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Communication relating to family members' involvement and understandings about patients' medication management in hospital

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Abstract

Background Many patients with complex health-care needs are prescribed several medications on a daily basis. With admission to hospital, patients are often placed in a vulnerable position. Family members can therefore play an important role in supporting patients in decision making about managing medications and negotiating communication exchange with health professionals.

Objectives From the perspective of family members, to explore family members' involvement with health professionals and patients about how patients' medications are managed in hospital.

Design Using an ethnographic design, interviews were conducted with family members of patients admitted to hospital who had at least five medications prescribed in hospital. A purposive sampling approach was used for recruitment. A thematic framework process was used for analysis.

Setting Interviews took place in four surgical and four medical wards in each of two Australian hospitals.

Results Forty interviews were conducted with family members in relation to their respective relative's medications. Family members tended to participate in passive, rather than active or shared decision-making activities. Those who demonstrated active or shared decision making were extensively involved in managing medications and in addressing problems relating to continuity of care. Communication with health professionals was generally insufficient, despite family members' keenness to speak with them.

Conclusions Improved communication is needed between family members, health professionals and patients in hospitals. Greater attention should be played by health professionals in initiating communication proactively. Family members possessed valuable, unique information about patients' medications that can be utilized to facilitate patient safety.

Background

Responsibility for the management of medications is an integral part of the informal caring role undertaken by family members. A vast array of medication-related activities can be undertaken by family members. These activities include relieving symptoms with medications, acquiring medications, assisting with medication adherence, recognizing and interpreting wanted and unwanted symptoms associated with medications, conveying knowledge about medications, recognizing and interpreting symptoms, and understanding and responding to patients' medication needs.[1–4]

Past work examining the supportive medication role played by family members has focused on their input in the community and at hospital discharge. Knight *et al.*[2] conducted interviews with 12 family members and seven older people to explore their experience of hospital discharge in organizing and managing medications. Participants were not happy about the discharge process and were concerned about delays. They were dissatisfied about the adequacy of explanations about medications, which led to incorrect dosage, omitted medications, anxiety and confusion. Poor communication was also evident between hospital staff, general practitioners and community pharmacists. Francis *et al.*[1] conducted interviews with 47 older patients and informal carers after recruitment from community pharmacies. Participants commented that their teamwork in sharing responsibilities for managing medications varied widely. Medication activities undertaken by carers were often dependent on their health and well-being, as they had health problems of their own. Some information was deliberately concealed or withheld by patients or informal carers, in effort to avoid unnecessary worry. In the work by Lau *et al.*,[5] involving interviews with 22 hospice providers and 23 family caregivers, key aspects of care by family caregivers involved the ability to relieve symptoms with pharmacological interventions, the use of skills related to teamwork, organization, symptom knowledge, and medication knowledge and understanding patients' needs.

Gaps in past work include a lack of focus on family members' experiences of medication management in the hospital context. Insufficient attention has been paid to family members' understandings about medications prescribed to patients in hospital. In addition, past research has largely ignored how family members communicate in different ways with doctors, nurses and pharmacists – the three key health professional groups involved in medication management.

Aim of study

To explore family members' involvement with health professionals and patients about how patients' medications are managed in hospital.

Method

An ethnographic research design was undertaken,[6] examining the interactions between individuals in a hospital culture. In-depth interviews were used as the data collection method. Family members were defined as individuals who played a significant role in the patient's life. Examples included family members who spent regular time with their relatives, either by visiting, making telephone calls, assisting with household chores and attending doctors' appointments. They may have either lived with the patient or in another home.

The study was conducted in eight surgical and eight medical units. These units were located in an inner metropolitan public teaching hospital and an outer metropolitan teaching hospital in Melbourne, Australia. Ethics approval of the study was obtained through the two hospitals.

A purposive sampling approach was used. In selecting possible participants, efforts were made to ensure family members resided in diverse environments, including metropolitan, regional and rural areas, comprised a range of age groups and maintained different relationships with patients, including spouses,

parents and adult children. This variability of characteristics ensured that the resulting data findings can be transferable and applied to different clinical contexts of care. A matrix was drawn up to provide information about selecting family members, in terms of residing environments, age groups and relationship to the relative. Family members were chosen systematically to ensure certain characteristics were covered and were considered for inclusion if they understood English, and they had a current relative admitted to one of the units. Conversely, family members were excluded if at the time of interview, the patients related to them were extremely physiologically unstable and therefore at risk of having a cardiac or respiratory arrest. During the time of interviews, such situations never occurred. Patients were purposively selected if they had at least five medications prescribed in hospital.

The nurse-in-charge of a working shift was contacted every couple of days to determine which family members had an understanding of English and if their patient relatives were physiologically stable. A research assistant approached potentially suitable family members at the patient's bedside during visiting hours to determine their eligibility and possible interest in the study. Family members were given verbal and written information about the study. For those family members who gave written informed consent, a mutually agreeable time was organized to conduct the interview.

In the initial part of the interview, information was sought from the patient and accompanying family member. They were asked about the living arrangements of each party, the reason for hospital admission, and the ways that the patient's medications were managed at home. After this information was obtained, the family member was interviewed separately in a quiet area of the unit. The intent was to obtain reflective and honest perspectives of their experiences, which may not have been possible in the patient's presence (Table 1). All interviews, which were about one hour in duration, were conducted by the research assistant, and were audio-recorded and transcribed *ad verbatim*. The research assistant received interview training, and the main researcher was present for the first five interviews to ensure appropriate interview techniques were used. Rigor of the interview process also occurred (Table 1). Data analysis of transcripts was conducted independently by the research assistant and the researcher using the thematic framework process.[7] This process comprised five, interrelated steps, including familiarization, conceptualization of themes, application of themes to the data, rearranging the data according to themes and finally mapping, which enabled the data to be interpreted as an entity. Complete agreement was obtained between the research assistant and researcher in developing themes, and interviews ceased when saturation of themes was achieved.

Results

In total, 40 interviews were conducted with family members, comprising 35 women. The mean age of family members was 53.9 years (SD = 15.3), and 18 family members were aged 50 years or younger. Relationships of family members included 18 daughters, 15 wives, five husbands and two mothers. In all, 23 patients were men and 17 were women, and 35 patients were aged over 50 years. Table 2 shows the characteristics of family members and patients, and the ways in which family members contributed to medication management at home. A median of nine medications (range: 5–17 medications) were prescribed per patient. Family members' understandings about the purpose of patients' medications prescribed in hospital ranged from 14 to 100%. Table 3 shows examples of family members' understandings of patients' medications.

Three major themes were derived from the data: involvement of family members in decision making, family member and health professional relationships and use of medication-taking strategies in hospital.

Table 1 Interview schedule, interview training and rigor of interview process

Questions posed to family members
What do you understand about the reasons for prescribing each of your relative's medications? [Research assistant states each medication name to the family member and asks the family member why it is prescribed.]
How do you communicate with doctors in hospital about your relative's medications?
How do you communicate with nurses in hospital about your relative's medications?
How do you communicate with the pharmacist in hospital about your relative's medications?
How involved do you feel in medication decisions with health professionals?
How do you think you contribute to the management of your relative's medications in hospital?
Interview training for research assistant
Main researcher was present for information sessions with family members for the initial five interviews to ensure the consent process was undertaken appropriately.
Main researcher was present for the initial five interviews with research assistant to ensure interviews were conducted appropriately.
Funnelling approach encouraged for interview questions, to obtain more details about a specific issue.
Family members were encouraged to provide information relating to their particular experiences rather than talking about issues generally.
Family members were asked to provide descriptions of events, people, places and experiences.
Family members were asked how they are affected by various influences that may impact on their current situation of their relative's hospital stay.
Family members were invited to compare various situations and experiences in relation to their relative's management of medications in hospital.
Family members were encouraged to provide their opinions and values, to find out what a participant thought or felt about a particular person, issue or experience in relation to their relative's management of medications in hospital.
Rigor of interview process
Credibility: facilitated by prolonged engagement in the field; multiple readings of the data transcripts; use of a research assistant and researcher to independently analyse data; and triangulation of approaches by considering patients' perspective at the start of the interview process as well as family members' perspective.
Dependability: facilitated by producing evidence of a decision trail through a researcher journal at each stage of the research process; providing evidence of the decisions and choices made regarding methodological issues throughout the study; and discussing the reasons for these decisions. Each stage of the research was traceable and clearly documented.
Transferability: facilitated by the purposive sampling process to ensure the findings could fit into other contexts; and use of comprehensive descriptions of data findings.

Involvement of family members in decision making

Involvement of family members comprised two subthemes. It concerned participation in various forms of decision making by family members. In addition, it was associated with type and extent of involvement.

Passive, shared and active involvement in decision making by family members

Family members participated in three forms of decision making: passive, shared and active. Passive decision making involved health professionals making medication decisions while shared decision making concerned health professionals making medication decisions in conjunction with the patient and family member. Active decision making comprised the patient or family member making medication decisions independently or after consulting with health professionals. Most family members tended to demonstrate passive decision making. Interestingly, some family members who demonstrated shared or active decision making lacked understanding of patients' regular medications. Table 4 shows examples of the relationships between family members and patients, with respect to the three forms of decision making. It provides insights into complex barriers between them.

Family members posed many reasons for participating in passive decision making. Some family members stated that they did not feel comfortable in asking questions about medications because they were unsure about what to

Table 2 Demographic characteristics of patients and family members

Participant number and characteristics, patient's age	Reason for admission and assistance provided with medications at home and approach used in decision making
FM1 73 years Male Spouse Patient 1 72 years Woman	Patient admitted for surgical repair of fractured neck of femur. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in regional environment. Shared approach to decision making identified.
FM2 44 years Female Daughter Patient 2 71 years Woman	Patient admitted for bronchial pneumonia. At home, family member rang patient once or twice a week and asks about medications. She accompanied patient to doctor visits as her language spoken at home was Turkish. Family member lived in regional environment. Passive approach to decision making identified.
FM3 Female 71 years Spouse Patient 3 73 years Man	Patient admitted for removal of infected hip replacement. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in metropolitan environment. Active approach to decision making identified.
FM4 42 years Female Daughter Patient 4 71 years Woman	Patient transferred from another hospital following an anastomotic leak after a laparotomy and washout procedure. At home, family member rang patient once or twice a week and asked about medications. Family member in rural environment. Shared approach to decision making identified.
FM5 58 years Female Parent Patient 5 31 years Woman	Patient admitted for coronary artery bypass surgery complicated by cardiac arrest and ischaemic small bowel after surgery. At home, family member visited patient daily and checked if medications had been taken. Family member in rural environment. Passive approach to decision making identified.
FM6 44 years Female Spouse Patient 6 49 years Man	Patient admitted with severe cellulitis. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM7 74 years Female Spouse Patient 7 79 years Man	Patient admitted for left hip replacement. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM8 26 years Female Daughter Patient 8 49 years Man	Patient admitted with adrenal mass and diagnosis of pheochromocytoma. At home, family member talked daily on the phone to patient and asked about medications. She accompanied patient to doctor visits as his language spoken at home was Turkish. Family member in rural environment. Active approach to decision making identified.
FM9 67 years Male Spouse Patient 9 65 years Woman	Patient admitted for vascular graft surgery due to peripheral arterial disease. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in metropolitan environment. Passive approach to decision making identified.

Table 2. Continued

Participant number and characteristics, patient's age	Reason for admission and assistance provided with medications at home and approach used in decision making
FM10 78 years Male Spouse Patient 10 74 years Woman	Patient admitted for uncontrolled blood pressure. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in metropolitan environment. Passive approach to decision making identified.
FM11 38 years Female Daughter Patient 11 69 years Woman	Patient admitted for right hip replacement. At home, family member checked daily with patient and asked her about medications. She accompanied patient to doctor visits as her language spoken at home was Cantonese. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM 12 36 years Woman Daughter Patient 12 75 years Woman	Patient admitted for exacerbation of chronic obstructive pulmonary disease (COPD). At home, family member rang patient two to three times a week and asked about medications. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM13 55 years Female Daughter Patient 13 88 years Man	Patient admitted to hospital with decreased mobility and severe left hip pain for examination. Two different general practitioners (GPs) prescribed different diuretics. Mistake picked up in hospital. At home, family member rang patient once or twice a week and asked about medications. Family member lived in metropolitan environment. Passive approach to decision making identified.
FM14 69 years Male Spouse Patient 14 68 years Woman	Patient admitted for bowel resection surgery. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in regional environment. Passive approach to decision making identified.
FM15 32 years Female Daughter Patient 15 55 years Woman	Patient admitted with confusion and dehydration and was diagnosed with type 2 diabetes in hospital. At home, family member rang patient once or twice a week and asked about medications. She accompanied patient to doctor visits as her language spoken at home was Greek. Family member lived in metropolitan environment. Passive approach to decision making identified.
FM16 41 years Female Daughter Patient 16 68 years Woman	Patient admitted for fractured pelvis. At home, family member rang patient once a week and asked about medications. Family member in rural environment. Passive approach to decision making identified.
FM17 75 years Female Spouse Patient 17 73 years Man	Patient admitted with recent headache and flu-like symptoms after chemotherapy for non-Hodgkin's lymphoma. At home, family member wrote in big type on all medications and placed them next to bread tin. Family member lived in regional environment. Shared approach to decision making identified.
FM18 80 years Female Spouse Patient 18 81 years Man	Patient admitted with worsening heart failure. At home, family member reminded patient about taking medications. Family member lived in regional environment. Passive approach to decision making identified.

Table 2. Continued

Participant number and characteristics, patient's age	Reason for admission and assistance provided with medications at home and approach used in decision making
FM19 53 years Female Daughter Patient 19 86 years Woman	Patient admitted following fall on right hip and is scheduled to have surgery. At home, family member had been living with patient over recent weeks and regularly checked about medications taken. She accompanied patient to doctor visits as language spoken at home was Italian. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM20 58 years Female Spouse Patient 20 60 years Man	Patient admitted with unstable, high blood pressure. At home, patient was fully responsible for own medications but family member provided support if needed. Family member lived in regional environment. Shared approach to decision making identified.
FM21 42 years Female Daughter Patient 21 69 years Man	Patient admitted for fractured elbow and uncontrolled angina. At home, family member rang patient once or twice a week and asked about medications. Family member lived in regional environment. Passive approach to decision making identified.
FM22 61 years Female Parent Patient 22 34 years Man	Patient admitted for surgical management of extreme pain following removal of squamous cell carcinoma. At home, family member reminded patient about taking medications. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM23 46 years Female Daughter Patient 23 72 years Man	Patient admitted for infected leg ulcer. At home, family member rang patient once or twice a week and asks about medications. Family member in rural environment. Passive approach to decision making identified.
FM24 59 years Female Spouse Patient 24 63 years Man	Patient admitted for left thigh pain and amputation of leg. At home, family member placed medications in a box on the mantelpiece and brought the box down at breakfast and dinner. Family member lived in metropolitan environment. Active approach to decision making identified.
FM25 50 years Female Daughter Patient 25 78 years Man	Patient admitted for fractured left hip. At home, family member rang patient once or twice a week and asked about medications. She accompanied patient to doctor visits as language spoken at home was Greek. Family member in rural environment. Passive approach to decision making identified.
FM26 51 years Female Spouse Patient 26 58 years Man	Patient admitted for insertion of bilateral thalamic stimulator and required an external ventricular drain for bleeding. At home, family member assisted patient to put tablets in small plastic bag, one for each day of the week. She bought patient a medi-alert watch to remind him to take medications every 2½ hours. Family member in rural environment. Shared approach to decision making identified.
FM27 54 years Female Spouse Patient 27 78 years Man	Patient admitted for surgery of blocked peritoneal catheter to enable home dialysis. At home, family member kept all medications in a box and put out medications to be taken with food in a clear coloured cup and those to be taken after food in a black coloured glass. Family member lived in regional environment. Active approach to decision making identified.

Table 2. Continued

Participant number and characteristics, patient's age	Reason for admission and assistance provided with medications at home and approach used in decision making
FM28	Patient admitted for knee replacement.
32 years Female Daughter	At home, family member encouraged patient to write down instructions in
Patient 28 75 years Man	Chinese directly on the medication container.
	Family member lived in regional environment.
	Active approach to decision making identified.
FM29	Patient admitted with intracerebral bleeding and aneurysm for surgical repair.
41 years Female Partner	At home, patient was fully responsible for own medications but family member
Patient 29 34 years Man	provided support if needed.
	Family member lived in regional environment.
	Passive approach to decision making identified.
FM30	Patient admitted for left hip replacement.
70 years Female Spouse	At home, family member placed medications in plastic cup at breakfast, lunch and
Patient 30 78 years Man	dinner for patient to take.
	Family member lived in metropolitan environment.
	Passive approach to decision making identified.
FM31	Patient admitted following internal bleed after angiogram.
44 years Female Daughter	At home, family member rang patient once or twice a week and asked about medications.
Patient 31 77 years Man	Family member lived in regional environment.
	Shared approach to decision making identified.
FM32	Patient admitted for cerebral vascular accident.
68 years Female Spouse	At home, patient was fully responsible for own medications but family member provided
Patient 32 72 years Man	support if needed.
	Family member lived in metropolitan environment.
	Passive approach to decision making identified.
FM33	Patient admitted with unstable blood pressure.
38 years Female Daughter	At home, family member rang patient once or twice a week and asked about medications.
Patient 33 63 years Woman	Family member lived in metropolitan environment.
	Passive approach to decision making identified.
FM34	Patient admitted for collapse, dehydration and relapse from multiple sclerosis.
73 years Female Spouse	At home, patient was fully responsible for own medications but family member
Patient 34 75 years Man	provided support if needed.
	Family member lived in regional environment.
	Passive approach to decision making identified.
FM35	Patient admitted with an infected diabetic ulcer.
55 years Female Spouse	At home, family member assisted patient with administration of insulin injection.
Patient 35 60 years Man	Family member lived in regional environment.
	Passive approach to decision making identified.
FM36	Patient admitted with worsening heart failure and bronchial pneumonia.
72 years Male Spouse	At home, patient was fully responsible for own medications but family member
Patient 36 69 years Woman	provided support if needed.
	Family member lived in metropolitan environment.
	Passive approach to decision making identified.
FM37	Patient admitted with bronchial pneumonia.
34 years Female Daughter	At home, family member rang patient once or twice a week and asked about medications.
Patient 37 61 years Woman	She accompanied patient to doctor visits as language spoken at home was Greek.
	Family member lived in regional environment.
	Passive approach to decision making identified.

Table 2. Continued

Participant number and characteristics, patient's age	Reason for admission and assistance provided with medications at home and approach used in decision making
FM38 73 years Female Spouse Patient 38 75 years Man	Patient admitted for infected elbow joint following surgery and unstable gout. At home, family member placed a week's supply of medications in a box. Family member lived in metropolitan environment. Passive approach to decision making identified.
FM39 43 years Female Daughter Patient 39 79 years Woman	Patient admitted with severe dehydration, deep vein thrombosis and pneumonia. Doctors in hospital were worried about the possible immunosuppressant effect of prednisolone on pneumonia. At home, family member rang patient once or twice a week and asked about medications. Family member lived in metropolitan environment. Shared approach to decision making identified.
FM40 33 years Female Daughter Patient 40 66 years Woman	Patient admitted for cerebral vascular accident. At home, family member rang patient once or twice a week and asked about medications. Family member lived in metropolitan environment. Passive approach to decision making identified.

say: 'It is hard to think of questions on the spot especially when doctors keep changing their minds about the treatment. They take you by surprise and you don't know how to ask' [FM5]. In addition, other family members perceived that health professionals were best placed in making judgements about how medications were prescribed and administered: 'I don't really know much. The doctors tell us what tablets he needs to take and that's it. They know what they are doing' [FM29]. Family members justified their passive stance by saying that patients were on particular medications for considerable time, and therefore, it was unlikely that major changes were likely to be made that required their input in decisions. However, in many cases doctors had changed patients' medication regimen, and family members were not consulted about these decisions: 'His medications have all changed. I didn't know and I think we are just supposed to accept it' [FM38]. Family members also perceived there was an element of trust attached to doctors' expertise, and that their involvement could be construed as 'second guessing' [FM2]. In some situations where family members admitted they had little input, they wanted the opportunity to be more actively involved. As mentioned by a patient's daughter:

> I don't have involvement in any decisions, but I can't blame the system. It is probably my fault because I haven't been in control in seeking out when people are around to talk to. My work commitments don't help and it is very frustrating. I am really not sure how to go about it. [FM40]

Some family members were involved with shared decision making, whereby medication decisions were conjointly made. This type of situation required family members to be present and willing to converse when a doctor or nurse was available to speak to them at length about a medication issue. As commented by a patient's daughter:

> I saw them [the doctors and nurses] yesterday, which was really great because I happened to be there, and we started talking about her medications for pain. The doctor explained that they were putting up some intravenous Panadol [paracetamol] and that was going to help with her pain. They also wanted to put up something stronger and they noticed that mum had an allergy to morphine. And the nurse said, 'How does that make her feel and what does it do?' So I explained that she gets all itchy and it drives her crazy and she gets really sick with it. They were concerned and wanted to hear what she experienced in the past. They said that they would use fentanyl instead as it should not cause her any problems. So if she got any pain she had

Table 3 Examples of family members' understandings of patients' medications

Medication (actual purpose of medication)	Expression of understanding by family member
Examples demonstrating good understanding of medications' purpose	
Dicloxacillin (patient on medication for treatment of infected left hip)	'Well, the doctors have to get rid of the infection in his hip…This antibiotic, the dicloxacillin, is the only one that will halt the infection'. [FM3]
Warfarin (patient on medication to prevent clots developing from atrial fibrillation)	'Yes, I know about warfarin. It is a nasty thing that can mess up your dose and bleeding if you take too much. Mum has had atrial fibrillation and a mild stroke so the warfarin helps with that." [FM19]
Oxycodone (patient on medication for left thigh pain and amputation of leg)	"He has had this medication Endone (oxycodone) for pain relief in his leg, and I know it can cause him to have bad dreams, which can upset him'. [FM24]
Amantadine (patient on medication for Parkinson's disease) Cabergoline (patient on medication for Parkinson's disease) Carbidopa(patient on medication for Parkinson's disease) Carbidopa, entacapone, and levodopa (Stalevo) (patient on medication for Parkinson's disease)	'Oh, I know the names of all the medications that he [patient] needs for Parkinson's disease. There's Symmetrel [amantadine], Stalevo [carbidopa, entacapone, and levodopa combination], Sinemet [carbidopa], and Cabaser [cabergoline]. They all work in different ways. Symmetrel is a special one to control the dyskinesia – that's the jerky movements he gets. Stalevo stops the wearing off effects of his other tablets'. [FM26]
Trifluoperazine (severe anxiety)	'My mum has been on Stelazine [trifluoperazine] for a while now. She has been using it for when she gets very anxious. But when I talked to the doctor about it he said that we needed to wean her off it because it could cause Parkinson's effects'. [FM31]
Examples demonstrating poor understanding of medications' purpose	
Pantoprazole (dyspepsia, prevention of peptic ulceration)	'Pantoprazole – oh, I'm not sure about that one. Is that one for the bowel, to slow down her motions?' [FM5]
Isosorbide mononitrate (coronary heart disease)	'I really don't know about that one. I know that he is on some medications for his diabetes and he has some leg pain, and he has been taking some pain relief for that'. [FM13]
Amlodipine (blood pressure control) Atenolol (blood pressure control) Ramipril (blood pressure control)	'I don't really know about those medications. I have trust in the cardiac specialist who prescribed them. I think they are there to help with his heart'. [FM17]
Sertraline (for treatment of depression)	'My mum has been taking sertraline, I think that's what you call it. She has been taking it for cholesterol for the last couple of months'. [FM19]
Diazepam (allay anxiety and assist with sleep)	'He takes the Valium [diazepam] for pain. He has been on it for about 12 months now for a throat problem. It helps to ease the pain of indigestion'. [FM30]

> to press a button. They also wanted to know what I thought about that. [FM4]

Active decision making was shown by family members who made decisions themselves in conjunction with the patient. This form of decision making was demonstrated by family members who believed they were too complacent in the past, and they blamed themselves for health problems that occurred. A patient's daughter recounted:

> If we had been more involved we would have known how to deal with his insulin and his tablets. All of a sudden he's got tingling in his feet and losing his vision… so I have started to push and do what we think is right. You got to get over the belief that they [doctors] know all. I am always asking questions… You got to fight your own

Table 4 Relationships between family members and patients with respects to the three forms of decision making

Type of decision making demonstrated by family member with health professionals	Examples of quotes about relationship between family member and patient
Passive	'Dad is really stubborn…he was fine up to last year, but then when he became forgetful and wasn't watching his blood sugars, I had to be forceful with him about his eating and watching his medications. When I make him do things like that, he just grumbles at me… But that's what daughters are supposed to do'. [FM13]
	'Mum doesn't really ask the right questions with doctors, and she does get upset if any of her children start to question things. So we tend to hang back. She would go, 'Well, why are questioning that – don't you think I understand it?' [FM40]
Shared	'My husband and I trust each other – we treat each other with dignity and intelligence. I do question things with the doctors as it is important to know what they are thinking about the medications should do. I probably do most of the talking but my husband is fine with that' [FM17]
	'My mother and I have this wonderful relationship. For the first three days she was here in hospital, I didn't leave her side for 13 hours each day… I am from out of town and I didn't have any place to go… I have always been really involved with her. I haven't wanted to leave her – it's not just for my mother. It is for me too' [FM31]
Active	'I used to do everything for him [husband] and he became very dependent on me…he does it all himself, and he is in a routine now. My husband still likes me to do all the talking, and ask questions because men don't think about those kinds of things'. [FM3]
	'My dad's a big ox of a man. He thinks the number of medications he is taking is an indication of how bad or weak he is, whereas it does not necessarily mean that at all. He can easily get really anxious about it. But he trusts me and listens to me though when I follow up on things with the doctors, it helps him to cope. He really likes me to follow through with things' [FM8]

> battles and learn to ask for your opinion to be heard. [FM8]

Sometimes, active decision making led to medication-taking practices that were not necessarily condoned by health professionals. These practices were played out before the patient's admission and were discovered by health professionals during the patient's stay. As indicated by a patient's wife:

> My husband was ordered cholesterol tablets and we asked lots of questions with the cardiologist. We found that they were quite bad for the bones and when he started taking them, he couldn't walk properly. The tablets went in the fire! When he was admitted in hospital the cardiologist was not impressed to hear that he hadn't been taking the tablets… I told the cardiologist it was because they were damaging his bones and we got a burst from him and the other doctors. [FM24]

Type and extent of involvement by family members

Many family members were extensively involved with patients in managing medications. Various reasons were relayed about the need for family member participation, including a lack of trust of patients to become involved due to severe sickness, the patients' inability to understand about medications, the attribution of blame if anything should go wrong and lack of faith in the hospital system. A patient's wife indicated:

> I need to be involved because I am his next-of-kin. I know his mood swings and what he is like. If I saw anything different to the way he was I could say something to them. I could say… if the medication is affecting him in a way that it shouldn't be. [FM3]

Family members were involved in emotive ways by being a support person for patients and by answering queries that patients had about medications. They also helped in more practical ways by preparing dose administration aids in hospital to assist with medication-taking and by writing or recalling comprehensive medication lists for health professionals upon patients' admission to hospital. A patient's daughter commented:

> I am keeping a log of my mum's medications during her hospital stay. So when the medications started and stopped, information about the intravenous pain killers and when the nurses gave her certain tablets, I have been writing it down. The days are running into each other and this helps mum to know what's going on. [FM4]

> A patient's spouse stated, 'It is important to be involved so that I can communicate to the doctors and nurses when she gets confused' [FM10]. Another spouse commented that it was important to support his wife about medication activities while she had short-term memory problems. [FM38]

A patient's daughter reinforced the importance of her involvement in a pre-admission clinic:

> My dad is so forgetful. There were four tablets that he had to stop taking before his operation. The doctor gave the information verbally. They didn't call an interpreter and it was lucky I was there. I asked the nurse to write down the medication names for me. [FM28]

Family members also had an important role in patient safety:

> My husband is allergic to tramadol, and when he got back from theatre, they [theatre staff] had taken off his red band saying what he was allergic to, and I insisted that the nurse put it back on. She told me it was in the patient history and I said 'I don't care – I want the arm band back on'. [FM29]

Some family members experienced barriers from doctors, nurses and even patients in their attempts to be involved in medication management. A daughter who was asked by a doctor if she had a medical background as she 'asked so many questions' [FM31], got the impression that she was being asked to stifle her involvement. A patient's wife was 'asked by hospital staff to stop helping him [husband] as much with his medications because he has become too dependent' [FM3]. She became more covert in how she displayed her supportive role by waiting until nurses left the room before explaining his medications and showing him how to use them. Some patients who were independent in the home situation became defensive as family members tried to support them in hospital.

Family member and health professional relationships

Three subthemes comprised this theme. Quality and level of communication by health professionals was identified. In addition, negotiation of medication management and continuum of care were also key subthemes.

Quality and level of communication by health professionals

The quality and level of communication between family members and health professionals varied substantially. Most family members were keen to speak to doctors, nurses and pharmacists about the patients' medications. In terms of communication with doctors, the majority of family members felt there was insufficient contact time with them. Doctors conducted their ward rounds at haphazard times during the day, and it was often impossible for family members to seek them out. As mentioned by the following spouse:

> I haven't seen the doctors. They are messing around with how my husband's gout medications are given and he is in lots of pain. The nurses are giving him Panadol but that is not helping. They do their rounds at odd times so it is hard to catch them.[FM38]

There were also concerns about the technical language used by doctors, and family members perceived that patients were either too afraid or embarrassed to ask what they meant. One daughter mentioned:

> My father just hates doctors…the main reason is that he never gets any information about his medicines. He just thinks they pick and poke him without trying to work out what he understands. [FM15]

With respect to nurses, communication involved nurses informing patients about medications being administered. According to family members, this communication was often brief, with few details offered. Nurses largely provided patients with a medication cup containing

all the medications to be given at a specific time with no clarification about medication names or their purpose. As mentioned by a patient's mother: 'I don't really talk to the nurses at all. They just come and give my son his medicines without saying much' [FM22]. On the other hand, with nurses who had a specialist role, such as acute pain nurses, family members commented about the engaging nature of their communication with patients and of their need to make patients feel comfortable. As mentioned by a patient's wife:

> The pain nurse explained that the acute pain team had given him oxycodone and that this might cause him to have bad dreams. She would check up on him and if it gets too bad or it upsets him, the team will change it and try something else. [FM24]

According to family members, communication rarely involved pharmacists. Pharmacists were observed checking medication supplies in patients' drawers, and restocking medications when supplies were low. As commented by a patient's daughter, 'They are into demand and supply' [FM2]. In addition, pharmacists checked patients' medical records to retrieve data about medications taken before hospital admission. However, these data were rarely obtained from conversations held with patients or family members. A patient's daughter who was keen to obtain medication information from a pharmacist commented on how she instigated the encounter:

> When we saw the pharmacist, we just baled her up. 'What are these tablets for, why is he on two pain tablets?' Once we asked a question she was able to answer it and in good detail. She could explain why the tablets were split between taking in the daytime and night time. [FM11]

Negotiation of medication management in hospital by family members

Family members were involved in negotiating how medications were managed in hospital in effort to improve patients' experiences. This involvement was more apparent in family members who demonstrated characteristics of active or shared decision making in hospital. Negotiations occurred around changing medication administration, maximizing effectiveness of treatment and managing side-effects.

Changes in medication administration involved family members making suggestions about dose, frequency and day of administration. In one situation, the patient's wife explained the patient's routine with taking medications for Parkinson's disease:

> My husband's very active at home. He takes his Parkinson's medications every two-and-a-half hours. That keeps him going for the day. We have had talks about how often he should be having them here [in hospital] and because he is just lying there, they have been giving the medications 3-hourly. [FM26]

In the following interview excerpt, a patient's daughter explained how she attempted to organize epoetin injections to be administered on a particular day of the week to mimic the home situation:

> The nurses told me they were going to give mum the EPO [epoetin injection] on Friday, and I said, 'No. mum's got to have it on Saturday because otherwise she will start to get confused about the days.' They said that they'll change it on their file. But then when I went in on Friday afternoon, they had given it to mum, and I had to talk to them about it. This doesn't help with preparing her to come home. [FM39]

Family members also contributed to ensuring medication effectiveness. Prior to hospital admission, family members had been able to work with patients to tailor their medication regimen. During their hospital stay, family members endeavoured to ensure effective management of unwanted symptoms continued. In one situation, the patient and his wife made plans to commence alternative medications to assist with psoriasis symptoms when they were informed that methotrexate had to be withheld before a surgical procedure:

> The surgeon told us we had to stop the methotrexate before surgery. So I organised for my husband to see a dermatologist. He started Derm-eze in the morning and night and a cortisone medication, for any serious flare-ups, and they have continued during his time in hospital. [FM27]

Some family members were involved in attempting to reduce side-effects. In the following situation, the patient's wife noticed that her husband was ordered atenolol. The product information sheet that was left by the bedside indicated that caution should be exercised in peripheral vascular disease:

> So I looked at the sheet and it said in big black letters, extreme care needed in people with blood vessel problems and diabetes. I said to my husband, 'I'm not sure you should be taking this.' So I spoke to one of the doctors, and he said, 'No, it's fine, we do it all the time.' [FM20]

Continuum of care within hospitals

Due to the complexity of health-care needs affecting patients, many different health professionals were involved in managing patients' medications, which meant there was greater chance for problems to occur. Problems occurred in relation to medications that should have been prescribed, withheld or administered. Family members possessed valuable, unique information and played a key role in identifying and rectifying problems. Those family members who contributed extensively in medication activities at home were particularly vocal about identifying these problems in continuum of care compared with patients who were fully responsible for their own medications. In regard to medication that should have been prescribed, a patient's wife complained that her husband's antidepressant medication was abruptly ceased following surgery:

> The doctors put him off Aropax [paroxetine] and he nearly went off the planet. I told them that they shouldn't have taken him off it, and they quickly put him back on it. I just said to them 'You've got to be very careful and see what the tablets are. [FM3]

There were problems with medications that should have been withheld. In the following example, the patient was scheduled to have neurosurgery later in the week. The patient was informed by the neurosurgeon that she should not take her aspirin medication for five days leading up to surgery. According to her daughter:

> I told Mum, 'If they give you aspirin, don't take it because you are going for your operation.' So when the nurses came around, she said, 'No'… and I asked her about it and she said she didn't take it… But the same thing happened yesterday, but this time the nurse was with three doctors doing their round. And this time she took it because she felt pressured…Then the neurosurgeon comes around today and he is annoyed about it… And I am frustrated because we want to spend a little time in hospital and this is delaying it. [FM19]

Problems existed with medications that should have been administered. According to the following family member, she waited with her husband in the orthopaedics ward to see if he was going to have surgery:

> He [patient] was supposed to be fasting because they didn't know if they were going to operate or not. I am a layperson, and I knew that he still needed to take his heart medicine…I said to the nurse, 'I've got his heart tablets here,' and she said, 'No, he is fasting.'…And then I asked another nurse and she actually agreed with me. But then she said, 'I've got to get the doctor to write it up.' And I am thinking, 'Four hours later, why hasn't it been written up?' [FM24]

Use of medication-taking strategies in hospital

Two subthemes were involved in the use of medication-taking strategies. Written information from health professionals was a key subtheme. Use of interpreters was also identified.

Written information from health professionals

Family members were concerned about how their relative's medication regimen was changed from what was managed at home. Health professionals were busy, attempting to complete clinical activities with competing demands on their time. Conversations held with family members tended to occur irregularly and involved 'quick grabs' [FM35] of their time. Even if opportunities were available for verbal exchange, family members wanted written, comprehensive information. While many commented that they would appreciate receiving a written list at discharge, most wanted a list that could be updated periodically during the

patient's hospital stay. As mentioned by a patient's daughter:

> The difficult thing with verbal information is that it all makes sense when someone is talking to you but the minute they leave, you can't remember what they said and you may not understand. And not just a list, but include things like what the medications do and what to expect. [FM8]

Use of interpreters

Nine family members came from non-English speaking backgrounds. Unfortunately, none had encountered an interpreter during the patient's hospital stay. Yet, these family members commented that they would have appreciated meeting with an interpreter to clarify misunderstandings about medications. In all of these cases, family members played the role of informal interpreter for patients, which was not ideal from their perspective. As mentioned by a patient's daughter:

> He [patient] can't speak English and he is an old man–that's double trouble… It would have been good if interpreters could spare about 15 min just going through what Dad's on. Look at what's new, what is he on, are there any questions. [FM28]

Discussion

This study provides important new knowledge about family members' experiences in managing patients' medications in hospitals. Family members contributed in different ways in decision making on behalf of, or in conjunction with, patients. They communicated with health professionals with varying levels of success and provided information about the use of various medication-taking strategies in hospital.

Communication with health professionals was largely insufficient, despite family members' keenness to speak with them. Constraints on time and competing responsibilities meant that health professionals could participate in reactive roles, despite family members' desire for their input. Some family members had little insight into medications initiated in hospital or about patients' regular medications used at home. In view of the supportive role portrayed by family members and the compromised position confronting patients due to their illness, more attention is needed on enhanced communication between family members and health professionals.

Because nurses are regularly at the patients' bedside, they can easily emphasize changes to medications and the desired actions and unwanted effects of medications.[8, 9] Family members spoke of pharmacists doing nothing more that restocking patients' medications in bedside drawers. Past work undertaken on the advice giving role of pharmacists during home consultation for medication review has shown that they provide extensive advice, information and instruction.[10] Similarly, in the hospital context, bedside encounters should be used as learning opportunities by pharmacists. In terms of interactions with doctors, family members often commented about coming in at different times during the day in effort to speak to doctors, without success. Inviting family members to ward rounds can be a possible means by which doctors can inform them about medication changes and providing opportunities for more proactive care. In a prospective study by Rotman-Pikielny *et al.*,[11] patients and family members felt their participation in ward rounds improved their communication with medical staff and facilitated collaborative decision making.

This study demonstrated that family members who showed active and shared decision-making abilities negotiated how medications were managed in terms of changing medication administration, maximizing effectiveness of treatment and treating side-effects. These family members were assertive in undertaking this role, and they strongly perceived that this was a valuable contribution to patient care. Nevertheless, there did not appear to be active encouragement from health professionals in seeking this involvement from family members. Past work has shown that health professionals tend to communicate with each other rather than use patients and family members to guide medication management.[12–14] Findings from

the current study indicate the benefit of this devalued activity.

In relation to continuum of care, family members played a key role in identifying medications that should have been prescribed, withheld or administered, particularly those who contributed extensively in medication activities at home. Past work has shown that family members are a useful resource in determining an accurate medication list at the time of patient admission.[15, 16] The findings highlight the importance of health professionals regularly checking with family members about these issues not only at admission but for the duration of the patients' stay.

Strategies for improved medication management nominated by family members included the use of written lists, which could be updated periodically and the utilization of interpreters. Past research has shown these strategies are effective in improving medication safety,[17, 18] and they have been included in hospital policy guidelines for ensuring good quality care.[19, 20] It is a major concern that these strategies have largely not been implemented or translated into actual practice.

Limitations

Attempts were made to involve participants from non-English speaking backgrounds. However, only those who could speak English were interviewed. Most family members comprised women, as women predominantly visited patients during the study period.

Conclusions

Improved communication is needed between family members, health professionals and patients in hospitals. Decision-making activities tended to be passive, and greater attention should be played on health professionals initiating communication in proactive ways. Family members possess valuable, unique information about patients' medications that could easily be utilized to facilitate patient safety.

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Conflicts of interest

No conflicts of interests have been declared.

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