patient is, not feeling well or is drugged [pause] not as cognisant of what they are hearing. Then they get the information from the nurse or the doctor and they've got to relay that to their wife or their family, and the information that they're passing to the family might not necessarily be what the doctor or the nurse said. Families can go away with either false hopes or false beliefs*” (P2-I). Observations also revealed that opportunities to enhance family understanding of care processes were missed, for example, family members were not involved or included during the admission process or bedside handover in the MAPU despite being present.

Transitions generate uncertainty

Transitions in care forced patients and their families into new and unfamiliar situations that led to ambiguity in what to expect with their ongoing care, processes, which generated feelings of apprehension or frustration. For example, it was observed, in one case, a male patient with chronic lung disease had his wife present, and she said, *“I am worried about going home and having BiPAP, I would like to know if we get this and how we get it?”* (F1-O). The patient is then heard to sigh, and state, *“I bet you have to sell your body to get one!”* (P1- O). This uncertainty was a common feature from patient interviews when several highlighted that their admission to the MAPU from community care had placed additional burden on their families. For example, one patient recounted an incident regarding his medications that caused additional unnecessary pressure on his family: *“I came in here with no meds [medications], and they [staff] had a go at the [nursing] home. They [nursing home staff] said they don’t send patients from the nursing home with meds to a hospital. They get all my meds here. Now I found out I’m missing out on two meds, and they [hospital] don’t stock them. They [staff] want my daughter-in-law to run around and get them. I think that’s unfair to ask a thing like that. It’s too much pressure on me and on the family”* (P4-I).

Context influences information sharing

The complex nature of patient-family lives influenced information exchanges on the MAPU. Patients recognised that their families’ capacity to become involved, share in information or contribute to care decisions was limited because of existing commitments or circumstances. Additionally, family members also acknowledged their capacity to be present in the MAPU was hindered by existing family commitments, such as *“It’s really hard having them [her children] here [for rounds], that’s the problem. I can’t have them in this room -toddlers*

and a tiny baby. It's hard to get people to watch the kids especially since my mum's been a bit sick" (F5-I). Patients in our study felt information sharing with families could be optimized if staff employed novel, and flexible approaches such as, "[We] *want more flexible visiting hours...if they [family] are coming from out of town – [they] could not necessarily come and leave by 11am-8pm*" (P9-O). Further, other patients believed additional specialist staff were needed to foster information sharing with family members. One suggested: "...*especially in my case, because when the doctors and the nurses come and do that [bedside round], she's [my wife] not necessarily always there. So that makes the whole process incredibly difficult. I know how incredibly busy they[staff] are, you know, but maybe if they had one person who was a dedicated, you know, patient family liaison officer*" (P2-I). This highlighted that patients felt staff on MAPU had limited opportunities to effectively connect with their family and promote information sharing

Family influence quality

In the second category three major themes were identified from observation and interview data. Three themes: being the rock of support, keeping watch, and participation enhances care, reflected how family participation promoted quality patient care on the MAPU.

Being the rock of support

Acutely ill hospitalised patients valued having their family present because they provided vital emotional support, and improved their ability to cope. For instance, following a period of observation, a patient was asked about the benefit they gained from having their family present,

and they stated, “*They’re **an emotional tie**, just talking to them is good*” (P12 – O). Similarly, another patient interviewed commented “*Just **having a loved one**, and they [wife] came in today, just arrived probably two minutes before I was getting my spinal tap [pause] but for me **that was good**, because it **gives you a lift***” (P9-I).

Two-thirds of the family participants interviewed stated that they felt it was important to be present and support their relative because they recognised that hospitalisation for an acute illness placed patients under significant physical, and psychological stress. One family member who stated she was involved in her mother’s care in MAPU, commented, “*It’s **up to us**, then to, sort of, basically **pick her mood up**, type of thing*” (F9 -I). Further, during observations family members would communicate with nursing staff if they believed their relative was in discomfort. For instance, whilst a patient was receiving nebulised medication, a family member was heard to say to the bedside nurse, “*She just wants to get rid of her cough and get out of here... she [patient] wants to sit up higher in the bed*” (F6-O).

Keeping watch

Family members felt they had unique knowledge of their relative’s health needs, which positioned them well to recognise gaps in care, or care that may have a negative impact. Consequently, family members felt they needed to scrutinize the treatment provided to their sick relative, for example, one patient’s wife said: “*We seemed to have to go through the whole procedure all over again and, and you think, **oh, not another set of blood tests**, because we’ve just had those, so then I’d say look, we’ve had those blood tests... **I’ve got to keep my eye on all this**, I don’t want him [husband] **getting more or less of whatever he needs***” (F1 -I). Patient interviews also revealed that family members were often knowledgeable in care practices,

particularly when patients had a chronic illness. Subsequently family members were vigilant to ensure quality patient care was maintained on MAPU. For example, one patient who had experienced a severe spinal cord injury over a decade ago who was admitted for a separate illness commented: *“My mum came in yesterday, and **she immediately** went and had a look at me feet and see if they were resting against the bed board. **She just knows.**, she looked after me for a while when I first got out of hospital and **she learnt everything in the spinal unit the same time as I did. She was taught what to look for and checks them**”* (P14-I).

Participation enhances care

Patient care that was enhanced through family participation was observed when families acted as a patient advocate or assisted in direct care activities. For example, while a family member was observed to complete their relative’s hospital menu request form, the researcher queried with the family member as to why this was important for them, and they stated: *“**I help to feed him, to advocate for him, to follow up with allied health...he needs a dietician review and I’ll make sure he gets one...**”* (F7-O). Patients also revealed how family members influenced them to seek medical help and follow through with treatment on MAPU. For example, one patient who was newly admitted to the MAPU following complaints of chest pain, had his wife and adult daughter present, and commented: *“**She [wife] pushes me to get the tests done...you know what men are like! She encourages me to see things through [pause] I haven’t done this before (no real experience of hospitals)**”* (P5-O).

Discussion

In this study we investigated patient and family perceptions towards family participation in patient care within the acute adult setting. Further, healthcare staff behaviours that supported or hindered family participation in care processes were explored. Our findings revealed that many patients and families perceived staff communication as disconnected and inadequate, which constrained them from engaging in care processes or decision-making. However, when family felt empowered to participate, the quality of patient care was enhanced. The findings of our study demonstrated that communication, empowered families and care transitions influenced family participation in the acute setting.

Our data suggest that the interpersonal communication between healthcare staff, patients and their families was frequently ineffective and one-directional, which contributed to their feelings of confusion or frustration for patients and family members. Moreover, a key finding in our data was that despite family being present, staff appeared unable to employ a communication style that fostered information sharing as evident in the 'feeling out of the loop' theme. Complementing our findings, other researchers have described how healthcare professionals in the acute care setting often fail to communicate with patients and families because they: (1) neglect to employ techniques known to improve communication (68,69); (2) believe they have insufficient time to communicate (70) or (3) believe the onus is on family members to initiate interactions (71).

Nurses spend the most amount of time engaged in direct patient care when compared to other healthcare professionals (37,72,73) and it is therefore essential they can communicate effectively. Educative and recall interpersonal communication strategies such as Teach-Back (27), Show-Me (26), and Ask-Tell-Ask (74) are effective strategies that nurses can learn and apply to clarify information or correct misunderstandings (75-77). Failing to consider the health

literacy of patients and family members, and tailoring information appropriately may lead to a misunderstanding of medication instructions, which can place the patient at greater risk of a serious adverse event (75). Further, sharing unbiased information with patients and families in ways that improves their understanding is a core concept of PFCC (18), and is a fundamental requirement for safe and high-quality healthcare (78).

Family participation in patient care relies on health literacy, engagement and healthcare professionals applying a PFCC approach to care (75, 53). Improving health literacy ensures that families can share in decision-making, and meaningful participate in patient care (75). However, our study data revealed that patient's and family's individual health literacy needs were neglected, and staff on MAPU failed to screen for risk factors that can influence individual health literacy, such as age, education, disability, culture and language (79,80). Health literacy is a complex phenomenon that has moved from a narrow conceptual focus on an individual patient and family members health literacy skills and abilities to being more multi-faceted, where a person's skills and abilities interact with cultural, family, media, community resources, health system, health care provider, environmental and structural influences (77, 81,82). Patients and families with lower health literacy may ask fewer questions (83), and health information needs can vary for an individual depending on their current situation (79). This further supports the need for health professionals to be proactive and engage routinely with patients and families to assess their information needs. In clarifying and checking health information with family members there is the capacity for them to be ready and confident to participate in patient care.

In our study, the quality of patient care was enhanced when family members felt empowered and took proactive steps to participate in patient care, or act as the patient's advocate. Other researchers have reported similar findings that family involvement in patient

care has a positive impact and improves their hospital experience (84-86), and can help patients to improve self-management (1). To overcome the seemingly slow uptake of PFCC practices in the acute setting (15), health care staff must place greater emphasis on activating and empowering families. Family empowerment can be identified when healthcare staff create opportunities to increase families' knowledge, and support family to contribute their expert understanding of patient needs or preferences (87). Early childhood and family researchers have unique insights into building the capacity of families (88,89). Empowerment models of care from this context (90) emphasise: (1) the family not just the patient as the unit of intervention; (2) interventions focus on meeting the needs of the entire family; and (3) healthcare professionals should employ helping behaviours to enhance a family's ability to manage uncertainty, and could underpin the development of interventions aimed at empowering families in the adult acute care setting.

Transitioning between healthcare settings were perceived by patients and family members in our study as unsettling because inconsistent information hindered the continuity of patient care. Fragmentation and discoordination of healthcare is a significant cause of inappropriate care and increased healthcare costs (91). Nurse care-coordination or patient navigation roles have been effective at promoting shared decision-making, enhancing health literacy and self-management skills (92,93), which are important aspects in the continuity of care. In addition, care coordination can mitigate the tension patients and family feel when a transition in care occurs (94-95). The value of a care coordinator/navigator was highlighted in our study when patients acknowledged the need for a dedicated person to facilitate communication with family members during transitions. Family members often support patients

to seek follow-up care with community providers (96), which emphasises the need for meaningful discharge communication that will result in a safe and effective transition (97).

Nurse coordinator/navigators have been implemented in some Australian, Canadian, and European facilities (92, 94,98) in response to empirical evidence suggesting that they are successful at improving key hospital indicators (99,100), and reducing the fragmentation of healthcare services (101). The role of nurse coordinator/navigators has enormous potential to foster family participation in patient care (95). Furthermore, nurses undertaking a coordination/navigator role are uniquely placed to champion the PFCC philosophy of building patients' and families' capacity for decision-making and engagement. It would be important to conduct further research to determine the impact of a nurse coordinator/navigator in the adult acute care setting and the influence it has on family participation in patient care in units similar to MAPU.

Patients in our study expressed feelings of uncertainty, however, they felt more at ease and better able to cope when their family were present and participated in their care. Consistent with this, other researchers have found that social support provided by a family member helps patients to overcome uncertainty (102,103), and may also be of benefit to family members (7,104). Mishel's (105) 'theory of uncertainty in illness', asserts that uncertainty peaks during acute illness or while awaiting a diagnosis in hospital (106); thus, represents a crucial period where family involvement should be fostered. Further, a recent study by Ruckholdt et al. (107) highlighted that hospitalisation can represent a time of great vulnerability and imposed stress for both the patient and their family. This further supports the need to support family participation in patient care in real ways from the first acute phase onwards (42).

The delivery of care on in our study was similar to other MAPUs and patient discharges occurred within 48-72 hours (108). The regulated timeline to provide patient care in this setting highlights the need for nurses to maximise each opportunity to connect and develop a relationship with patients and their family (109). Similar findings have been identified that effective nursing is based on relationships and the ability of the nurse to establish a therapeutic relationship with the patient and their family is fundamental (110). Establishing positive and trusting therapeutic relationships with patients and their families facilitates PFCC practices (111). Therefore, nurses must be mindful of the expectations patients and families have about their relationship and change their behaviour to align with the PFCC core principles (50,110,111).

Strengths and limitations

A strength of this study was the success of the purposive maximum variation sampling strategy involving a representative sample of the patients, and their family. Furthermore, a significant proportion of patients and families were interviewed together. The current study is limited in being confined to a single site, in one medical unit, at a regional hospital, which limits the transferability of the findings. However, the acute ward area was strategically selected based on hospital wide data that indicated it would provide circumstances where PFCC could be identified. Such limitations are accepted within naturalistic inquiry, and all diligence was taken to remain true to the data and limit interpretations of researcher bias. *The findings are not intended for generalization but rather to enhance our understanding of the core concepts of family participation in patient care within the acute care setting;* rich descriptions of the setting

and sample have been provided which strengthens our study, allowing researchers to judge applicability of findings to their own practice setting.

Conclusion

While effective engagement of patients and their families in treatment is viewed as a priority in many healthcare systems (112), our study uncovered that despite family being present, healthcare staff did not modify their interpersonal communication style to promote their involvement. The communication strategies employed by staff in this acute care setting need to be considered when developing strategies that are directed at enhancing family participation in patient care. Furthermore, it was evident in our themes that because patients and their family felt disconnected from important health information they were unable to meaningfully share in decision-making. Our study findings highlighted that family participation enhances the quality of patient care and is best achieved when family members feel empowered. Finally, changing the behaviours of healthcare staff to align with the core concepts of PFCC has the potential to improve family participation and should be the focus of future interventions and research.

Acknowledgements

The authors would like to thank all the nurses, patients and families at the regional hospital for their participation in the study as well as the nurse leaders who supported the study. Additionally, the lead author was a grateful recipient of an Australian Government Research Training Program Scholarship. The funder had no input into any phase of the project or publication decisions.

**** insert Authors' contributions here****

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