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Becoming a Carer for an Elderly Person after Discharge from an Acute Hospital Admission

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ABSTRACT

Objective: To describe the perceptions of people taking on a new or expanded caring role for an elderly patient recently hospitalised with a new or intensified health problem. Design: Observational study collecting qualitative data monthly for six months following patients' discharge from hospital and attempted return to independent living in the community. Setting: Four South Australian acute hospitals (one metropolitan, three country). Subjects: 34 unpaid carers were nominated by 100 patients. 24 carers participated (17 elderly spouses, 3 younger family members, 4 neighbours and/ or friends). Results: The study highlighted carers' perceptions of being unprepared for their new tasks, and their frustrations at the long-term and frequently significant changes to their lives brought about by assuming a caring role. Many carers felt their role had been imposed upon them without real choice, and that their own physical and emotional fitness for their new role had not been considered during discharge planning. Carers claimed to have been provided with little information about how to care for the patient, particularly when community services were seldom provided in the first week after discharge. Stresses developed in many of the carer-patient relationships, and patient and carer morale was often low for months post-discharge. Discussion: Carers indicated that their tasks could have been made easier by more timely, targeted education about their patient's condition and their role in managing it. They would have liked greater inclusion in discharge planning processes whilst the patient was in hospital, and more timely and appropriate provision of post-discharge services that were patient- and carer-focused, and which addressed their ability to live independently in the community. Conclusion: Discharge planning systems should take greater account of the motivation and needs of carers, especially when this role is new or becoming expanded, and of the barriers they face in undertaking their role.

INTRODUCTION

The presence of a 'carer' is believed to assist in the patient's transition from illness to recovery.¹⁻⁴ In many instances, the carer is unpaid, and has variable ability, willingness and skills to undertake the tasks involved.⁵ Unpaid carers are often 'on-call' all day, every day, dealing with a range of tasks, such as medication management, medical and nursing care, transport, meal preparation and feeding, hygiene, dressing and mobility.⁶ Carer concerns are reported as lack of information on how to safely lift and handle patients, their lack of training to undertake the tasks required to manage illness, fatigue, depression, and their own health concerns, suboptimal availability of, and access to, community supports and the often high financial costs associated with caring for an elderly ill person at home.⁷⁻¹²

There are two imperatives for understanding the role of unpaid carers for elderly ill people: the first being continuing reductions in the length of acute hospital admissions (to redress rising inpatient costs and decreasing availability of beds), and the second

being limited availability of, and access to, residential care places.¹³⁻¹⁵ Early discharge from the hospital means that many elderly people are discharged unwell, and thus require ongoing care.¹⁶ While post-discharge care may be delivered formally (in early discharge programs, domiciliary care services, care packages etc), day-to-day management is most commonly undertaken by unpaid carers (family, friends, neighbours).^{8,17-20} Accordingly, there is the potential for shifting costs and burdens from formal to informal services. Thus, in order that appropriate, timely and effective formal health services are provided to support elderly people recently discharged from hospital back to the community, it is essential that the roles and concerns of the people who thereby become unpaid carers are better understood.

This paper presents findings from a longitudinal study which described perspectives and experiences of unpaid carers in relation to the tasks they undertook in the management of elderly patients, following their discharge from an acute hospital admission that marked a change in their future health prospects.

METHODS

Ethics approval: Ethics approval was obtained from the Human Research Ethics Committees of the researchers' universities, and from participating hospitals. Patients and carers consented in writing to participate at project commencement, and verbally reconfirmed this consent at each study contact.

Subjects: Participating patients were asked to nominate a primary carer, whom we defined as the main person who would assist the patient in activities of daily living post-discharge. Four South Australian hospitals participated (one metropolitan tertiary teaching hospital and three country hospitals), and data was collected between February and July 2000.

Data collection: Data was collected separately from patients and carers in individual confidential semi-structured interviews one week after the patient's discharge from hospital, and then every month thereafter for six months. Most interviews were by telephone, and approximately 10% were conducted face-to-face in patients' homes for data validation. Carers were interviewed when the patient was not present (mostly when patients were resting during the day) to ensure that carers were not constrained in their interview comments. All interviews were recorded and later transcribed for analysis. At each interview, carers were asked to comment on their recent caring experiences, their concerns about caring for the patient, their concerns about their caring role, use of formal and informal community support services, and whether these services met the patient's and their needs.

Analysis: Qualitative analysis focused on identification of key themes, synthesised from the carer interview data. The analysis identified and contrasted key themes at each time period in the study.

RESULTS

Carer sample: Of the 100 eligible, consenting patients, 34 nominated a primary unpaid carer. Ten of those nominated carers refused to participate in the research. In nine instances, this was because the nominee seemed not to have considered that they would be undertaking any 'caring' tasks for the patient after discharge. The other nominated carer would not commit to repeated interviewer contacts. This paper reports on repeat interview data obtained from 24 primary carers of recently ill, elderly patients over a six month period following patient-discharge from an acute hospital admission. As some carers were unavailable at some interview times, this amounted to 132 carer interviews in total.

Carer descriptors: There were 16 city (8 males and 8 females) carers and 8 country carers (2 females, 6 males). City carers were younger than country carers, with a mean age of 67.5 years (SD + 15.0) (range 37 years to 80 years) compared with country carers [mean 74.7 years (SD + 4.9) (range 69 years to 83 years)].

Who is a carer? Seventeen carers were spouses of the patient (10 city carers, 7 country carers), and all but one couple was both aged over 60 years. The remaining carers were other family members (N=3) (adult child, grandchild) or unrelated individuals (N=4) (neighbour, boarder, friend) (two country, two city). All but one of the male carers was the spouse of the patient, whilst female carers reflected more diverse relationships with the patient.

Preparation for caring: During their patient's hospitalisation, carers mostly felt themselves to be unimportant to hospital discharge planners. Only two carers reported being included in any way in discharge planning whilst the patient was in hospital, and in both instances, this occurred during a fortuitous meeting with a nurse, when discussion about patient discharge plans was precipitated by the carer. Almost no information was provided to any carer about medication or wound management, or how to physically care for the patient (including how to ambulate and transfer them safely). No carer reported being given information on the extent or length of the caring role following discharge, or what to expect of the patient's changed health status in the weeks to

come. Carers reported that there was little attempt by hospital staff to ensure that they were sufficiently physically and emotionally fit to undertake 'caring' tasks for the patient, or that they understood the extent of their role.

The need to consider carer health and willingness to "care" was highlighted by the length of time over which many of the patients who nominated a primary carer (N=34) required active caring (21 for the entire study period). In the instances where carers who were nominated by patients at study commencement did not participate in the study, information about the provision of ongoing caring was gleaned from patient interviews.

Carer choice: Carers expressed frustration throughout the study at their lack of choice in assuming the "caring" role, this frustration in many instances increasing as the study went on. In the early days post-discharge, many carers saw their caring responsibilities as a natural extension of a familial or friendship commitment to the patient. However, as time went on, and the caring role became more routine, realisation of the full extent of the caring role and the time period over which it would extend often seemed demoralising: "It was then I realised I'm the only one to totally care for my husband - he's not their 'problem' now."(Mrs O).

Use of formal community health and support services: The researchers suspected that the presence of a carer often influenced hospital staff's decision to organise health and support services for patients, as only two patients with nominated carers received formal health or support services in the first week post-discharge. The remainder waited up to four weeks post-discharge for any service to commence. Once in place, formal services were provided with variable frequency, with a maximum service provision of three times per week for eight weeks. Consequently, all carers undertook some caring tasks (generally nursing / hygiene / rehabilitation) for their 'patient' within hours of returning home, and for some time after, without formal assistance.

Carers seemed ambivalent about the value of formal health and support services. While agreeing that the provision of formal services in their home relieved them of responsibilities in caring for their patient, carers queried the relevance of infrequent provision of formal services. Carers were particularly sceptical of the value of formal services that took weeks to implement, with common responses being that by then the patient's health situation had changed, and/or the patient and carer had successfully implemented their own (often innovative) management strategies.

Three months after discharge, Mr S remained the carer for Mrs S. He believed his wife was making progress "but slowly". He attended to all of the chores. "Things are different now – she is not able to do anything where she has to exert energy."

Carer tasks: Carers reported undertaking a wide variety of tasks for which they were felt they were untrained and often unprepared. These ranged from regular personal care for the patient (hygiene, assistance with toileting, dressing), health care (changing dressings, assisting with injections, monitoring blood sugars or blood pressure, managing and delivering medications), mobility assistance (walking, transfers, setting up walking aids), patient management and advocacy (attending doctor's appointments, keeping health diaries, monitoring medications), counselling (dealing with patients' mood changes, fatigue, depression and frustrations) and house-hold tasks with which they were not familiar (for men this was often cooking, shopping and cleaning, whilst for women this was house and garden maintenance). Undertaking unfamiliar tasks was perceived by carers as contributing to their own increased fatigue and stress levels.

Mr A: I've never done much cooking, always left it to the wife... now I have to produce interesting healthy meals every day for both of us..... It takes a lot of work and planning guess I should have learned to do this a long time ago!

Managing in a changed environment: Not being able to leave the patient alone safely if the carer needed to go out of the house (for instance shopping or attending medical appointments) was highlighted by almost all the carers at some point in the study. Therefore, in the early days post-discharge, some carers organised temporary "sitters" for the patient, or went out while the patient had a day-time nap. In several instances, patients were left with instructions by their carers 'not to get out of bed' until they returned.

Major changes in carer routine occurred when the patient had been the only driver in the family, but now could no longer drive due to changes in health status. This resulted in non-driving carers dealing with their own frustration at what was often significant difficulties with transport, as well as their patient's frustration at not driving. We observed increased physical, time and financial costs in undertaking shopping trips (the most commonly reported reason for going out). Where non-driving carers could not

organise (or afford) regular alternative car transport, they relied on walking or catching public transport to go to the shops. Not only did this take far longer than the pre-illness car trips, because of distance or public transport timetables, but the trips needed to occur more frequently because only a few items could be physically carried at once.

Mr Z was becoming increasingly frustrated and continued to be depressed over the loss of his driving ability. Transport was a big expense, as Mrs Z had to use taxis or the local bus. 'A loaf of bread can prove expensive if not planned ahead', said Mrs Z.

By the second to third months of the study, most carers had started to become better organised, using local support services, such as home delivery services for shopping, or paid help to 'mind' the patient when they went out. We noted that carers also started making appointments (medical or other) at times when they could organise car rides with others, thus improving their time management and decreasing their energy expenditure and worry. Consequently, it seemed that the greatest level of carer frustration, disorganisation and worry occurred immediately post-discharge when the caring role was new, formal support services were not in place, local support services were unexplored and the patient was still unwell.

Carer illness: Illness in the carers themselves was common throughout the study. Carers often had pre-existing medical conditions which were apparently often not taken into account by the carer, the patient or the hospital staff when the patient was being discharged from hospital, yet which physically and emotionally constrained the carers' ability to manage the patient as they would have wished, as well as putting the carers' own health in jeopardy. One example of this was of a carer whose diabetes was unstable prior to his wife's illness. Following her discharge from hospital, he found he could not attend regular medical appointments because he could not leave his wife alone. As the GP would not undertake home visits, the health concerns of both the carer and his wife increased significantly.

Stress on former relationships: A pervasive and unsettling theme throughout the study was conflict between patient and carer, most often surfacing within the two months after patient discharge. Carers perceived that conflict mostly arose from difficulties in coming to terms with their own, and their patient's changed roles, self image, anxieties and frustrations, as well as their worry about providing continual care for an ill patient despite insufficient preparation for the tasks involved. In some instances, married couples who reported being happy together prior to illness found that they had few coping mechanisms to deal with the new stresses on their relationship.

Three months after discharge, Mrs O commented "I'm not going as well as I hoped – maybe I expect too much!" Mr. O assisted her "a lot". She found it difficult to maintain independence as "he always wants to do everything for me". Mrs O likened their relationship to when he first retired and they had to get used to each other again.

Where the carer was not a family member, the caring role frequently altered the relationship the 'carer' had previously enjoyed with the patient. An example of this was an elderly male boarder who was unwillingly cast in the role of carer for his equally elderly widowed childless landlady, and who subsequently moved out because of the stress, leaving her without any assistance.

We also interviewed a young mother who provided hours of daily assistance for her elderly male neighbour, including shopping, meal preparation, personal hygiene, dressing and house cleaning on top of the work she did in her own home. She felt frustrated at the long term commitments on her time, brought about by a casual offer of help when the patient was first hospitalised.

We observed what we judged to be significant grieving by both carers and patients, irrespective of the relationship, generally related to lost independence, dealing with changed health and social circumstances, financial burdens, and loss of the future that they had planned together (in the case of spouses). There seemed to be few formal opportunities for carers to express their concerns or frustrations outside the home, or to seek independent advice about how to deal with their own, and their patient's grief for lost lives.

Mrs J described a marked deterioration in Mr J in the seven weeks following discharge. She became very upset and sobbed on the phone. She felt they were not able to cope any longer. They were arguing constantly. Mrs J felt that her husband's memory had deteriorated significantly and he was displaying behaviour he was not aware of. Mrs J had discussed the concerns she had about coping to her GP, but she felt that he wasn't much help. He prescribed anti-depressants for her. She took these for one week and then stopped because she was "frightened of getting hooked on them". Neither Mrs J nor their children had spoken to each other about their concerns about Mr J until now. "It's so silly because we are a close family."

Change in pre-illness routine: All carers reported curtailing their usual social activities, with over 50% of carers not having resumed their pre-caring social activities by the end of the study. Younger carers had to juggle work and family commitments to provide regular care for their patient, often finding themselves in the position of managing two households and demands from several people (the patient as well as their own family). In fact, caring for others in addition to the 'patient' was reported by 25% of carers. This had both positive and negative impacts, highlighting the need for carers to be flexible and innovative. One good outcome from an innovative decision occurred when a carer took her ill mother home to live with herself and her husband, four teenage children and an infant grandchild. The carer reported that, apart from her mother requiring supervision to prevent falls, the carer no longer had the worry of her mother living alone, she did not have to manage two households and her mother enjoyed the company of the younger family members.

The need for education: Carers generally expressed frustration (mostly early in the study) at their lack of knowledge, the scarce opportunities to learn about their patient's condition, and how they could best assist in its management. Our carers all saw themselves as being primarily responsible for day-to-day patient management, and they had many practical questions in the early days that were often not satisfactorily answered by any health professional. After the first few weeks following discharge, many carers independently sought information about their patient's condition from a range of sources, including their GP, community pharmacist, various health professionals (community and hospital), the local library, the internet and support groups.

Mrs N learned to use the local library to get information on diabetes, and appropriate recipes for her husband who had been recently diagnosed with diabetes. She had been unable to get useful information from anyone at her local hospital prior to her husband's discharge, or from any community health personnel who visited her husband at home. While she admitted initially to being frustrated by the lack of information provided to her by health personnel, with the help of the librarian she learnt to navigate the information systems at the library and on the internet, became more confident about asking informed questions, and developed into a competent diabetic cook on a budget.

Irrespective of their age or relationship to the patient, carers readily identified key aspects of education that they believed could have assisted them in managing their 'patient' better, particularly in the first few weeks post-discharge. These included what to expect from the patient's condition, how to assist with medication (and what side effects to look for), how to lift, ambulate and transfer the patient, how (when, how often) to bath them, what clothes were easiest for dressing the patient, what foods to cook, how to feed the patient efficiently while maintaining their dignity, how to deal with patients' ongoing pain, fatigue and depression, how to give themselves a break from caring duties, where in the community to seek assistance, and who else in their community was managing the same problems. While some form of formal respite care was available in each locality, only three patients with carers accessed this service during the study, this being for a two week maximum.

Maintaining the status quo: Carer commitment to delaying nursing home placement for the patient was notable. As all patients at study commencement were coming to terms with a changed health state impinging on their ability to live independently, throughout the six months of interviews most of them experienced significant decline in their health, and their ability to undertake activities of daily living. Many spouses viewed the provision of high level care for their patient as testing their wedding vows ('for better or for worse, in sickness and in health'), and they seemed, on the whole, highly committed to maintaining their current living arrangements with the patient. Consequently, they considered residential care for the patient only if there was permanent deterioration in their own health.

Location differences: Country carers generally had better support networks than their city counterparts. These networks were informal and frequently did not involve family, but rather long-standing friendships, neighbours, or members of local community organisations. Unlike children of the city participants, many children of country couples lived considerable distances away. When these adult children visited their country parents, it was for longer periods of time than city children, and they frequently undertook pre-planned major maintenance tasks such as gardening, spring cleaning or repairs. These activities were highly valued by carers, and seemed to confirm their ability to manage the patient at home in the short- and long-term. This was illustrated by comments such as 'now I don't have to worry about the garden until spring', or 'that's got the curtains fixed up for another 12 months'.

We suspect that when anticipating a lengthy visit from children, country carers planned ahead to identify important household maintenance tasks. In the city, there did not seem to be the same emphasis on planning ahead, as children visited often (but for shorter, and less organised periods of time). This possibly resulted in patients and carers not identifying important tasks for which they required assistance. Non-completion of large household maintenance tasks seemed to undermine the confidence of many city carers about their own and their patients' ability to remain independent in the community.

DISCUSSION

The interviews provided detailed information on the entry into a new or expanded caring role, by untrained, unpaid carers for recently ill, elderly patients. This study highlights carers' significant physical, financial and emotional costs that are not adequately taken into account in budgeting for post-discharge care for elderly patients. This study moreover, raised the question of whether having a carer actually assisted recently ill elderly patients to regain and maintain their long-term community independence. This was particularly so when the carer's health status was also poor, and when friction developed between them over dealing with long term changes in health status and quality of life.

Being identified as the primary 'carer' did not necessarily imply that the carer was physically or emotionally prepared to undertake the tasks of caring for their 'patient'. Voluntary, informal, unpaid carers were found to be performing even more extensive tasks than trained health providers, and often for longer periods and without the necessary training or equipment that would be deemed essential for a place of paid work.⁷ Most carers initially undertook the caring role from a sense of friendship or family duty. Carers appeared to have minimal opportunity to vacate their role once their patient and /or the health system had cast them in it, even if the caring role was physically or emotionally beyond them.

Constraints on caring: Most carers were constrained in their ability to act efficiently or confidently by lack of education about their role and their patient's condition. They were also constrained by their own health status, or by work, or other family or social commitments. There was not much evidence that hospital staff had attempted to identify the presence, willingness and ability of individuals to assume the caring role once patients left the hospital, leading to inadequate carer education and training, and inadequate organisation of community supports for carers after patient discharge.

These issues have all been highlighted by others.^{7,11,21,22} It is also possible that, when hospital staff realized that a patient had a carer, the organisation of formal services post-discharge became of less priority, on the (mostly untested) assumption that carers could provide the requisite care. The researchers contend moreover, that deeming a patient to have a 'carer' may not actually indicate a useful support system for the patient. Dysfunctional relationships between carer and patient often resulted from the strains of dealing with changed health or social circumstances. Indeed, decisions regarding placement or ongoing care seemed in some instances to have been more difficult because the needs of two people had to be considered, rather than merely the patient.

Carer supports: Carers were generally insightful about their situation, and their relationship with the patient. They readily identified their frustrations, short and long term needs, and the services they required to meet these needs. These insights were remarkable in view of their often obvious distress at having to adapt to permanently changed health and social circumstances for their patient and themselves. Availability of strong local support networks (particularly observed in the country) seemed to assist carers to continue with aspects of their own life as well as putting the caring role in greater perspective, and thus the provision of support networks for all carers in the short and long term deserves more consideration. Carers universally noted that better education prior to patient discharge - about the natural progression of their patient's condition, the long term demands of the caring role, and how to be efficient in caring for their patient and themselves would have assisted them in better undertaking their tasks. Additionally, being put in touch with other carers in similar situations was deemed by carers to be useful in improving carer confidence and decision-making.

The study findings support other reports that carers have higher levels of anger, anxiety, sadness and depression than non-caregivers.^{9,10} The researchers propose that many new carers are so 'shell-shocked' by their caring role that they fail to understand their own physical and emotional limits. This is coupled with concern and sympathy for the patient, and a frequently romantic (but genuine) notion of the role they would like to play in assisting the patient to return to health. This seemed to affect carers' ability to work pragmatically with hospital staff pre-discharge, and community health staff post-discharge, to acquire the knowledge and establish the supports they require to provide appropriate and efficient care for their patient in the long term. We found that while patients and carers were cognisant of what was required for them both to remain independent in the community, the extent of the carers' duties was frequently unrecognised by the health system, even when major problems occurred. Whilst respite care is reported as beneficial for the patient as well temporarily relieving carer responsibilities,²² it was remarkable that so few patients with carers appeared to have been offered this option.

CONCLUSION

Our findings call into question a number of widespread presumptions about the adoption of a new or expanded carer role. Patients and hospital staff can be mistaken in assuming that someone is, or is willing to be, designated as a carer. Those who are willing to be so designated find many unacknowledged barriers to the successful implementation of carer tasks and to achieving a satisfactory quality of life for themselves and for the person for whom they are caring.

If unpaid carers continue to be the main source of patient support post-discharge, it is important that they are appropriately resourced, to minimise their frustrations and concerns, and to maximise patient and carer long-term independence in the community. This study underlines the need for recognition and involvement of carers by hospital staff prior to the patient's discharge from hospital, to equip them appropriately for their role in the care of their patient. Many of our carers made critical, and mostly uninformed, decisions about their patient's future throughout the study. Thus providing patients and carers with appropriate community supports, empowering carers to provide effective and appropriate care safely, and assisting patients and carers to plan adequately and realistically for the future could ensure healthier older people with long-term planned, supported independence in the community.

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