ALZHEIMER'S AUSTRALIA RESEARCH

DEMENTIA GRANT

Improving hospital discharge preparation and support for families of patients with dementia

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EXECUTIVE SUMMARY

Background

Little is known about how family caregivers of people diagnosed with Alzheimer's disease or other dementia experience hospital discharge planning, preparation and support, although it is well recognised that family may play an important role in the care of the older person and that hospital discharge practices for older people generally, are often less than satisfactory.

Aims

The aims of this study were to understand the family carers' experience of the hospital discharge planning process for a patient with a dementia. Specifically, the study sought to understand whether the hospital discharge plan met the needs of the family carer and what improvements family carers thought could be made to assist the transition from hospital to residential, sub-acute, or home-based care.

Method

A qualitative constructivist research design was used to report the family carers' real life experiences of hospital discharge. Twenty five family carers were interviewed within two months of the person with a dementia being discharged from either a rural or metropolitan hospital in Victoria. Interviews were subjected to thematic analysis.

Findings

Family carers described their perceptions, expectations and needs in relation to hospital care and preparation for discharge. Three key elements of family carer and health professional engagement, namely (1) Consultation, (2) Coordination and (3) Conveyance, require the attention of hospital management if hospital discharge is to meet the needs of family carers.

Recommendations

From the findings of this research, twenty two recommendations are proposed to improve hospital discharge planning as it relates to consultation, coordination and conveyance, involving the family carer of a person with a dementia. Nine recommendations are offered that require changes to hospital systems; six recommendations that concern the practices of health care professionals and seven that relate to relationships between families and health care staff.

Conclusion

The planning and execution of hospital discharge practices for older people with a dementia and their family carer are in need of change. This research has identified that the discharge planning policies, processes and procedures that hospitals and health care professionals engage in, frequently do not meet the needs of family carers.

INTRODUCTION

The ageing of the Australian population has increased the demand for health care at a time when access to acute hospital beds is competitive and cost containment is foremost. Moves towards economic rationalisation within the health care sector have placed pressure on hospitals to decrease the length of patient stay resulting in older people being discharged sicker and more dependent (Bours, Ketelaars, Frederiks, Huyer Abu-Saad, & Wouters, 1998 ; Grimmer, Moss, & Falco, 2004; Hills, 1998; Russell & Foreman, 2000; Shepperd, Parkes, McClaran, & Phillips, 2004; Tilus, 2002).

Family carers often take on the responsibility of providing supportive care for older people including those with a dementia, who are no longer able to completely care for themselves. A family carer may be a wife, husband, daughter, son, other relative, or even a close ‘family like’ friend. Many of these family carers play a supportive role for older people with a dementia living at home, or in an aged care facility. Access Economics (2003) has estimated the total value of this contribution of families and carers for people with a dementia at $1.71 billion. The planning and execution of discharge from hospital for patients with a dementia and their family carer is of particular concern, since a significant amount of post hospital care is provided by the family (Dellasega & Nolan, 1997; Goodwin & Happell, 2006; Shepperd et al., 2004). Unless hospital discharge is conducted in a thorough way, hospital readmissions as a result of adverse outcomes may increase (Bours et al., 1998 ; S. Cummings, 1999; Driscoll, 1999; Naylor, Stephens, Bowles, & Bixby, 2005; Tilus, 2002) and family carers may experience further frustration and anxiety related to the care of the older person (Grimmer et al., 2004).

AIMS OF THE RESEARCH

The study sought to understand the family carers’ experience of the hospital discharge planning process for a family member of a patient with a dementia. Specifically, the research aimed to:

- understand the family carers’ experience of hospital discharge planning
- understand how well the discharge plan for patients with a dementia met the needs of the family carer and
- ascertain what improvements family carers thought could better assist the transition from hospital to residential, sub-acute, or home-based care.

BACKGROUND AND SIGNIFICANCE OF THE RESEARCH

Many spouses and adult children provide care to a relative or loved one who has a dementia and although this activity can be very satisfying and personally rewarding (Nolan, Keady, & Gordon, 1995), it also requires a significant investment of time and in the long term is known to be both physically and emotionally taxing (Zarit, Todd, & Zarit, 1986). This is particularly the case for women, who do most of the work and are therefore more vulnerable to the negative consequences of providing care. The issue of family-staff relationships in the hospital health care system has received scant attention to date however it is widely accepted that good care accommodates the perspectives of not only the recipient of care, but all stakeholders involved in the caring process including the family and health care staff (Nolan, Davies, & Grant, 2001).

Overseas research has shown that families of older hospital patients want more meaningful relationships with staff, greater emotional support, more exchange of information concerning the patient’s care (Higgins & Cadd, 1999; Laitinen & Isola, 1996) and more involvement in the decision making process (Ross, Rosenthal, & Dawson, 1997). The evidence indicates that a continuum of care model, where the discharge process commences on admission and continues throughout the hospital stay and beyond, is a good model to assist family caregivers, yet no evidence has been identified that caregivers currently experience this type of discharge planning for a family member with Alzheimer’s disease or other dementia (Australian Health Care Agreements Reference Group Report, 2002). A systematic review of the literature on the factors that underpin constructive staff-family relationships in the health care setting by Haesler, Bauer & Nay (2006; 2007) found that four factors essential to the formation of relationships with family, namely communication, information, education and administrative support, are often lacking, either singularly or in combination.

The need for further research on the supports given during the hospital discharge process to family carers is clear in view of the evidence that family involvement in the health care system is less than satisfactory and that few health care professionals effectively translate their understanding of family caregivers’ needs or problems into clinical practice. Very little is known about how the family caregivers of people diagnosed with dementia experience hospital discharge planning, preparation and support. This project sought to bridge this gap in our knowledge by exploring whether caregivers who take the responsibility for caring for a family member diagnosed with dementia are included in the hospital discharge planning process and consulted on matters of health care as it relates to the patient.

TERMS AND DEFINITIONS

Throughout this report the term ‘patient’ is used to refer to a person diagnosed with Alzheimer’s Disease or other dementia, who has been admitted for hospital health care.

LITERATURE REVIEW

Discharge planning is ‘the process of identifying and preparing for the patient’s anticipated health care needs on discharge from an in-patient facility’ (Maramba, Richards, & Larrabee, 2004,p 123). Hospital discharge planning bridges the gap between care in the hospital and subsequent care in the community following an episodic illness that necessitates hospital admission. The Australian health care system is large and complex with acute health care services offered by a range of different metropolitan and rural hospitals. The rapidly growing elderly population and the decreased length of inpatient bed days stays, along with the increased acuity and complexity of in-patient care means the importance of assisting the transition of people home from hospital has grown (S. Cummings, 1999). In the case of people diagnosed with dementia, the discharge practices of hospitals have become critical in preparing family carers to receive their family member back into the community.

A sizable proportion of older people with a dementia however are discharged without adequate aftercare plans which causes them to be at a greater risk of readmission to hospital (S. Cummings, 1999). An investigation of discharge planning by the Australian Health Care Agreements Reference Group (2002), showed that the discharge planning processes in Australia varies markedly from hospital to hospital and that there is general dissatisfaction with the quality of discharge planning.

Discharge planning is a multifaceted process. It involves assessment of the patient, the provision of education to both the patient and family caregivers and the development of a comprehensive plan of action that includes strategies and processes for follow-up and post-discharge evaluation (Chenoweth & Luck, 2003; Chow, Wong, & Poon, 2007; Driscoll, 1999; Shepperd et al., 2004; Tennier, 1997). To develop appropriate strategies that will meet the needs of the patient and their family carer, discharge planning requires the collaboration of a range of health care professionals from a range of health care settings, as well as the involvement of the patient and the family caregiver (Chenoweth & Luck, 2003; Driscoll, 1999). When discharge planning is effective, it contributes to positive patient outcomes, including a reduction in unplanned readmissions; a reduction in post-discharge complications and mortality; an increase in patient and caregiver satisfaction and a reduction in post-discharge anxiety (Chenoweth & Luck, 2003; Chow et al., 2007; Cox, 1996; Driscoll, 1999; Maramba et al., 2004; Mountain & Pighills, 2003; Shepperd et al., 2004; Shyu, 2000; Tennier, 1997).

Discharge planning can be a complex issue for people diagnosed with a dementia. The evidence suggests that the complexity of discharge planning, particularly for those people diagnosed with a dementia, is a primary cause for longer hospital stays (Lyketsos, Sheppard, & Rabins, 2000; Victor, Healy, Thomas, & Seargeant, 2000). In a National Health Service (NHS) Trust study investigating the discharge planning process for cognitively-competent older adults, interviews with multi-disciplinary health professionals identified three primary factors impeding the discharge of patients: (1) breakdowns in communication between the patient, family caregivers and health professionals; (2) insufficient systems to support the discharge process (e.g. guidelines for access to services; shortage of community services); and (3) indecisiveness on the part of family caregivers regarding their commitment to undertake the caring role. These factors were the main reasons for an extended hospital length of stay (Bull & Roberts, 2001).

A study investigating nursing staff perceptions of discharge planning in a United Kingdom (UK) hospital, identified three similar primary causes for discharge delays: (1) non-constructive inter-disciplinary relationships; (2) breakdowns in communication between health professionals; and (3) a failure to perform a comprehensive patient history on admission. These causes lead to a delay in information acquisition for discharge planning (Atwal, 2002). In the United States of America (USA), a retrospective review of 83 medical records investigated discharge delay factors for older adults in a large acute care hospital. The researchers identified administrative barriers (e.g. accessing community services) and communication breakdowns between patient, family caregivers and staff as primary impediments to patient discharge (Tracey, Taylor, & McConnell, 1998). Similarly, in a

Canadian hospital survey of 81 staff members from various disciplines, respondents highlighted communication and documentation breakdown between family, staff members and administration and insufficient community resources, as the primary factors impeding the discharge of older adults from the facility (Tennier, 1997).

Discharge plans often do not meet the needs of the person diagnosed with a dementia in hospital since these people not only have complex care needs related to their medical conditions, but are also lacking in a range of cognitive, functional and/or social skills. Reducing hospital length of stay as is the current trend, leaves less time in which to assess the person and develop a comprehensive discharge plan (C. Cummings & Cockerham, 1997; S. Cummings, 1999; Maramba et al., 2004; Mountain & Pighills, 2003; Payne, Kerr, Hawker, Hardey, & Powell, 2002; Victor et al., 2000) and moreover, allows less time for recovery from acute illness, thereby increasing the person's dependency level at discharge (Courtney, Tong, & Walsh, 2000; Payne et al., 2002; Rosswurm & Lanham, 1998; Victor et al., 2000). This can lead to an increase in discharge planning requirements, further complicating the already complex process and increasing the risk of compromising the quality of patient care through a failure to meet the discharge needs of the patient (Maramba et al., 2004; Shyu, 2000).

The importance of involving family caregivers in the discharge planning process has been repeatedly reported in the literature (C. Cummings & Cockerham, 1997; S. Cummings, 1999; Jordan & Lindsay, 1998; Maramba et al., 2004; Rosswurm & Lanham, 1998). Comprehensive discharge planning that includes both the older person and their family caregiver is related to a reduction in hospital readmission, shorter hospital stays and improved satisfaction (Cummings & Cockerham; S. Cummings; Naylor et al, 2004; Shyu, 2000). Discharge planning policies that comprehensively address the needs and wishes of family caregivers, as well as those of the older person, are imperative to enhancing the quality of care for older people with a dementia and maximising recovery following hospital admission (Grimmer et al, 2004; Clark et al, 1997).

What do family caregivers require in the discharge planning process?

Family caregivers seek more involvement in the hospital discharge planning process and report that they feel they have little influence in the decision making process for the discharge of their family member (Cox, 1996). Family satisfaction with the patient's discharge plan is an important consideration, as there is an established link between satisfaction of the family and patient satisfaction (Maramba et al., 2004).

Research has shown that family caregivers frequently perceive the discharge planning process in a negative light, expressing frustration, lack of knowledge and education, poor communication, poor trust and lack of involvement in the process (Bowman, Rose, & Kresevic, 1998; Bull, Hansen, & Gross, 2000). This state of dissatisfaction is further heightened when a family caregiver takes their family member who has dementia, home as opposed to them being transferred to an aged care or other facility (Proctor, Morrow-Howell, Albaz, & Weir, 1992). While hospitals routinely collect information about inpatient satisfaction with their hospital stay, there is a difference between patient satisfaction and family satisfaction with discharge planning (Proctor et al., 1992). Understanding what aspects of discharge planning increase family satisfaction with the process is important in identifying discharge planning interventions that are most likely to be successful for people diagnosed with a dementia.

The needs of family caregivers of older people diagnosed with a dementia prior to discharge from hospital have been reported by a number of researchers (Nay, Fetherstonhaugh, Pitcher, Closs, & Koch, 2004; Naylor, Campbell, & Foust, 1993; Stewart, Archbold, Harvath, & Nkongho, 1993; United Health Fund, 2002). Nay et al. found that in the transition of the frail elderly (including those with a dementia) from hospital back into the hands of the family carer, caregivers had several pre-discharge needs that included information on the family member’s health condition, education on medications, symptom monitoring/management, help in the mastery of personal care skills, personal care delivery, emergency management, handling the family member’s emotions, managing compliance with care, setting up continuing services and emotional and manpower support. In addition, Nay et al. also identified the need to prepare early, the caregivers themselves before discharge of the family member with a dementia, as this also impacts on the success of discharge and non readmission.

METHOD

A qualitative constructivist research design as described by Guba and Lincoln (1989) was used for this study. Constructivist research acknowledges that all aspects of reality are interrelated, and that reality cannot be separated from the world in which it is experienced, that is people’s experiences of reality, in this case family carers of people diagnosed with a dementia, cannot be understood or described without reference to their interrelationships or contexts. The task of the investigators was to elicit the constructions that the various participants held and as far as possible, bring them into conjunction (Guba & Lincoln, 1989). The research sought to understand the entire context in question and provide a rich and contextualised picture of the experiences and needs of family carers with regard to hospital discharge practices of patients with a dementia.

Recruitment

This project sought to understand the family carers’ experience of the discharge planning process of a family member diagnosed with a dementia, from acute care hospitals in metropolitan Melbourne and rural areas in Victoria, Australia. Qualitative research typically relies on the use of non-probability sampling techniques. The researchers maximised the range of views elicited by purposefully seeking as wide a range of participants as practicable to get variation on the topic.

Data collection was guided by two goals; understanding the needs of the family carers’ of people diagnosed with a dementia at the time of discharge from hospital; and identifying family carers’ views about how current discharges practices for people diagnosed with dementia could be improved. Spouses, daughters, sons and other relatives of the person who were primary carers, or who provided direct support for the family member diagnosed with dementia, were therefore sought for inclusion in the study (Table 1).

Participants were recruited to the study by means of flyers displayed on the wards of two metropolitan and one rural hospital, referral by the clinical ward staff, an advertisement posted by Alzheimer’s Victoria in their newsletter and an advertisement placed in the Council on the Ageing (COTA) Newspaper. Only participants, who had been the principal family carer of a person diagnosed with a dementia who had been discharged from hospital within the last two months and who had made the transition from hospital to sub-acute, residential or home based care, were included.

Where participants were referred by hospital health care professionals, clinical staff had identified potential participants in the hospital ward and provided them with a flyer about the project. If an interest in the project was expressed, permission from the family member for one of the research team to contact them after discharge, to provide further information about the project, was obtained by the health care professional**.** The family member's contact details thus obtained were then forwarded to the researchers, who contacted the family member within eight weeks of discharge. Recruitment and data collection occurred over a 15 month period.

Participants, 'cared for' persons and their relationships

Twenty-five (25) family carers were recruited into the study. The majority were female (*n*=20) with 14 daughters who were nominated carers for family members and five (5) wives cared for their husbands (Table 1).

Table 1: Number of family carers and 'cared for' family members.

Carers	***n***
Foster sister	1
Husband	4
Son	1
Wife	5
Daughter	14
Totals	**25**

'Cared for' family member	***n***
Foster sister	1
Wife	4
Father	7
Husband	5
Mother	8
	25

The maximum acute hospital stay was more than 20 days (*n*=2) with the majority of family members staying between 6 and 10 days (*n*=9). The maximum carer commitment was 100% of the time (*n*=4) with 56% (*n*=14) of family carers spending 50% or more of their time to care for a family member diagnosed with dementia (Table 2).

Table 2: Length of hospitalisation and family carer commitment to 'cared for' family member.

Length of hospitalisation	*n*
< 3 days	2
3 to 5 days	6
6 to 10 days	8
11 to 15 days	2
16 to 20 days	3
> 20 days	2
unknown	2
Totals	**25**

Family carer's commitment %	*n*
20%	1
25 %	2
30%	4
50%	3
60%	2
70%	1
80%	2
90%	2
95%	1
100%	4
unknown	3
	25

The majority of cared for family members lived in their own homes (*n*=15) and nine in residential care before being admitted to acute care hospitals. Nine were discharged home; eight were transferred to rehabilitation facilities; and one to a high care facility (nursing home). Of the nine (9) cared for family members residing in residential care, two (2) were transferred to a rehabilitation facility before being discharged back to the original low care facility (Table 3).

Table 3: Original residences of 'cared for' family member and the residences to which they were discharged.

Before hospitalisation	*n*
Live with daughter	1
Low care facility	5
High care facility	4
Own home	15
Totals	**25**

After discharge	*n*
Rehabilitation facility	8
Low care facility	3
High care facility	5
Own home	9
	25

Data collection and analysis

Data were collected using semi-structured interviews (Holloway & Wheeler, 2002). This approach entailed the exploration of a list of issues during the interview and made interviewing across a number of different people more systematic and comprehensive (Patton, 1980). Interviews took place at a location and at a time convenient to the family member. An interview guide (Appendix A) was used and interviews were audio-recorded.

Interviews began with the broad explorative open ended question: 'What has been your experience of the hospital discharge process?' Further questions explored the participant's experience of the discharge process including critical incidents and focused on meeting the research objectives. Prompt questions arising from the systematic review on staff/ family relationships (Haesler et al., 2006) were used to guide but not constrain the interviews. The audio recordings were transcribed and the data were managed using the QSR$^{©}$ software program NVivo 7.

A constant comparative method of thematic data analysis as described by Guba & Lincoln (1989) was used to explicate issues. Each participant was asked to share their experiences and views of the issue under investigation as well as comment on the views of previous participants to allow for the inductive generation of co-constructed narratives of each participant's experiences. This inductive approach developed theoretical propositions that accurately reflected the participants' views on the topic, that is, as data were coded, categories and themes were developed, and data were compared to look for patterns, similarities and differences. The study aimed for in-depth understanding of the issues rather than generalisability to specific families or hospitals. Interviewing continued until redundancy (Guba & Lincoln, 1989) had been achieved, that is, no new issues emerged.

Rigor

The credibility and transferability of the research was established using the following strategies as described by Guba and Lincoln (1989).

1. Trustworthiness of the research findings was established by purposively seeking as many divergent views as possible.
2. Sufficient time was spent in the context under investigation to establish the rapport and trust necessary to elicit the participants' views on staff-family collaboration.
3. The researchers continuously subjected the data and findings to critical reflection and challenged emerging propositions by deliberately seeking alternative interpretations for the data (negative case analysis).
4. Emerging propositions were tested by a process of 'peer debriefing'.

5. ‘Member checking’ was used to verify emerging propositions and authenticate the data with the participants. During each interview interpretations of data collected in earlier interviews was verified and participants were given the opportunity to correct errors of fact, or challenge interpretations. Participants were invited to comment on interview transcripts.
6. The researchers have endeavoured to provide sufficiently detailed descriptions of the data in context to enable the reader to make their own judgements about the transferability of what has been reported.

Ethics

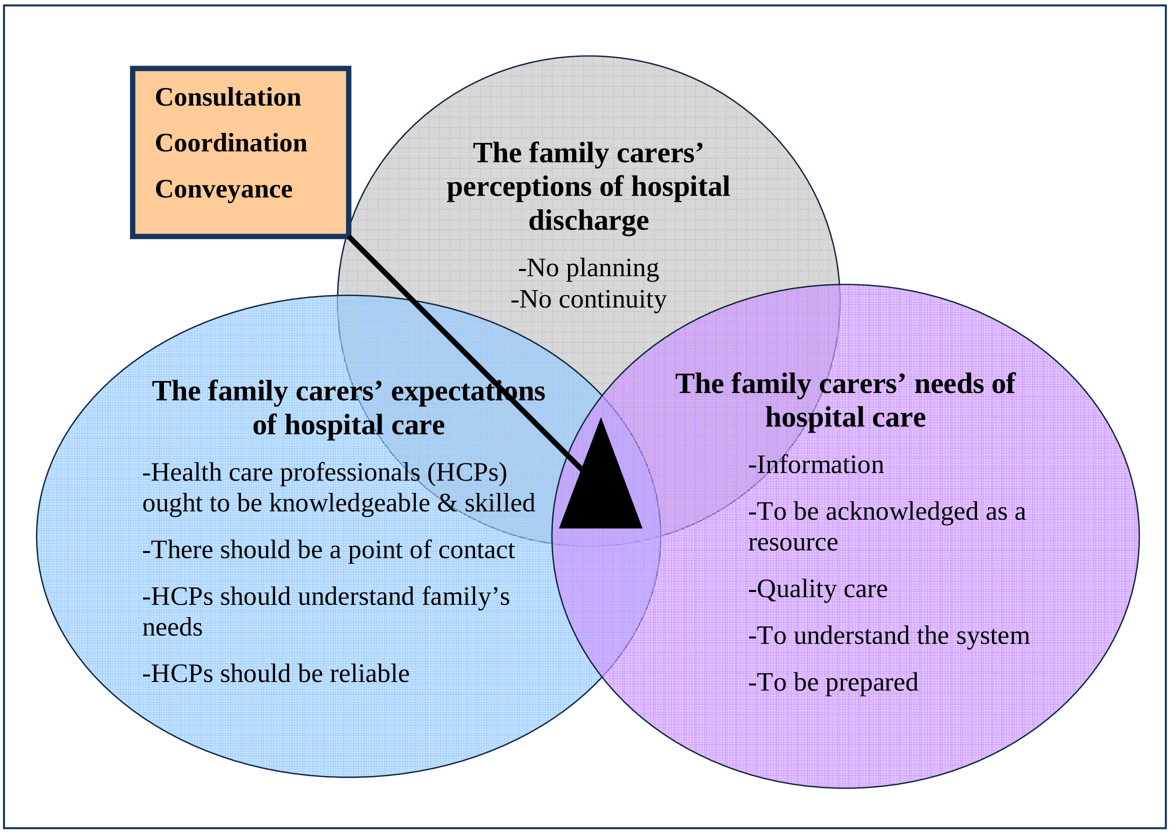
The anonymity and confidentiality of all participants and institutions have been preserved in this study. Pseudonyms have been used throughout the report when referring to any persons or facilities involved in the study. The research project was approved by the ethics committees of participating hospitals and the University prior to the commencement of the fieldwork.

FINDINGS

Family carers' interviewed had varying experiences of hospital care and hospital discharge for their family member. Their views about discharges practices were informed by their expectations of hospital care for someone diagnosed with a dementia, their needs as a family carer and how they perceived the hospital's planning and execution of the discharge plan.

Participants highlighted the lack of a consistent care pattern and the apparent absence of any system driving the discharge arrangements of patients with a dementia. The participants perceived discharge planning to be unclear and without exception, preparation for discharge was seen to be 'ad hoc'. Discharge planning processes that may have been in place were not obvious and were moreover apt to be overshadowed by the stressful and anxiety provoking experience of hospitalisation. Participants interviewed all had particular needs and expectations about how the person diagnosed with a dementia should be cared for. Participants' needs and expectations were an important determinant of their advocacy role for the patient and for many family carers, coloured the experience of the care provided by the hospitals. Figure 1 summarises the factors that family carers found significant with regard to hospital discharge. These factors, together with the participants' narratives are presented in the ensuing section.

Figure 1. Summary of the factors impacting on family carers' experience of hospital discharge



Family carers' perceptions of hospital discharge and discharge planning

What discharge plan?

This research found little evidence of the existence of a formal routine plan for the hospital discharge of a patient with dementia that involved the family carer. Participants' recollection of how they were notified of an impending discharge varied markedly, however most family carers were of the view that there was no formal discharge plan when the patient diagnosed with a dementia was discharged from the hospital. The majority of family carers were advised about discharge either on the day of discharge, or one or two days prior. One family member was given 1.5 weeks advance notice of discharge. Others were not notified at all about discharge and discovered, much to their surprise and dismay, that the person was no longer at the hospital when they came for their routine visit.

Notification about discharge was typically by a phone call from staff on the ward, a chance conversation with a staff member, when the family member visited the person, or when the family member telephoned the ward to ask how the person was progressing.

> *I happened to go in and they said, 'Oh she'll be going home later this afternoon and this is what's going to happen. This is what we've done (Denise: daughter).*
>
> *I went in there and her suitcase was packed and she was going home that day [I found out when] I just turned up. There was no discussion really. I was a bit disappointed to be honest (Gary: husband).*
>
> *There was no round table discussion or prediction. I was expecting her to go on the Friday but nobody said on the Thursday she'd be going tomorrow. I think I rang up that morning and they said she's in transit - so she'd gone (Kate: daughter).*

One family carer was informed by one of the catering staff on the ward that delivers the meals that his wife had already been relocated. He recounted this distressing anecdote.

> *As I came around into the ward he [catering staff member serving afternoon tea] said 'She's gone.' And I said 'what do you mean she's gone?' He said 'They've taken her, they've taken her out.' 'Oh God' I said, 'Where to?'. He said, 'Well I don't know for sure.' So I went out and saw the nurse and she said, 'Oh yes, she's gone to [hospital]. And I said, 'That's a bit rough'. I wasn't told when she was going, or how she was going. I immediately went out and got in the car and went to [hospital] and she was in ward two as I found out eventually. My God. You've got no idea, no idea… (Jo: husband).*

There was little consistency in the formal process of informing family carers about when the person was going to be discharged. For one son, preparations for discharge home for his father were not required as the support services were already in place, however a signature was needed to continue. The process of getting his father discharged was charged with friction and perceived threats by the staff.

> *Really all we had to do was fill in the form to get Dad out, but to get the doctor and the social worker from the hospital together and get the paper work done - that probably took about a week and a half. Trying to get him a discharge process was very difficult. [The ward staff said], 'Oh, we've assessed him - spoken to the doctor, doctor doesn't think he's ready.' [Then said] 'Oh look – Ok, if it keeps you happy.' I mean as it was, I had to force them - had to fill in these forms to do this. I really had to drive it (Allister: son).*

This family carer felt that he had to assert himself to the point of pushing the boundaries of reasonableness to discharge his father in opposition to the health professionals' concerns. The experience of trying to get a discharge process in place that would benefit his father and his mother (who was also elderly), was a very frustrating one and one that left him angry about the experience.

One family carer was under the impression that the staff would prepare her husband for discharge to ensure that he could participate in his care as he had done previously. She relied on his participation in order to keep him at home. The expected discussion about her husband's physical abilities never eventuated. As a result, she experienced great disappointment when she eventually realised that there was no plan for ensuring he was capable of returning home with the same functionality as before he was admitted to the hospital ward.

> *I was quite in shock you know. They said, 'Yes he's well. We're planning on sending him home on Sunday'. But in the mean time, I thought, 'Oh yes, they'll get him out of bed because they can't just send him home like that' [but] there was nothing. I'd go there [the hospital] and here he was… [the staff had] no idea and no plans to sit him out of bed either (Vera: wife).*

While family carers were not included in the planning for hospital discharge back to the previous place of residence, that is, home or an aged care facility, they were made more aware of plans when discharge was to be to a rehabilitation setting. This planning was usually conveyed by allied health professionals, however in the main, these plans were rarely negotiated with the family member.

> *The nurses rang me and said, 'he's now going … at ten o'clock in the morning'. I knew then that he was on his way to [rehabilitation]. So they arranged everything. They told me.… I said, 'Did we have to take him?' They said, 'No, they would arrange everything.' They were just telling me that [on the last day of stay] (Carol: wife).*

Some physiotherapists, occupational therapists and social workers informed family carers about what was going to happen when the patient was discharged from the hospital to a rehabilitation ward. Family carers usually perceived the plans to be wholly decided by these health professionals, without any input from them.

> *'It wasn't discussed with me' (Denise: daughter).*

> *No we weren't involved in it. Perhaps if she was coming home to my home it would have been different. Or it certainly would have been different because I would have had to organise her, her transport and all that sort of thing. But because she lives at an aged care facility, they'd probably do all their planning with them (Estelle: daughter).*

Despite the above grievances, not all family carers verbalised dissatisfaction with the hospital discharge experience. One family carer who lived in a rural area and whose wife was admitted to a country hospital said he was happy with the discharge planning for his wife. The only concern that this carer had, was that the services needed, had to come from a different district and there was no care manager available to assess his real needs.

> *Well there was quite a bit of information given to me and a lot of the services that I could expect after she came back home, that was all arranged by the welfare people. [which began] during the whole four weeks. I remember the relevant people in the welfare department [saw me] and they would give me some information. And a couple of times I was actually in an office, invited to talk with someone in the office, and quite a bit of information was given to me. I'm quite happy with what was provided (John: husband).*

There is no continuity of information exchange

All those interviewed gave different accounts about when and what information was provided to them about the imminent discharge of their family member with dementia. The discharge destination (home, aged care or rehabilitation unit) determined the information provided by the hospital to the family carer. If the patient usually lived in a residential care facility, family carers generally understood that discharge and follow-up care was discussed and arranged with the facility staff and the resident's general practitioner. Many family carers reported being contacted by residential aged care facilities who informed them that their family member had returned. There was however limited discussion with the family about the transition arrangements in place from hospital to the aged care facility, or home.

Family carers of patients who were discharged home frequently criticised the perceived lack of co-ordination and preparation in arranging support services and the absence of discussion about the patient's needs and discharge times. Plans for preparing the patient for the return home that were in place, often failed to meet the requirements of the family carers in terms of timing and needed levels of service provision. The perception of family carers was that their issues were "not heard" by the hospital staff and that the planning process was 'hit and miss'.

> *They were telling me this was going to happen and I was going to get help with this that and the other. They said, 'Look we can get you help'. Some sort of package that gives me help with getting her bathed every day. I said, 'yes, I want every bit of help I can get so that I can keep her at home as long as I can'. And then when I got home, the district nurse said, 'Well is this in place? Is that in place?' And I said, 'well no'. They told me it would be in place but when I got home I found that things weren't … so I was chasing them up. Well it was hit and miss, that's the best way to explain it (June: daughter).*

The hospital experience left many families feeling unimportant and frustrated since health professionals failed to keep them fully informed about what was happening with the patient, in addition to not being perceived to take their concerns seriously. The perceived failure of health professionals to involve them in the planning for the discharge of their family member with a dementia, highlighted gaps in the care provided in hospital that were understood to compromise their family member's health outcome immediately after discharge.

> *I told the aged care doctor 'I don't think you should be sending my husband home'. When they did send him home, they sent him home far too early. And I nursed him through the night, all night. I got his temperature down but the doctor rang me up on the Saturday morning and said, 'Vera get your husband back here. He's got blood poisoning…' (Vera: wife).*

> *I was a bit disappointed that they sent her home when they did. Even the district nurse said ' we just felt she was too wobbly on her legs still' (June: daughter).*

> *I told them she has trouble with her legs and I was very insistent on that. I make sure her legs are creamed and she has the support stockings that the doctors had ordered. I don't think [the nurses recorded that] because she had an outbreak on her leg. They listened to me but I was doing it in the end. But then they knocked off the cream because the leg was blown up and there was an infection in it. So she's going to have to stay longer now, because now the issue is the leg. I was a little bit mad about that because they didn't listen to me (Ingrid: foster sister).*

Participants were generally satisfied with the information exchange between themselves and health professionals when the person with dementia arrived at the accident and emergency department and when they were initially admitted to the ward. After a time however, the perception of health professionals on the wards shifted from being informative and helpful to being uninformative and disinterested.

> *I was really happy at the emergency when I asked for information. If there wasn't a doctor available, they would get the file and read it out to me, or they would get a doctor. It may have not been straight away, I might have to wait [but] I'm quite happy with that [On the ward I said],' I would like to know if he did have this stroke or heart attack or not? The doctor said to me, 'look, we'll run some tests and let you know.' Well towards the end when my father was supposed to be sent back to the nursing home, there was a doctor and I asked her, 'Do you have the results? Were the tests carried out?' And she really avoided my questions. She said, 'I think your father's ready to go back to the nursing home and whatever - we'll see in the next couple of days.' And I repeated again, 'Do you have the results of the test?' And I got the impression that they were never carried out (Louise: daughter).*

Some family carers talked about inappropriate discharge planning by staff that put their family members at risk. Denise realised that the information about her mother's condition was not relayed correctly to staff. It was only because of Denise's assertive intervention that her mother remained safe and was appropriately transferred to recover from her illness.

> *They were saying, 'we're planning to put her in a taxi and send her home'. And I said, 'You can't do that, because she's got dementia. She'll be really disoriented and I don't even think she's got a house key … and she won't know what to do with the taxi driver, you know.' I mean, it's really unsafe even if she was alert, to send someone just off in a taxi, who's been unwell and frail. And so from that I went over [to the hospital] and was talking to them about her situation. The case manager had obviously gone off duty and she'd thought she'd given a good handover. And the outcome was that she was actually transferred from that hospital to the sub acute hospital attached to that one. She spent a month in hospital. So she was far from being able to be sent home in a taxi by herself (Denise: daughter).*

A lack of continuity of information sharing about the patient put this person at risk and moreover caused the daughter much stress. When information became confused or lost, family carers were more likely to develop a distrust in health professionals.

> *I said [to the OT], ' I kept saying, isn't she going to rehab? The doctor said she was going to rehab.' And [the OT] said, 'Oh, I was of the understanding it was you that didn't want her to go'. And I said, 'no way…' (June, daughter).*

Family carers also perceived that there were no discharge summaries about the condition of the family member. They had to take the initiative, follow up issues and pursue information related to such things as changes to medications and what to ‘watch out for’. Unless they were assertive and proactive in the pursuit of information, they remained unaware of their family member’s condition.

> *I think what we were really disappointed with, was the fact that there was no discharge summary for Dad (Rachel: daughter).*
>
> *We were trying to get information about what they had found with my father. My sister and I are both [family] carers and every time we were there, we tried to get a doctor paged but never managed to. We left our phone numbers for a doctor to call us. So by the time my father was discharged - we had no information about what they’d found. We only gained that information by lodging a complaint with the health service and they sent me discharge papers which gave me some information, in writing, about what was found (Bertha: daughter).*
>
> *When Mum went in there with this Warfarin thing, and she went out to rehab, no-one ever, ever explained they had put her back on Warfarin. When she went in with the bleed a second time, the man in emergency said to me, ‘… we’ve brought her down with vitamin K. If she’s had this, she won’t go back on Warfarin for a minimum of six months.’ Well why didn’t somebody say that the first time before she had the bleed? (Maura: daughter).*

It was apparent from participants’ anecdotes that details about the patient were often lost in the exchange between health professionals and family carers, thereby putting the patient at risk and necessitating readmission to hospital. Assertive and proactive family carers were more successful in gaining discharge summaries. Furthermore, family carers with experience of the health system reported better discharge preparation experiences than those new to the role of caring.

Family carers expectations

Family carers interviewed shared a number of expectations about the hospital experience including discharge planning and discharge processes. Nearly all participants associated discharge planning and discharge processes with quality care delivery and furthermore linked this to how satisfied they were with their experience at the time of discharge and post-discharge. Participants all described how they experienced the patient’s care and how it could have been done better. While the hospital may have been the best environment for a medical cure, it was not seen as the best environment for the care of someone with a dementia.

> *It was an unfamiliar setting and quite stimulating with lights and noise and environment and people with Alzheimer's or dementia can have a catastrophic reaction to loud noises, or loud people, or people who don't ease into the situation. I know my wife's got very poor eyesight now and you've really got to calmly get her ready for the next thing. You've got to do it so. [The acute ward is] just equipped for every day patients that can understand what they're talking about, it was difficult for my wife (Gary: husband).*

Health care professionals should be knowledgeable and skilled in dementia care

Families were frequently critical of some health care professionals who they believed lacked the necessary knowledge and skills to competently care for someone with a dementia. While remaining respectful of staff, family carers expressed varying degrees of distress about how the patient was treated in hospital and the sub-standard care. They gave examples of poor continence management, inaccurate assessment of compliant behaviour and inappropriate use of sedation. Family carers expected that health professionals would have knowledge of caring for the elderly. It was an expectation that nursing staff had been educated and trained in aged care, so when nurses failed to provide what was considered by families to be acceptable care for the patients, some family carers were at a loss to explain why. A number were forgiving of nurses' apparent lack of competency and attributed this to limited experience, declining standards of education and the busyness and high technical nature of health care that is provided in hospital.

> *The type of nursing that he would require was not in their area. That's what I felt… And I think I was right, because they're in acute nursing not in aged care. They are not into rehabilitation. It's not part of their work - what the nurses have been trained to do. I think the college trained nurses today, do not have the hospital training, the old standards of how to care. They think machines do everything, the physical lifting and turning is really not their area (Carol: wife).*

Many family carers observed nurses interacting with patients and they surmised from these interactions that a number of nursing staff simply did not know how to care for someone with a dementia.

> *The simple thing is that he cannot speak. He can't reach for anything. They put a drink in front of him and he's supposed to get that drink and he can't. And it doesn't matter what all this writing down is about, they still do not realise that he cannot feed himself, or get himself a drink. He's got to have help with those. Most of them are very good, but then there are some that would just leave him [and not assist] (Vera: wife).*

Kate became angry and frustrated when nursing staff recorded that the patient refused medication when according to her, her father did not understand.

> *The nurse had come up to Mum and said 'Pill [name] like here …' She can't even see it… and she's say again, in a little bit of a foreign accent 'Pill [name]'. Mum hasn't got a clue what's happening and then the nurse goes and writes in the book 'refused' (Kate: daughter).*

Some nurses, family carers noted, assumed that all patients with a dementia would be incontinent, so they used continence pads instead of attempting to reinforce the usual toileting regimes. There was no individual management of patients' personal hygiene needs. This threatened caregivers' ability to manage the patient at home if such matters as continence were not able to be maintained. These observations distressed family carers.

> *She became very, very incontinent while she was in there. She's in hospital and with dementia. She wouldn't have known where the toilet was to get herself there, even though they took her there. I kept saying to them, 'look you're asking Mum, 'Do you want to go to the toilet?' I said, 'you cannot ask her. I just take her. She'll say where are we going? Don't mention toilet, just say over here'. Once you steer her in and you put her on [the toilet], she goes' (June: daughter).*

Some patients were left in wet beds and nursing staff failed to maintain individual continence management regimes. There was no individualised care.

> *When she went in, she was sort of functionally continent in that if you remind her and take her to the toilet, she'll go to the toilet. Well that wasn't happening because obviously they don't have the people to do it. They were quite happy for her to sit in a pad and change it when it's all wet. I felt that the continence management was a bit lax. I suppose, they didn't understand the personal needs that she has . It was more of a global approach to what should have been a personal one (Gary: husband).*

Some participants complained that the patient would often be sedated when in hospital because of behavioural problems. The patient would be sedated and restrained because they had become 'difficult' when in fact, as interpreted by the family carers, the patient simply did not know what was occurring or where they were. Family carers were very aware of the importance of a consistent environment for people with a dementia and how being out of the usual environment could have a significant impact on the person's behaviours. Health care professionals at times seemed unaware about this and moreover did not avail themselves of the family's intimate knowledge and expertise when managing the patient's care.

> *…apart from this thing about the haematoma, which makes me think that maybe someone wasn't quite as experienced with dementia patients as they might have been. Because it must have been a hell of a whack, to do that - but mainly they were very good with her (Heather: daughter).*

> *So the problem is that it depends on how the nurse treats him. That's how the assessment gets made. Then, 'Oh he's a bit aggressive because he's waving a knife around.' 'Ok - what did you ask him? Maybe he was just trying to butter his bread!' And then they give an injection which dopes him up. Then you go and see him and he's half asleep. You know he's been doped up, because he has not been managed (Allister: son).*

> *My father's sedated, which isn't good for people with dementia, and he's restrained which is just awful. And generally with this hospital stay, we found he saw a doctor ten minutes on every day he was there. We found his hospital stay was unnecessary, unnecessarily long, particularly for someone with dementia. It's not an environment in which they're comfortable and it just increases their anxiety. It's not the best (Bertha: daughter).*

When sedation was used to manage a patient's behaviour in the hospital, family carers noted that it could take days or weeks for the effects of the medication to wear off once the person had returned to their usual place of residence and a familiar environment. While not discussed in any depth, family carers identified this as a potential problem in them being able to manage their care at home.

The family's intimate knowledge about the person was not utilised in planning care. Family carers reported that sometimes physical restraint would be used to manage the confused person in hospital. This, from a family carer's perspective, could have been avoided if staff had only utilised the intimate knowledge possessed by the family and developed a better understanding of the person with the dementia.

> *Each time something happens to him medically it seems to set off the confusion. I think half the problem is he's always been very active, he's not one to just sit down in a chair all day and he likes to walk around, he was a bike rider, so I think in his mind he was just going for a walk. But because he was a falls risk, they needed to keep an eye on him – because his confusion is so great he'd have no understanding of people telling him he needs to stay in bed, or in the chair.…he got agitated and they've had to strap him down (Ursula: daughter).*

Family carers also expected staff to be helpful, yet nursing staff were often too busy to assist and sometimes ignored their requests for assistance. This left some families feeling uninvolved and unsupported. Many family carers were willing to assist the patient with basic care activities, often arriving early in the morning and leaving late at night. Some staff were found to be less approachable than others, and families often experienced difficulties in identifying the right staff member to approach for information and advice, as all staff appeared to dress the same and many wore no readily visible identification. Nurses were expected to be information providers yet they were often not available to answer queries about the patient for the family member. As a result nursing staff were sometimes discounted as being important information providers.

> *Well in the end I thought, 'I'm not going to worry about chasing the nurse around. They're limited to what they can tell me anyway. I understand that, so I just thought I've got the doctor's pager number. If she's too busy to answer, she won't answer. So I'll just keep trying until I can I get to talk to her', which I did a couple of times (Estelle: daughter).*

One concerned family member, who had been referred to the project by a hospital staff member, contacted the researchers to advise them that she did not think that her elderly relative had dementia. Her mother, she advised, had been admitted to the hospital because of confusion related to a urinary tract infection. This family member's understanding was later confirmed by the hospital when queried by the researchers. It would appear that some hospital staff are of the view that cognitive impairment equates with a diagnosis of dementia and document 'dementia' on the 'handover sheet'. This misunderstanding lead to this label being assigned by other staff, who also assumed that the person was diagnosed with dementia, when it was in fact an acute confusional state (delirium).

There should be a point of contact

Family carers reported there was no one person leading a plan for discharge. Rather, discharge information came their way by them asking randomly who ever they could find to answer their questions. This ranged from the cleaner to the medical officer in charge and everyone in between. While there was no pattern identified, the family carers assumed that the medical and allied health professionals were the health professionals who discussed and arranged discharge and planning for discharge because they were often the people they encountered at the bedside. From their experiences, they assumed that the nursing staff did not play a role in discharge planning because more often than not, their questions could not be answered by the nurse. However, there were also other occasions where the person they may have been speaking with was the nurse but not identified as such by them.

> *There was just the fact that the physios and the occupational therapists [OTs] were the ones that really spoke to me and consulted me regarding [my husband] being discharged. They said that he would have to go to a rehabilitation facility as he needed to be rehabilitated into walking and doing things for himself? I am not doubting the nurses at all, they were very good. The fact of the matter was that the area was for physios and OTs and also the doctors (Carol: wife).*

Health care professionals should understand the needs of families

Family carers wanted to be informed about hospital discharge arrangements and the post-discharge health care needs of their family member. They wanted to know what had happened to their family member in hospital and what specific care they would need to deliver post-discharge. While a discharge summary document detailing post-discharge care was provided for other health professionals, such as those in an aged care facility, none of the participants reported receiving this type of documentary information when discharged home.

Family carers reported that they were rarely consulted by hospital staff about any changes to their family members' care regimes that would impact on post-discharge care. It was felt that health care professionals made numerous assumptions about the information needs of families. Where a patient was discharged to a place other than the family carer's home, information would be provided to the people in those establishments, but not to the family carer. Family carers were of the view that many of decisions and post discharge health care requirements involving the patient should have been discussed with them as well as the staff at these other places.

> *I think there might have been an assumption that the main people they [the hospital staff] needed to talk to, were the hostel staff about her care and about what she was going to need and what they'd done. And I think there should be more talking to the family, because the hostel's there and really good, but they're very bounded by their territory, and once your family member is out of their territory, then it falls back on you. So you need to know what's going on. You need to know, 'yes they've changed her diabetic medication' (Denise: daughter).*

In each example of poor communication between health professionals, service providers and families, the family carer reported feeling frustrated, stressed and confused about post-discharge care. Participants frequently commented on the absence of clear and continuous lines of communication between hospital health care professionals, service providers and themselves. Poor communication was often the source of frustration, particularly when health care professionals made varying assumptions about the care, or services that they thought the family carer needed. Confusion about post discharge care needs added to the stress the family carer experienced in the lead up to and at the point of discharge. In the example below, the family carer was of the view that her father was too unwell to be discharged from hospital to the care of an residential aged care facility. It shows the different assessments and conclusions drawn about the patient's condition and poor communication.

> *Well I assumed he was going to stay a couple more days, because he was still on the drip and not well at all. As a matter of fact when they brought him back to the nursing home, the RN that's in charge said, 'Oh he looked dreadful when he came back.' (Louise: daughter).*

Another family carer provided an example of how the system of care also contributes to poor communication. The point is made that some health professionals seemed to assume that once a person had been assessed for a community care package, that they had no further responsibility in ensuring the care and services needed in the home were in place before discharge and moreover, did not discuss the issue with the family member. Poor systems communication also adds to the mix of poor communication practices involving family carers.

> *I had told them that she was going onto the ACAT's* [Aged Care Assessment Team] *package. I just assumed that they assumed that that we had sufficient support at home which was probably not an unreasonable thing to think. But it wasn't (Heather: daughter).*

Health professionals' lack of understanding about the unique needs and circumstances of the patients gave rise to uninformed decision making. In this example the assumption was that a person with a dementia should live in a residential care facility. This view angered one family carer whose mother was, with support, able to live in her own home. During each hospitalisation, health professionals would conduct assessments and push for admission to residential care.

> *It's the same experience each time anything happens with her and she ends up in hospital. There is a massive assumption that she can't return to her own home and she must be discharged to an aged-care home. I find that assumption is based on no facts other than she has moderate to advanced Alzheimer's. [Health professionals think] 'Surely she can't live in her own home?' (Pam, daughter).*

Some family carers considered whether the health professionals, or the health care system itself, was prejudiced against people with dementia receiving in-home care. Family carers spoke about various instances in which it was described as a battle to get the patient out of hospital and back to in-home care. It was felt that hospital staff assume that people with dementia should be in care facilities so that families could get on with their lives.

> *I find that I actually equate it to that prejudice many years ago when people had disabled children, that those parents would immediately be told 'put them in a home now and just get on with your life'. Well I find the same prejudice from the medical system. It's 'put them in a home and get on with your life' (Pam: daughter).*

The majority of the family carers interviewed believed people with a dementia have a better quality of life when they can live in their own home and familiar environment. They wanted sufficient support to be available to allow home-based care to continue, since this was believed to be essential for the well-being of the person.

> *What if we can put in enough infrastructure (sic) around Mum and Dad at home where he can get up and go to bed. I mean sometimes he's got to wake up at three o'clock in the morning - and as long as Mum can get occasional respite. I think, my assumption, is that they're better in their own environment as long as possible (Allister: son).*

Aged care assessment teams would sometimes undertake reassessments and would initiate changes to accommodation without consulting the family carer, or gaining their consent. The below example is further evidence that communication with a family carer is poor even in a face-to-face meeting such as a 'roundtable' multidisciplinary family consultation. It shows that the family carer thought their views were not considered until she strongly asserted her position.

> *And in the end they recommended that she go to a nursing home. And I said, [laughs] 'Oh'. Well that was when we had the round table discussion with the physio and the doctor and everything and I just listened to them and then I had a think and I just said, 'look get everything ready and please send her home on Thursday' (Kate: daughter).*

Health care professionals could be relied upon

Family carers trusted that health care professionals would deliver the needed care to their family member without prejudice to age, or diagnosis of dementia. There was an assumption that health professionals could be relied upon to keep them updated about the care of the person in hospital and would provide the stated follow up care. When this expectation of a care standard was breached participants felt disappointed with the health care professional/s concerned. It was assumed that health care professionals would do the 'right thing' and contact them if there was a problem with the patient.

> *The social worker there, I assumed would contact me. I really wouldn't have had a name of a person. I was just assuming that they would get in touch with me. I thought if it was needed, then they would get in touch with me (Ingrid: foster sister).*

Family carers assumed that if a health professional said something was going to happen, then it would. They were disappointed when they had to chase health professionals for supplies and information.

> *They also told me, I think it was the OT [occupational therapist], that they'd be giving me Kylie sheets [absorbent linen] and things like that to bring home. Well none of that happened. (June: daughter).*

Family carers assumed that they would be told by the health professionals about any necessary alterations to medications and care requirements. They assumed that if they were not told about any changes, then the existing regime continued.

> *She went into hospital taking four medications and she came home with a bag full… and a couple of them were combining to lower her blood pressure, and the pharmacist came and took her blood pressure, and it was so low. She said, 'you'd better get to a doctor or the emergency department.' So we went to the doctor - we'd already been to the doctor - not the same one. The hospital gave me no information about what she was taking. I just assumed she was taking what was necessary because of her condition. That continued on when she came home. Obviously the eating was closely related with those things [medications], because I was having trouble with her eating at home. As soon as those particular pills were halved, she ate a whole meal (Kate: daughter).*

Some family carers feared the level of active care was decided by the doctors according to a patient's 'age' or disease label. It seemed to some family carers that health professionals were prejudiced towards patients who were older and diagnosed with a dementia.

> *Whether another reason for [treatment recommendations] going nowhere, is that at 88 there's only one end point to any of it…and really, the sooner, the better? Whether that's it, that people in this kind of situation are a hopeless case? If it was my six year old, I could go and beat 'the dunny door' down (Maura: daughter).*

Family carers' needs

Family carers needed information about their family members in hospital and information about post-hospitalisation support services. They wanted to be informed and prepared for the care of their family member with dementia and the impact on the family unit. Equally, they want to be seen by health care professionals as a resource, a person able to contribute to the quality of care provided. Then, when in hospital, the family carer needed to be confident that their family member, as a patient, was safe and well-cared for. They also held the view that understanding the hospital system and how it 'works' is important and something they must do because it helps ensure they get access to the resources that can benefit their family member.

The need for information

Family carers needed to know about what to expect as the dementia progressed and to understand why certain behaviours occurred. They also wanted to know about how to provide specific care.

> *I wanted to know why we were experiencing these behavioural things - behavioural problems. To talk about incontinence management and just discuss her normal patterns (Gary: husband).*

Families also wanted to know about the course of Alzheimer's Disease and its impact on the family so they could understand and deal with the gradual cognitive deterioration of the individual.

> *My brother needed information because he couldn't quite understand. He came from a mechanical background and he couldn't understand how they couldn't fix his brain. Certainly information was needed because Dad fluctuated so much. For a few days he'd be really well, then all of a sudden he'd be back to being very, very confused and restless and we just couldn't understand why he was going up and down (Tracey: daughter).*

> *Well Dad's become incontinent now. They're saying that he's now totally dependent so he has to have the pad type things on, whereas before he went into hospital, he's always been independent in that area. Information probably would be useful because it is a concern now if we bring him home, or if I take him out, just for a little drive or something. It's just a major concern. So yes, probably some more information on that would be handy (Ursula: daughter).*

Knowing about the changing needs of people with a dementia allowed families to formulate contingency plans for dealing with the various trajectory patterns of the disease as well as discharge home.

> *With dementia, it's not a gradual slippery slope, it seems to go in steps and we'd just experienced a major step here… and there's the whole grieving thing that happens again. And it's a shock. It's like you're hit with a shock wave. It's the strangest feeling. I don't know how else to explain it, but it certainly is an adjustment period. It's all very well to say, 'well we've accepted that this is happening' but when there's a drop. Boom, it just starts again. We had to make that adjustment, as well as preparing to get her home and in a bit more relaxed atmosphere (Gary: husband).*

Family carers varied to the extent to which they were active information seekers. Some family carers expressed a desire for more information and education about specific aspects of care such as continence management and how to use and care for consumables such as catheter bags, while others did not mention such needs.

> *A little while ago, I'd contacted the Alzheimer's Association. So I have, through them, read some information about dementia – Dad was diagnosed with Vascular Dementia – which a few of the nurses have told me can be quite rapid. So what affects me, is that it has been so rapid, the deterioration. Because last January he was away on holidays with us, and then it just got to the point he couldn't cope at home and I couldn't cope, because I've got young children and I've started back at work. I was too scared to leave him alone. [I could have used] more information from the hospital (Ursula: daughter).*

The need to be acknowledged by health professionals as a resource

Family carers needed to be acknowledged by health care professionals as a resource for understanding and interpreting the patient's behaviours and care needs. Family possessed intimate biographical knowledge about the person with a dementia and they knew how to work with and care for that person, some having been in the carer role for many years. Participants reported instances of poorly managed care that was largely due to a failure of the health professionals to gain an understanding from the family carer of the behaviour management techniques unique to the patient. Instances of poorly managed care were identified as distressing, because the family carers were of the view that such instances could have either been easily resolved, or avoided altogether, if they had been consulted.

> *I was there most days from about twelve to about eight o'clock at night, because I can calm her, but it was more the medication. Medication was due at eight o'clock in the morning and eight o'clock at night. She was asleep at eight o'clock at night. They needed to give it to her at two thirty in the afternoon so she's calm for the afternoon, and ok for meals. When I told them that they said, 'Oh gee, I wish someone had told us'. Well they didn't ask (Gary: husband).*

Family carers indicated that they wanted to be listened to by hospital health care professionals and moreover they wanted the staff to take notice of what they said. When they were not listened to they became angry and frustrated, particularly when communicated care regimes were not formalised as part of hospital care.

> *Dealing with Mum's incontinence…because I said to them about taking her to the toilet every so often and I proved it to them on the home visit with the OT [Occupational Therapist]. The OT said 'Do you want to go to the toilet Anne?' and I said, 'No, no, no, no, you're not listening!' I said, 'just take her there.' So I steered her there. I got them to do it for about three more times during the day – 'Oh this is working - we've got no wets' [said the OT]. This is lovely then what happens. The next day I go back and it's all reversed! Everybody's too busy (June: daughter).*

The need for high quality care

The delivery of quality care to the patient was a prime concern for family carers. They wanted to be assured that their family members were treated with dignity and respect. This did not always occur. Equally, they wanted to know that the person was safe in the hospital environment and in receipt of equal care to all others in hospital. For some family carers, other concerns were secondary to this need, because they understood the hospital system does not cater well for patients with dementia.

> *As far as I knew, her needs were being satisfied in there and that was really all I required, to know that she was being properly looked after and monitored (Heather: daughter).*
>
> *To know that he's safe and being well looked after. It's been really worrying, because he seems to have declined so quickly (Ursula: daughter).*
>
> *She was just like a number on a chart, she was just nobody and it's just lucky that I have a team of people going in everyday to be with her, that she had any dignity at all, because whenever somebody went in there, the bed was wet, the sheets were everywhere. The night she was admitted, there wasn't even a proper pillow, the bed was broken and we went to find some dinner and there was no meal available…and when I asked for something, it was like "how dare you ask for something". It was just like a third world country. If I could have got her out of there, I would have (Stella: daughter).*
>
> *'Can I have a towel to go and help him to clean up?' and that was brushed aside. 'Oh we'll get you one' and it never came. If I'd known that sort of thing was going to happen, I would have gone in [to hospital] with a towel. It was just a minor thing I suppose, but it was a very, very anxious moment, because it was a very unhappy moment for him, a very bad moment (Nola: wife).*
>
> *The hospitals are really designed to deal their own way, to fit in the patient with their system, the system doesn't move to meet the patient's needs (Gary: husband).*

The need to understand the hospital environment

Family carers wanted to be accommodated by the hospital wards yet not be perceived as a nuisance. They wanted to know about visiting hours and who they could approach to ask questions about current and post-discharge care. In order to fit in they needed information about how the hospital environment functioned. Acquiring this information was difficult however.

> *They're obviously fairly flexible about our visiting hours. I guess I was as much help to them as anything, because I was doing quite a lot of the caring. I really did feel like I was annoying the staff and I don't like feeling like that. I just had that impression. I just got a bit of body language there and I would have liked someone to come and say, 'Look let's sit down and I'll explain it to you'. Maybe, they're just too busy, but it would have been helpful to me (Gary: husband).*

> *Obviously you got to know after you'd been there a few days the nurses, but once you got a bit further up the hierarchy, I wouldn't know the difference between a nurse and I don't know what they call them now – nurse's aid or what have you. It was difficult to know whether you were talking to a doctor or a senior nurse. When they were behind the desk… sometimes when you speak to them, they'd say, 'I'll get the doctor.' And right, you're not the doctor [laughter] (Heather: daughter).*

The need to be prepared

Family members had particular needs concerning discharge and these were, from their perspective, linked to everything that was lacking in discharge planning. Overwhelmingly they wanted to know when their family member as a patient was being discharged so they could prepare and ask questions about post-acute care. They wanted to know in advance so they could be prepared.

> *I really didn't get to discuss the medication [long pause]. Yeah, I know about the discharge (Gary: husband).*

> *Well it would be nice if you were told … have advanced notice, so you can plan to do other things. It would be good to have at least one or two people you knew you could talk to each time to get feedback on whether or not she could come home or not. Obviously one would like to be told if the patient was injured in hospital so that you could do the right thing. And as I say, if it's something like a possible blood clot, when you really need to know (Heather: daughter).*

Family members needed to know the formalities of discharge and wanted information about the post-discharge support services. These included advance notice for discharge and the provision of consistent information about the timelines for discharge. They wanted information about follow-up appointments that had been arranged; information related to the person's care and whether there were any changes from the usual regimen. This included information related to medications such as administration issues and any untoward side effects that may arise. A discharge summary could provide this information but this was rarely offered and to obtain one, required a great deal of effort from family carers.

> *…we want to find out what's happening with my father's health, so we can talk to the doctors and try and manage his health. We've got no understanding of the treatment, or the outcomes (Bertha – daughter).*

> *I know he had pneumonia but I don't know the rest. And then I thought, well, whether he had it or not, it's not going to make any difference, but I still would like to know about it (Louise – daughter).*

Family carers needed to know that post-discharge supports were available and in-place before the family member returned home, or was sent (back) to residential accommodation. They needed to know that there was a co-ordinated approach to discharge processes to ensure in-home care was sufficient for the needs of the family member with a dementia and the family carer, or that the home care services were continued, and that any needed extra support had been organised so the person could be cared for at home.

> *We've got to make sure that Mum's capable with looking after Dad and the services are in place. So getting the health care worker, getting the respite care, getting someone to come in and shower him…we had all that in place. We need for that to continue because he's gone to a different hospital this time (Allister – son).*

Similarly, if the family member was discharged to a residential care facility, family carers also wanted to know that extra support services were already in place and that the discharge had been co-ordinated with the facility before the person had been discharged. Family carers believed that they also needed the discharge information which was provided to the facility receiving their family member.

> *…you need to know what's going on (Denise – daughter).*

> *Just to be kept informed about what's happening. Certainly kept informed if there's any ideas that maybe she won't be able to continue the kind of care that she's been getting – those sort of things (Denise – daughter).*

DISCUSSION

The key aspects of discharge planning and execution that were identified as lacking in this research were consultation, coordination and conveyance.

Consultation

The family carers of people with a dementia found the events leading up to and culminating in the patient's discharge from hospital, overwhelmingly stressful. Hospital discharge plans and procedures which may have been in operation and which would have informed the process for families, were not discussed with them, nor were families in many cases aware of their existence. Good practice mandates that discharge planning commences at the time of admission (Bull & Roberts, 2001; Cox, 1996; Hegney et al., 2002; Naylor et al., 1999), however there were no instances of discharge planning discussions reported in this research that commenced at this time. Reports of family members satisfied with the level of discharge planning and preparation leading up to and extending beyond the point of hospital departure were rare. Family carers consistently reported that planning for discharge appeared to occur only one or two days before leaving the hospital. Some family were notified of discharge at the time of the actual discharge and a number reported that they received no notification at all. A few family members were completely unaware that the person had left the hospital, until they enquired about the person's status over the phone, or when they visited the ward and discovered that the person was no longer there. It has been proposed by some authors that changes in a patient's condition during a period of hospitalisation make early discharge planning problematic (Clemens, 1995; Tracey et al., 1998), however intervention studies point to positive outcomes for older people and their family caregivers when planning for discharge is commenced early (Mountain & Pighills, 2003; Naylor et al., 1999; Rosswurm & Lanham, 1998; Seltzer, Litchfield, Kapust, & Mayer, 1992).

It was noted that information relating to the outcomes of hospitalisation; including the care received, changes to existing care regimes, post-discharge care requirements and how to provide this, follow up care and the provision of post discharge support services, was not routinely provided by health care professionals. This information it was reported, was often difficult to obtain from hospital personnel and yet it was of vital importance to family carers (including those whose family member lived in residential aged care), to continue their caring role. The care provided by the family is one the most significant factors impacting on the success of the discharge plan for frail older people by helping the patient to recover from the acute illness and responding to the complementary care needs of the older person (Bauer, Fitzgerald, Haesler, & Manfrin, in press). None of the family members interviewed however, had ever been provided with any sort of written discharge plan that detailed post-discharge care needs and arrangements, despite this being acknowledged as best practice (Department of Veteran's Affairs, 2005).

Because information about in-hospital and post-hospital care was not always offered by hospital personnel, family carers frequently found themselves ‘chasing’ health care professionals for the information that they required. Family carers who were more assertive often had more success obtaining this information, as did family carers with previous experience of the hospital system. Having more knowledge about hospital processes however, did not make the experience of acquiring this information any less frustrating for the family carers.

Coordination

A multidisciplinary model where all health professionals have input into the preparation for discharge is seen as the most effective approach to discharge planning (Driscoll, 1999; Hedges, Grimmer, Moss, & Falco, 1999), however such an approach did not seem to be well operationalised by the hospitals in this study. Families acknowledged that some health care professionals were helpful in providing information about the patient. Nursing staff, a number of families noted, were often not in possession of the information that was needed by them and while medical and allied health professionals generally tried to be accommodating, most were either difficult to contact, or on occasion unreliable by failing to follow through with undertakings. By all accounts, the dispersal of information relating to discharge planning and preparation appeared to be uncoordinated and not well communicated to family carers.

Information provision by hospital health professionals is critical if family carers are to continue to function in the caregiver role. Families of patients diagnosed with a dementia are known to have a need for education on on-going care requirements and assistance with managing and negotiating care services and psychosocial support (Naylor et al., 2005). Failure to provide this can leave families feeling unprepared and unsupported in their role and moreover, result in frustration and anxiety which can impact on their relationship with the older person (Grimmer et al., 2004).

As reported in earlier literature dealing with family-staff relationships in the health care setting (Harvath et al., 1994), participating family carers in this study also overwhelmingly wanted to be acknowledged as a resource that health professionals could draw upon to benefit the care of the older person. The experiences recounted however, indicate that they did not feel included in any decision-making about hospital care, or discharge arrangements, and often felt that their concerns were not being acknowledged. This finding is consistent with recent overseas research where the vast majority of families perceived no participation in discussions about the goals of, or the nature of the hospital care (Almborg, Ulander, Thulin, & Berg, 2009). Because health care professionals did not seek information from family carers about individual patient's established routines and care practices used at home, family members' concerns about all patients being treated the same, with little regard for individual preferences, were reinforced.

Family carers were of the view that many health care professionals did not have an understanding of their needs and largely made no attempt to inform themselves by asking questions, or discussing care arrangements. A number of families believed that some health professionals' decisions about discharge planning and post-discharge care were driven by false assumptions about what was best for people with dementia and their family. Family who wanted to continue to provide care for the person at home, were left feeling unsupported and frustrated when confronted by health professionals who held the view that residential care would be seen as the preferred care option.

Conveyance

The experience of hospitalisation was described as stressful by family carers. Not only did they worry about the person's immediate poor health, but they had to confront the possibility of witnessing a further decline in the person's cognitive status due to the illness. A further concern was that the person was now dependent, to varying degrees, on nursing and other staff to meet most of their daily needs and many families were concerned about the abilities of the staff to provide the appropriate care. It was a commonly held view that the hospital was not the most conducive environment for someone with a dementia, although families had to accept that there was no alternative. Family carers were however, frequently critical of health care professionals who were seen to lack the necessary knowledge and skills to competently care for someone with a dementia.

Many families described how hospitalisation contributed to a further deterioration in the person's cognition and led in some cases to the use of sedatives, or physical restraint to manage the person. Many examples of what was construed as inappropriate care delivery were witnessed and described by families, including the abandonment of prior continence management regimes, inaccurate assessment of unmet need behaviours and the inappropriate use of medications to control behaviours. Hospital care that failed to take into account the unique needs of the older person was distressing for families and often led to an increase in their apprehension, as they were all too aware of the additional burden that a physical and/or cognitive deterioration would impose on them once the person returned to their care.

It was an expectation that health professionals were knowledgeable about caring for the older person and those with a dementia, but this was not always borne out in the hospital setting. Family carers believed that it was important for the staff to be educated about caring for someone with a dementia, since without this knowledge, the abilities of the person to independently attend to activities of daily living could be lost and furthermore their dignity compromised. The need for health professionals who work with older people to be better educated about dementia and dementia care, has been previously highlighted in the literature (Ballard et al., 2001; Hansen, Robinson, Mudge, & Crack, 2005) and this clearly remains an area where further work is required.

While not all family carers, had negative experiences all the time, such events when they occurred had a significant detrimental impact on family carers’ views of the health care system and hospital processes. It was noted that the greatest satisfaction with hospital personnel and hospital processes was often in the emergency department and on first admission to the ward. Other research has found that when family are included and involved, satisfaction with the health care experience is improved (Cox, 1996; C. Cummings & Cockerham, 1997; S. Cummings, 1999; Hancock et al., 2003; Shyu, 2000). Where a close association with the hospital, or particular health care professionals had developed, families in this study perceived improved communication with hospital staff and a better experience overall. This finding underpins the importance of having a comprehensive discharge plan that includes the family carer as partner.

Care that failed to take into consideration the uniqueness of the individual and the needs of the family, that is, was not person centred (Kitwood, 1997), was frequently criticised and moreover shattered the family’s confidence in the ability of hospitals to deal with more than the immediate disease process. Against this background, many family carers were keen to have the person discharged from hospital as soon as possible. One family carer was so concerned about his father’s well-being in hospital, that he discharged him himself.

In summary, discharge planning appeared to be ad hoc and information, communication and care standards families expected were often not provided. Common issues about discharge planning and execution raised by family members included; their lack of involvement in the process; the difficulty in obtaining information identified as being important to continue care; inadequate communication about hospital care and post discharge care and health care professionals lack of appropriate knowledge and skills to provide the best care for the person with a dementia.

CONCLUSION

The transitional needs of family carers of patients with dementia in this study were not always being met and the discharge practices of health professionals is in need of change. The hospital discharge planning processes described here frequently did not take into consideration the needs of the family carer of someone with dementia. Families were often unaware of the existence of a hospital discharge plan and they were rarely consulted about their particular in-hospital, or post- discharge care needs. Obtaining information about the in-hospital medical and other care provided, as well as the post discharge care requirements and supports available, was not straightforward. Many hospital health professionals, particularly nurses, were also identified as lacking the necessary knowledge and skill set to enable the competent care of someone with a dementia.

This research highlights some important considerations about the execution of discharge planning as it relates to consultation, coordination and conveyance for hospital health professionals. An awareness of how the execution of the hospital discharge plan is perceived by the principal family carer of the person with dementia, will allow health care professionals and others involved with the discharge process to better reconcile the family caregivers' needs and expectations with hospital discharge processes.

RECOMMENDATIONS

Hospital systems

The findings of this research suggest hospitals review their discharge planning consultation, coordination and conveyance policies, processes, and procedures to assess the degree to which they comply with the following recommendations. To improve the discharge planning in hospital it is recommended that:

- Hospitals develop policies, processes and procedures for discharge planning that take into account the needs of the family carer of a patient diagnosed with dementia.
- Hospitals develop key performance indicators against which to measure discharge planning best practice and seek feedback from family carers.
- Hospitals adopt best practice discharge planning activities by implementing early engagement of the primary family carer in the discharge planning process.
- Hospitals adopt a ‘person centred care’ approach to discharge planning of people diagnosed with dementia.
- Hospitals develop a discharge planning system that has the primary family carer an equal partner in decision making about the health care of the patient diagnosed with dementia.
- Hospitals identify a health care professional who is based on the ‘ward’ as the person or persons responsible for liaising with the primary family carer of the patient diagnosed with dementia.
- Hospitals develop a discharge plan that identifies the primary family carer as the person to communicate with in regards to assessment, decision making and the ongoing care of the patient and that each instance of communication is documented.
- Hospitals commence planning for discharge within 1-2 days of admission and a date for potential discharge identified in the plan.
- Hospitals develop a policy that requires the primary family carer to be notified of an impending discharge before discharge is initiated.

Family and health care staff

- The primary family carer is consulted regularly and kept informed of the treatment and care requirements of the patient, that include:

    - in hospital consultation about changes to pre-admission care regimes and identification of their impact on in-hospital and post discharge care of the patient.
    - in hospital identification of post-discharge medical treatment and the requirement for education and support of the primary family carer.
    - in hospital identification of post-discharge care that supports activities of daily living and arrangements made to ensure ongoing care provided by the primary family carer is able to be provided and supported.
    - at the point of hospital discharge the primary family carer is;
        - knowledgeable of the prescribed medical treatment/s where the patient is discharged home or to a health care facility, and competent to provide the medical treatment/s where the patient is discharged home.
        - knowledgeable and able to provide ongoing care in the form of the required activities of daily living where the patient is discharged home,
        - knowledgeable and in agreement with the post discharge medical treatment/s, care related to activities of daily living and community support service/s arranged.
- The primary family carer is provided with a copy of the written discharge summary that includes information about outcomes of tests, medications and reasons for change to any medications, current care requirements and post-discharge support services. Where post-discharge support has been organised on the behalf of family, details are provided. This document will provide the name and contact details of the nominated hospital staff member responsible for organising the discharge.

Health care professionals

- Health care staff receive education and training on:
    - the needs of family carers of people diagnosed with Alzheimer’s disease or other dementia,
    - discharge planning activities that are inclusive of the patient and family carer,
    - dementia care.
- Health care staff be required to use family as a resource to facilitate the provision of optimal care for patients diagnosed with dementia.

- Health care staff incorporate in their care of the patient, assessment of the primary family carer’s stress and frustration and where appropriate offer in hospital support and/or counselling.
- Health care staff be required to inform the primary family carer about the grievance procedure of the hospital and the patient satisfaction survey.

STUDY LIMITATIONS

This study has captured the views of twenty five participants who had experience of hospital discharge for someone with a dementia from a range of public and private acute care hospitals in metropolitan Melbourne and rural Victoria. It cannot be concluded that the views expressed by these people will be shared by other family carers of a person with a dementia that have also experienced hospitalization. The participants in this study were all volunteers that agreed to share their views with the researchers and the researchers readily acknowledge the possibility of ‘elite bias’ (Sandelowski, 1986), whereby only those family members who were keen to convey problems with the discharge experience agreed to participate.

As is the case with all naturalistic research, the reader will need to be the final arbiter of the study’s broader relevance and transferability. However given the consistency of views that were expressed about hospital discharge planning consultation, coordination and conveyance and the consistency of the findings with previous research, this research suggests that the issues raised may have broader applicability and warrants further consideration by hospital administrators and members of the health care team.

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APPENDICES

Appendix A: Interview Guide

Improving hospital discharge preparation and support for families of patients with dementia

Demographic information

Gender: M/F

Relation to patient: husband, wife, son, daughter, other (define)

Self reported degree of care provided by the primary carer:

(10 cm visual analogue scale) - 100% of care provided to 0% of care provided

Primary reason for hospitalisation:

Length of hospitalisation:

Discharge destination:

The following questions/issues will be explored during the interview:

What has been your (family carer's) experience of the hospital discharge process?

How were you (family carer) involved in the preparation and planning for discharge of (X)?

What did the hospital discharge planning process/discharge plan comprise?

How was this enacted?

What hospital staff were involved?

How were you involved?

Describe the planning for discharge activities you (family carer) were involved with and the time lines for these.

Did any hospital staff influence the role you were to play in the discharge process?

Which staff involved you most in the discharge process?

Were you satisfied with this? – explain.

How supported did you (family carer) feel:

- in hospital prior to discharge?
- at the point of discharge? - after discharge?

What were your (family carer) needs:

- at the point of discharge?
- in the lead up to discharge?
- after discharge?

How do you think the hospital discharge planning process should work and how would you as a family carer, like to be involved?

What needs did you (family carer) have that were not met by the hospital discharge process?

What were the three (3) most helpful things staff did for you (family carer) in assisting you to prepare for the discharge of (X)?

What were the three (3) least helpful things staff did for you (family carer) in assisting you to prepare for the discharge of (X)?

Was there anything in the discharge process that caused you to be stressed, upset or requiring immediate attention by hospital staff?