

Hospital discharge: recommendations for performance improvement for family carers of people with dementia

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Abstract

Background. It is acknowledged that discharge planning benefits both consumers and hospitals. What is not widely understood is the experience that the family carer of a person with a dementia has and whether the hospitals meet their in-hospital and post-hospital needs.

Objective. To explore whether metropolitan and rural hospital discharge practices meet the needs of the family carer of a person with dementia.

Results. Although this and other research indicates that a continuum of care model is beneficial to family caregivers, no evidence has been identified that family carers currently experience this type of quality planning. Family carers were often unaware of the existence of a hospital discharge plan and were rarely engaged in communication about the care of their family member with a dementia or prepared for discharge.

Conclusion and recommendations. Discharge planning processes for family carers of people with dementia could be substantially improved. It is recommended that hospitals develop policy, process and procedures that take into account the family carer's needs, develop key performance indicators and adopt best practice standards that direct discharge planning activities and early engagement of the family carer in healthcare decisions. It is recommended that health professionals be educated on communication, consultation and needs of family carers.

What is known about the topic? The literature shows discharge planning can increase in patient and caregiver satisfaction, reduce post-discharge anxiety, reduce unplanned readmissions and reduce post-discharge complications and mortality. To be effective, discharge planning requires interdisciplinary collaboration; yet for people with a dementia there are insufficient system processes to support discharge planning, routine breakdowns in communication between patient, family caregivers and health professionals and inadequate admission and aftercare plans. There is little known about the discharge planning as it affects the family carer's of people with dementia.

What does this paper add? This research provides evidence of the family carer's experience of metropolitan and rural hospital discharge as it relates to planning, preparation and support. It investigates how well the discharge planning process met the needs of the family carer and what improvements are required if hospital discharge planning is to be more effective. The research identifies a range of initiatives that hospital and health professionals can implement to improve current discharge practices for family carers of people with dementia.

What are the implications for practitioners? This report makes recommendations for changes to hospital health systems and the discharge practices of health professionals. Hospitals need to develop policy, process and procedure that take into account family carer's needs, develop key performance indicators that measure discharge planning practices, and adopt best practice activities that include such items as early engagement of the primary carer's, the identification of a liaison health professional and implementation of a policy that requires family carers to be involved in and notified of an impending discharge. It is recommended that health professionals be educated on the needs of family carers as it relates to communication and consultation. The primary carer is involved in discussions and decisions about in-hospital and post-hospital treatment regimes and is in agreement with, and competent in, post-discharge treatments, therapies and support services.

Introduction

This study sought to understand the family carers' experience of planning for hospital discharge of a patient^A with a dementia and makes recommendations for changes to the health system and clinical practices of health professions. Since family carers provide a significant amount of post-discharge care, planning for discharge requires their input and preparation, be that in their home or in a healthcare facility. Hospital discharge that fails to meet the needs and expectations of the family carer increases the risk of harm to the family member with dementia, the carer and the need for readmission to hospital.¹⁻³ 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 family carers currently experience this type of discharge planning for a family member with a dementia.⁴

Literature review

A search of the literature was conducted for English language papers in the following databases for the year 1990–2009: Medline, CINAHL, Ageline, Psycinfo, Embase, Informit, Proquest and SUMsearch using the search terms 'dementia', 'Alzheimer's', 'mult-infarct', 'patient discharge education', 'discharge planning', 'early patient discharge' or 'transfer discharge'. Reference lists were also checked for relevant sources of information.

Discharge planning is 'the process of identifying and preparing for the patient's anticipated healthcare needs on discharge from an in-patient facility' (p. 123).⁵ 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. 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.⁶ An investigation of discharge planning by the Australian Health Care Agreements Reference Group,⁴ 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.^{3,7-10} 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 healthcare professionals from a range of healthcare settings, as well as the involvement of the patient and the family caregiver.^{7,9} 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.^{3,5,7-13}

The importance of involving family caregivers in the discharge planning process and their needs has been repeatedly cited in the literature.^{5,6,14-20} Family caregivers report that they feel they have little influence in the decision making process for the discharge of their family member.¹¹ 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,^{21,22} which is made worse when the person is discharged home as opposed to a healthcare facility.²³ 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 and 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 for caregivers to prepare early before discharge of the family member with a dementia, as this also affects the success of discharge and non-readmission.

Aims of the research

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.

Research design

A qualitative constructivist research design as described by Guba and Lincoln²⁴ was used for this study.

Recruitment

Non-probability sampling techniques were used to recruit a range of participants (Table 1) from hospitals in metropolitan Melbourne and rural areas in Victoria, Australia. These included invitation flyers displayed on the wards, referral by the clinical ward staff and invitation advertisements in the Alzheimer's Australia, Victoria newsletter and the Council on the Ageing (COTA) newspaper. The only participants included were those 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. Recruitment and data collection occurred over a 15-month period.

^AThroughout 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 healthcare.

Table 1. Number of family carers and ‘cared for’ family members

Carers	<i>n</i>	‘Cared for’ family member	<i>n</i>
Foster sister	1	Foster sister	1
Husband	4	Wife	4
Son	1	Father	7
Wife	5	Husband	5
Daughter	14	Mother	8
Totals	25		25

Data collection and analysis

Data were collected using audio-taped, semi-structured interviews.²⁵ Prompt questions arising from the systematic review on relationships between staff and family members²⁶ 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 was used with interviews continuing until redundancy had been achieved.²⁴

Rigour

Credibility and transferability of the research was established by using a range of techniques described by Guba and Lincoln²⁴ that included: purposive sampling to obtain a range of divergent views, establishment of participant rapport and trust to elicit quality data. The data and findings were continuously subjected to critical reflection and the postulation of alternative interpretations that challenged the emerging propositions. Emerging propositions were tested by a process of ‘peer debriefing’ and ‘member checking’ by participants. The conclusions reached are supported by detailed descriptions of the data that enable the reader to make their own judgements about the transferability of the findings. 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 research project was approved by the ethics committees of participating hospitals and the University.

Results

Of the 25 family carers,²⁵ 20 were female,²⁰ 14 were daughters and 5 were wives⁵ (Table 1).

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).

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 residential high care facility (nursing home). Of the nine⁹ cared for family

Table 2. Length of hospitalisation and family carer commitment to ‘cared for’ family member

Length of hospitalisation	<i>n</i>	Family carer’s commitment %	<i>n</i>
<3 days	2	20	1
3 to 5 days	6	25	2
6 to 10 days	8	30	4
11 to 15 days	2	50	3
16 to 20 days	3	60	2
>20 days	2	70	1
		80	2
		90	2
		95	1
		100	4
Unknown	2	Unknown	3
Totals	25		25

members residing in residential care, two² were transferred to a rehabilitation facility before being discharged back to the original residential low care facility (Table 3).

In this study the data showed most family carers were critical of hospital discharge planning. Carer frustrations with discharge planning centred on three key themes; insufficient communication, inadequate preparation for discharge and undervaluing the family carer as a resource.

Insufficient communication

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.

As I came around into the ward, [the 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]

Medical and allied health professionals were seen to be the health professionals who could provide the family carer with

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

Before hospitalisation	<i>n</i>	After discharge	<i>n</i>
Live with daughter	1	Rehabilitation facility	8
Low care facility	5	Low care facility	3
High care facility	4	High care facility	5
Own home	15	Own home	9
Totals	25		25

information because they were the people they encountered at the bedside. However, discharge information came randomly from whomever they could get it from – the cleaner to the medical officer in charge and everyone in between.

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]

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]

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 a 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]

Healthcare professionals rarely consulted the family carer and made numerous assumptions about the information needs of families, which had the potential to compromise post-discharge care. 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.

I think there might have been an assumption that the main people [the hospital staff] needed to talk to were the [aged care facility] 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 [aged care facilities], they are 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. . . [Denise, 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.

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]

Inadequate preparation for discharge

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.

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. [Vera, wife]

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 that were in place for preparing the patient for the return home 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]

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 manager to coordinate the services he needed between the two districts.

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]

Undervaluing the family carer as a resource

The hospital experience left many family carers feeling unimportant and frustrated as a result of health professionals failing to keep them fully informed about what was happening with the patient or being perceived to take their points of view or concerns, seriously. In the following example the family carer was of the view that had the health professional valued her assessment the compromise to her husband's health status immediately after discharge could have been avoided.

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]

Similarly, for one family carer, preparations for discharge home of 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. Health professionals readily dismissed his assessment of the family's ability to provide adequate care post-discharge. As he explains, 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.

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 paperwork 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]

Discussion

The family carers of people with a dementia found the events leading up to and culminating in the patient's discharge from hospital were overwhelmingly stressful. Insufficient communication about the hospital discharge plan 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^{11,27–29}; however, there were no instances of discharge planning discussions reported in this study that commenced at this time. Reports of family members being 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.

It was noted that information relating to the outcomes of hospitalisation, 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 healthcare professionals. Information and adequate preparation for discharge 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 of the most significant factors affecting 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.³⁰ 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.³¹ Because information about post-discharge care was not always offered by hospital personnel, family carers frequently found themselves 'chasing' healthcare professionals for the information that they required. Family carers who were more assertive or had previous experience of the hospital system had more success obtaining information. Having more knowledge about hospital processes, however, did not make the experience of acquiring this information any less frustrating for the family carers.

A multidisciplinary model where all health professionals have input into the preparation for discharge that values the family carer as a resource is seen as the most effective approach to discharge planning^{9,32}; however, such an approach did not seem to be well operationalised by the hospitals in this study. Nursing staff, several families noted, were often not in possession of the information that was needed by them and, although medical and allied health professionals generally tried to be accommodating, most were either difficult to contact or on occasion unreliable for 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.

Conclusion

The transitional needs of family carers of patients with dementia in this study were not always being met and the discharge practice by health professionals requires change. The hospital discharge planning processes described here frequently did not take into consideration the requirements 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 post-discharge care. Obtaining information about post-discharge care was not straightforward and better communication between health professionals and family carers is needed. Family carers

want to be identified as a valued resource and along with the patient, prepared for discharge.

Recommendations

Hospital systems

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 identify a healthcare 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 commence planning for discharge within 1–2 days of admission and a date for potential discharge is 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.

Healthcare professionals

It is recommended that:

- Healthcare staff receive education and training on:
 - The needs of family carers of people diagnosed with Alzheimer's disease or other dementia as it relates to communication and consultation.
- The primary family carer is included in:
 - In-hospital identification of post-discharge medical treatment and the requirement for education and support.
 - In-hospital identification of maintenance therapies to maximise the patient's functionality post-discharge.
- At the point of hospital discharge the primary family carer is:
 - Knowledgeable about the prescribed medical treatment(s) where the patient is discharged home or to a healthcare 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.

Study limitations

This study has captured the views of 25 participants who had experience of hospital discharge for someone with a dementia from a range of public and private hospitals in metropolitan Melbourne and rural Victoria. It cannot be concluded that the views expressed by the participants in this study will be shared by other family carers of a person with a dementia that have also experienced hospitalisation. The possibility of 'elite bias',³³ where family carers with strongly held views on the topic participated, needs to be considered; however, the study's findings are consistent with similar research in this area. The reader will be the best judge of the study's broader relevance and transferability.

Competing interests

The authors declare that they have no competing interests.

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