



Executive Summary

Study Overview

This report outlines the methods and findings of a longitudinal study which followed a group of elderly patients, and their carers, for six months following the patients' discharge from an acute hospital. We undertook this project to explore issues raised during our recently completed project, which had been funded by the South Australian Health Commission (now Department of Health Services, SA) through the Primary Health Care Initiatives scheme (Grimmer and Moss 1999). From the findings of that project, we drew attention to the many issues faced by recently ill elderly people on their return to the community after an episode of hospitalisation. We found that these individuals may be inadequately supported in their attempts to maintain independent living in the community, and that this may result in unnecessary and unplanned use of expensive hospital and residential care beds, as well as reactive (rather than proactive) use of community health and support services. The short time frame of that study precluded investigation of elderly people's ability to cope for longer periods after illness. Thus we undertook this current study, which was jointly funded by the Strategic Policy and Planning Division of SA Department of Human Services, and the SA Office for the Ageing.

In this study, our overall aim was to describe and analyse strategies and community supports used in the short and long term by elderly patients and their carers following discharge from the acute hospital setting. The focus was to identify strategies and services that were most useful, flexible and sensitive to change, which could be implemented in a timely and cost effective manner, and would empower patients and their carers to make decisions that supported independent and successful return to the community after hospitalisation.

This report collates several different aspects of our research.

- ◆ We wanted to set the scene from a research reporting perspective, as our previous research in discharge planning evaluations had highlighted the paucity of useful research in the area. We undertook a critical and systematic appraisal of the higher levels of the research literature regarding discharge planning and community supports for recently ill, elderly people. This report describes the variable quality of the published literature in the area, what the key findings, trends and deficits are, and how the generalisability of the findings is constrained. We highlighted the importance of fully describing interventions and measures of outcome, and the need to describe and understand the environment in which the research was conducted, in order to consider the wider application of the findings.
- ◆ We wanted to better understand and describe the structure of local (or regional) aged care systems and the variability within them. To this end, we conducted extensive pre-project interviews with prominent systems personnel in Government and non-Government organisations, and representative service providers. The key themes from these interviews were identified and synthesised, and were used as a framework to discuss systems issues in service provision for recently ill elderly patients on their return to the community after discharge from hospital.
- ◆ We sought longitudinal information on how recently ill, elderly patients coped after hospitalisation following a significant change in health status. We deliberately sought out a group of people who had been previously well, but who were now on what we called 'the cusp of chronicity' following their episode of hospitalisation. We recruited 100 recently ill elderly patients, and their carers, across one metropolitan site and three country sites in South Australia. Our inclusion criteria

were that patients be 60 years or older, male or female, with or without a carer, about to be discharged from medical wards of acute hospitals with any condition whose health implications would become more severe and / or chronic, may have consumed more than the average length of stay (LOS), had experienced one to two previous admissions only for the condition (but who were expected to become worse), had been admitted to hospital more than six weeks prior to this admission, lived within 20 kms of the hospital, and met ward nurses' perception that the patient was on the 'cusp of chronicity'. Comorbidities such as depression and anxiety were eligible. Our reason for seeking out this group was to identify how naïve sufferers of changed health and social status coped following the change, and how they learnt to use the aged care system.

- ◆ We sought information on patient and carer perception of the quality of preparation for discharge from hospital. To do this we employed the PREPARED instrument, which we had developed during our previous project (Grimmer and Moss 1999), and which has been recently reported in an international academic publication (Grimmer and Moss 2001). To our knowledge, this instrument is the only validated way of obtaining information from English literate consumers regarding the quality of preparation for discharge from hospital.
- ◆ We described changes in health-related quality of life of patients and carers over six months post discharge, using the SF-36 instrument for initial post discharge assessment, and the SF-12 instrument for subsequent assessments each month post discharge. We changed to the shorter version of the SF-36 instrument to minimise response burden on our subjects. This report provides a comparison of patient and carer health-related quality of life measures over the period of the study, and compares these findings with relevant population norms.
- ◆ We explored the experiences and concerns of our subjects using repeated in-depth, semi-structured interviews each month post discharge. This report provides an illustrative selection of case histories, and a synthesis of the key themes derived from the monthly interviews.
- ◆ The report provides commentary and discussion on a range of issues, including differences in experiences between rural and city participants, changes in experiences and concerns over time, differences in insights and opinions between patients and carers, use of, access to, and satisfaction with community health services, models of care currently operating in the participating hospitals and communities (and how these address patient and carer needs), identification of patient and carer needs (and whether these could be addressed within current systems), housing issues, issues of hospital / community communication, continuing education in transition planning for hospital and community service providers, and efficient ways of making information available to patients and carers.

This report provides recommendations on practical strategies that could be implemented in hospitals and communities to address the needs, concerns and expectations of recently ill, elderly people who are coping with significant changes to health and community status.

Key findings

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As with most studies of human adaptation to changed circumstances, we identified more areas that should be investigated, than areas for which we provided answers. We also identified the difficulties of conducting research in this area which minimised bias, and provided findings that could be generalised to other patient groups and health care systems. The key issues raised from our research were:

1. What are the long term health and social outcomes for patients and carers? For instance,
 - ◆ what is the effect of service rationalisation on patient and carer health?
 - ◆ how soon after discharge should support services be provided, and how long should they continue?
 - ◆ what messages are services giving to patients and carers in terms of how important they are, and what they can do to help themselves?
 - ◆ what other types of services (other than funded health services) does the client use?
 - ◆ what costs do patients and carers bear, and what is the effect of cost-shifting?
2. The role of the general medical practitioner as a gatekeeper / service coordinator.
3. What is the next study? For instance, what is the most appropriate type of research design to identify the best ways to assist patients and their carers in the transition from hospital to home, and from one health state to another?

Carers

The presence of a carer, overall, seemed immaterial to hospital staff at the time of preparation for discharge whilst the patient was in hospital. Most carers were not included in the 'loop' of planning for discharge. 'Carers' were the spouse (healthy, or otherwise), an adult child (who more often than not did not live with the patient and had other responsibilities within their own home / work settings), grandchildren (who had other commitments and activities), or neighbours and friends (who were often similar to children in their divided responsibilities). The need to consider carer health was highlighted by the length of time over which many of our patients required active caring (many for five to six months post hospitalisation), and by the diminishing mental health status of many of our carers as time went on. Deeming a patient to have a 'carer' may not actually indicate that they have a useful support mechanism. In many instances, the presence of a carer post discharge produced more stress for both patient and carer, than for patients managing alone. It seemed that many health-related and support roles were being provided for elderly, recently ill people by untrained 'volunteers' (carers) without financial recompense or consideration of occupational health and safety issues. These individuals had minimal ability to vacate the 'caring' role once they had assumed it (willingly or otherwise). There is currently little support in hospital or community health systems for new carers, and many carers are so 'shell-shocked' by their new role they fail to understand their own physical and emotional limits. We found, as illustrated in the case studies, that the role of, and burden on, the carer went frequently unrecognised by members of the health system (including the carer themselves) until major problems occurred that necessitated emergency action, often at high cost (such as hospital re-admission for the patient, or carer illness).

Systems issues

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There were few differences in the health systems in our four study communities, despite our expectation that country areas would have less complex and more transparent organisation of their health system than the city. However, we found that similar dominant constraints on systems operated in all sites, such as service funding complexities, service constraints due to hours of operation and availability of appropriately trained personnel, communication issues, service rationalisation, and changes in available services that were not well communicated to people within or outside the health system. In the country (but not in the city) we encountered instances where personality issues impacted on the provision of appropriate services. For instance, hospital staff had often known the patient and / or carer for years, and frequently did not seem to take the time to talk with them about their actual or changed needs for service. Services were thus provided (or not) on historical perception of need. We also found several instances where patients or carers were perceived to be 'difficult' and services were not offered appropriately. We found that in the country (more than the city) health providers frequently knew about the patient's family and social support network, and thus assumed that children or friends 'ought to' provide care for elderly patients, based on local knowledge, rather than a professional assessment of their ability and willingness to undertake this role.

We found in many instances that the elderly patients and their carers had a clearer understanding of health and community service structures and their failures than many of the professionals, policy makers and administrators who worked within these structures. Many of the inadequacies in services may not have occurred had patients and carers been involved in their conceptualisation, planning, organisation and evaluation. Patients and carers frequently provided us with useful and critical insights into service flexibility (when services should commence, how often they should be provided, how many hours they should be provided for, and the period of time for which the service should be available post discharge), service providers (who were the best people to provide particular services), what services worked well and how service success could be determined, how to evaluate the balance between service cost and perceived benefits, constraints on the usefulness of services, service influence on patient choice and individual decision-making, and what patients and carers perceived as value for money.

Metropolitan versus country patient and carer attributes

On the whole, country patients and carers were more resilient and adaptable than metropolitan patients and carers. They seemed more adept at drawing on existing networks (formal and informal) and adapting old methods of doing things to deal with changed health circumstances. Word of mouth, letterbox drops and local knowledge assisted many of our country patients to find gardeners, house-cleaners and personal assistants within four to six weeks of returning from hospital. Information for services was less available by this route in the city and many of our city patients were without organised home support services up to four months post discharge. For many of our country patients, their adult children had moved away, causing them to rely on friends, neighbours, church and other social supports for assistance. When families did visit, they did so for a longer period of time, and frequently undertook major tasks such as cleaning up the garden or spring cleaning the house. This was highly valued

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by our subjects, allowing them to positively re-assess their ability to remain in their own home. Conversely, in the city, whilst children often lived closer to the patient (relatively speaking), their ability to undertake regular caring roles was constrained by daily commitments and travel issues. Major house management activities were undertaken less frequently by children who lived close to the patient, because their time each visit was constrained and precluded identification of the need for major tasks, and / or the ability to complete them. It seemed that where patients and carers anticipated a lengthy visit from children, they planned ahead to identify important tasks to be completed for their peace of mind. Where children lived nearby and were frequent visitors, there did not seem to be the same emphasis on planning ahead.

Costs of being ill were far greater for country patients than city patients. Travelling to the city for medical consultation was an immense burden for many country patients, both in financial and physical terms. Where patients travelled to the city by car, often family or friends were required to drive them, thus incurring not only the financial and physical cost to the patient / carer for the journey, but financial, physical and opportunity costs for the person driving them. The costs of purchasing, installing and using equipment in the country was generally greater, as this frequently involved delay in home assessment longer than the city), higher costs of purchasing the equipment and its installation (which are often not covered by local support schemes), and additional costs and delays if the equipment was found to be faulty or inappropriate. Access to information about equipment choices was more limited in the country than the city.

Transport

Accessing public transport (buses, taxis) was a major concern for both city and country patients. Prior to their illness, few of our patients had used buses or taxis and so the complexities of access to these services required education and negotiation. Whilst the cost of buses was seen to be affordable, patients and carers identified inconvenience of routes, poor timetabling causing long waiting periods for a return bus, difficulty of physically accessing the bus, and lack of driver concern with user safety. Taxis, whilst being more expensive, were seen to be more flexible and user friendly, with many of our participants commenting on support they received from taxi drivers, such as assistance with entering and alighting the taxi, unloading shopping and sometimes carrying it inside and / or waiting outside shops for small errands to be done. Taxi fare reductions were available in all areas, but it was often not clear who was eligible, and how they obtained evidence of eligibility.

Shopping

Obtaining food in the country was frequently more difficult and costly than in the city, where often there was a local corner store that could be readily accessed by patient / carer / family / neighbour. A number of country participants recalled how, the early days post discharge, bread and milk cost around \$15 when taxi fares were taken into account. Where the patient had driven prior to illness, but after being ill could no longer drive, there were immediate concerns for the carer regarding how to get around. Costs were not only financial - where the carer had previously relied on

the patient not only to drive but also to assist with lifting groceries, carers now had to shop more regularly so as to carry less each trip.

Undertaking the physical tasks of shopping was a wider issue than just groceries. Many of our participants reported overwhelming physical constraints when undertaking extended clothing or gift shopping following their illness. If they had managed to organise transport to a shopping centre, they then needed to navigate considerable distances within the centre in order to undertake their tasks. This often required use of mobility aids (frames or scooters), and frequent use of benches for rest periods. Some shopping centres had a limited number of walking aids available for customers, but this required patients and carers to prioritise if they both required assistance with mobility at the one time. Our participants reported curtailing shopping trips because of fatigue, difficulties of access to shops, lack of courtesy of shop assistants, frustration with not finding what they wanted while they were still 'fresh', and lack of availability of benches for resting (a lack of benches, inappropriately located benches, or benches being used by young people as gathering places, while older people felt intimidated in asking them to move).

The role of the general practitioner

For many of our participants, their general medical practitioner was the key person within their health system. In many instances (particularly in the country) the patient and carer had known the doctor for many years. The advantages of this were that the patient's and carer's medical and social histories were well known to the doctor, and there was openness in discussion of 'where to from here'. The disadvantages occurred when the doctor assumed prior knowledge (without a full reassessment of the patient or carer in light of changed health status), thus potentially missing vital clues as to patient and carer ability to maintain their independence in the community. Country patients were more likely to be distressed by changing general medical practitioners than city patients, and city patients were more at ease with seeing multiple doctors. When country doctors left the district (for retirement, or holidays), their patients were often reluctant to commence a new relationship with another doctor for some time. We found extremes of satisfaction with the performance of the general practitioner, from patients not relating at all to their doctor and making health decisions largely uncounselled, to patients being maintained independently in the community mostly because of the strong relationship they had with their doctor. The most successful strategies used by general medical practitioners were telephone calls to recently discharged patients to check on their progress, and regular home visits to patients who found it difficult to get to the surgery. When the general medical practitioner made a home visit, patients and carers appeared to find it easier to discuss difficult issues, such as dealing with pain or grief, worry about managing at home, or worry over the health of a spouse.

We found repeated evidence that perceived inflexibility of appointment scheduling in general medical practitioners' practices often constrained full disclosure by patients of their concerns at any one appointment. Patients frequently reported being bothered by multiple health and / or social issues at the time of any one medical appointment, yet they consciously prioritised their problems so that the general medical practitioner could deal with one or two issues within the scheduled appointment. Issues that were most difficult for patients to discuss, or for their general medical practitioner to deal

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with, were pain, fear and anxiety, loss of confidence or mobility, lack of social supports, carer concerns and grieving for lost health and social role.

We found surprising resistance by our participants to the use of computers in the doctor's consulting room. Our participants told us that they often perceived this as a barrier to good communication with the doctor, and a waste of part of their consultation time, particularly if the doctor was not computer literate. The enhanced primary health care initiative did not feature to a large extent in this study. This was not surprising because care planning is generally undertaken for patients who are recognised as having chronic conditions. Our participants were on the 'cusp of chronicity' and therefore may not have been identified by their general practitioner as yet requiring care planning. We identified several issues as requiring further investigation:

- ◆ Training for general medical practitioners in identifying patients who require care planning (i.e. not just those with chronic conditions), developing appropriate care plans, ensuring the implementation of such plans, and evaluating their outcome
- ◆ The skills and resources required for general medical practitioners to identify patient need, match need with appropriate services, broker services and evaluate service success
- ◆ The funding and incentives required for other health practitioners to participate in case conferencing and care planning

Condition effect

It was the physical ramifications of recent illness that frequently constrained patients and their carers post discharge, not the nature of the illness. Preparation for discharge differed marginally with respect to diagnosis, with common issues being medication, community equipment and services, specific education related to changed physical functioning, or dietary needs.

The older person in the community

Our participants identified opportunities that could be addressed at low cost, which would make a large difference to the way elderly, recently ill people operate in the community. These included:

- ◆ Healthy and able bodied older people being encouraged to offer assistance to less healthy older people (home visiting, assistance with household chores, reading the newspaper, writing letters etc)
- ◆ More well placed street lighting and better designed footpaths
- ◆ Longer "walk" lights across busy streets, to allow more time to cross the road when there is traffic
- ◆ More vertical community integration strategies that recognise the worth of older people within the community

Many of our participants keenly felt a change in their social functioning, with many reporting not feeling "useful" any more. Social contacts which they previously valued, such as membership of community groups or sporting clubs often ceased during our study due to illness, pain, depression and / or transport difficulties, and for carers, inability to leave the patient alone. The importance of these contacts cannot be undervalued in maintaining elderly people's sense of belonging within their community, and in maintaining their independence.

Rehabilitation

The use and conceptualisation of the word 'rehabilitation' brings with it the expectation of full recovery from an illness. The use of this word within the context

of our patient group, and with the current variability of available services, seems to require revision. There are now few opportunities whilst patients are in hospital to address the issue of likely recovery from an illness, or how much recovery to expect. The length of stay in hospital is mostly too short to allow sufficient time for patients' health status to stabilise, for them to reach an acceptance of their changed state, or for staff to find the right opportunity to address with patients and their carers the issue of transition from being previously well to being permanently impaired. If hospital staff are not in a position to undertake counselling to address this need, then there is little opportunity for community health personnel to undertake this task. We found that delivery for community services such as allied health or nursing was too patchy, and too variable in timeliness, to be responsible for counselling. While general medical practitioners are probably the most consistent service providers, they indicated repeatedly in this study that they often feel inadequate to address patients' emotional, nursing, rehabilitation and social needs.

Solutions

Support groups

We identified a need for support groups for patients who have been recently discharged from hospital, and their carers. At present, these individuals are not catered for by the available support groups, which are generally for people with recognised specific chronic conditions. Support groups for recently discharged people could be arranged by the acute hospital, and operated at little cost as an outpatient service. They could be convened by a single staff member and information about the availability of such support groups could be provided to all patients prior to discharge. The support groups would provide a forum for patients and carers to express their concerns, learn from each other, reduce feelings of isolation and obtain information about service availability and access. These groups could provide 'breathing space' for patients and carers to come to terms with changed status, as they would recognise the temporary dependency of patients who are in transition from health states of previously well to impaired.

Checklist for going home

The success of immediate transition from hospital to the community lies in what happens in the first two to three days post discharge. This reflects the practical issues of leaving hospital and returning to the community. We propose the use of a checklist whilst the patient is still in hospital to flag practical and potential constraints for safe return to the community. We provide a draft checklist in this report, describing issues such as home access, lighting and heating, food, home comforts such as clean sheets and a clean environment, care of pets, sufficient medications, and alerting the appropriate people to the patients' changed health and social circumstances. This checklist addresses practical and common issues described by many of our participants as essential for them to feel in control, and safe, in the first few days post discharge. It is of interest that few of these issues reflected the actual supply of community services.

Assistance with going home

We highlight in this report the importance to our participants of kindly assistance and support during the immediate transition from hospital to community. This does not have to be provided by a trained health professional. A risk assessment tool could be implemented by hospital staff to identify people who are likely to have problems on transition from hospital to home, and then be used to pair the patient with a 'friend' (an appropriately trained and resourced volunteer) who could smooth the transition to living back in the community. Some of our participants craved a 'friend' who could ring or drop in regularly to see how things were going, and who could offer advice about who the patient and carer may contact for further assistance. For a few days post discharge some of our participants received this support from their general

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medical practitioner, or from the hospital discharge liaison officer, but most were on their own once they had left hospital. Almost all patients were left to cope by themselves after the first week, yet many required assistance for up to six months post discharge. Hospitals could recruit, train and support a group of volunteers to assist elderly patients, and their carers, who require help to return home by addressing aspects outlined in the checklist.

In summary

This project provided us with rich and rare opportunities to identify, conceptualise and discuss key issues for elderly people, that constrain not only their successful transition from hospital to community following an illness, but also their ability to adapt to changed health and social functioning as a result of their illness. We have attempted to present this information in a way that will assist all those involved with conceptualising, providing and / or monitoring the outcome of health services for aged people to improve the quality of their work, with the ultimate aim of improving the quality of life in recently ill, elderly people.

We found that recently ill, elderly patients and their carers are capable of identifying their needs, and ways in which these needs can be met in the short and long term. We also contend that once patients and their carers are re-established safely in the community, and are dealing with their changed health circumstances, they are generally able to coordinate support and health services for themselves

We believe that the current services offered to patients and their carers post discharge are inadequate in addressing both short and long term needs because they are not patient driven. Professional health services offered in the community are constrained by workforce and cost issues, and thus patients and their carers are forced into service substitution as soon as they are discharged from hospital.

We propose several practical ways in which patients' needs can be identified and met in the first few days following discharge. We contend that if recently ill, elderly patients and their carers are supported in a personalised way to return to the community, their chances of managing independently are increased.

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Executive Summary for policy makers

This report outlines the methods and findings of a longitudinal study that followed a group of elderly patients, and their carers, for six months following the patients' discharge from an acute hospital. The Strategic Policy and Planning Division of SA Department of Human Services, and the SA Office for the Ageing jointly funded this study. This report continues to support many of the previous findings of reports centred around older patients in their community and their carers, addresses why this is so, and offers some solutions for these issues.

Our overall aim was to describe and analyse community supports used by elderly patients and their carers following discharge from the acute hospital setting. The focus was to identify strategies and services that were most useful, flexible and sensitive to change, which could be implemented in a timely and cost effective manner, and would empower patients and their carers to make decisions that supported independent and successful return to the community after hospitalisation.

This report collates several different aspects of our research.

- ◆ We undertook a critical appraisal of the research literature regarding discharge planning and community supports for recently ill, elderly people.

- ◆ Extensive pre-project interviews were conducted with prominent systems personnel in Government and non-Government organisations, and representative service providers.
- ◆ Longitudinal information was sought on how elderly patients coped after hospitalisation following a significant change in health status. This was done using quantitative analysis of results obtained from the PREPARED instrument immediately after discharge, and SF-36 and SF-12 questionnaires over six months post discharge. In depth semi-structured interviews were also done to explore our subjects' experiences and concerns
- ◆ The report concludes with discussion of a range of issues identified in the results sections, and recommendations for practical strategies that could be implemented in hospitals and communities to address the issues pertinent to elderly people who are coping with significant changes to health and community status.

Key findings

Many of our findings support issues previously identified as being important to older people in publications such as 'Moving Ahead – A Strategic Plan for Human Services for Older People in South Australia' (Department of Human Services). We reiterate the findings important to our study population – older people recently discharged from hospital to the community – and suggest some appropriate ways in which these issues may be addressed. Many of the recommendations in this report do not only involve health policy makers, but also address issues pertinent to transport policy makers, local communities and commercial enterprises such as shopping centres. This supports the view that health care is not a single individual entity, but rather influences, and is influenced by, many other sectors and service providers.

Carers

We found that the role of the carer was frequently unrecognised by members of the health system until major problems occurred that necessitated emergency action, often at high cost (such as hospital re-admission for the patient, or carer illness).

Systems issues

Despite our expectation that country areas would have less complex and more transparent organisation of their health system than the city, there were few differences in the health systems in our four study communities. We found that similar dominant constraints on systems operated in all sites, such as service funding complexities, limited service flexibility due to hours of operation and availability of personnel appropriately trained in the area of discharge planning, communication issues, service rationalisation, and changes in available services that were not well communicated to people within or outside the health system.

Although professionals, policy makers and administrators have a clear overall understanding of the health and community services structures, they have limited knowledge of the effect of the services on the consumers. We found elderly patients and their carers were in a better position to identify particular gaps and deficiencies in the systems, and often had valuable advice regarding how these failures could be addressed. Many of the inadequacies in services may not have occurred had patients

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and carers been involved in their conceptualisation, planning, organisation and evaluation.

Metropolitan versus country patient and carer attributes

Word of mouth, letterbox drops and local knowledge assisted many of our country patients to find gardeners, house-cleaners and personal assistants within four to six weeks of returning from hospital. Information for services was less available by this route in the city and many of our city patients were without organised home support services up to four months post discharge.

Costs of being ill were far greater for country patients than city patients. Travelling to the city for medical consultation was an immense burden for many country patients, both in financial and physical terms. The costs of purchasing, installing and using equipment in the country was generally greater than in the city.

Transport

Accessing public transport was a major concern for both city and country patients. For our study population access to these services required considerable education and negotiation. Whilst the cost of buses was seen to be affordable, patients and carers identified inconvenience of routes, poor timetabling causing long waiting periods for a return bus, difficulty of physically accessing the bus, and lack of driver concern with user safety. Taxis, whilst being more expensive, were seen to be more flexible and user friendly. Taxi fare reductions were available, but information regarding eligibility was often unclear.

Issues regarding transport for elderly people are well known to policy makers. Extensive work has been done between Health and Transport service departments to improve transport for older people, and this study highlights once again the important of such work in improving the quality of life for elderly people recently discharged from hospital and their carers.

Shopping

Local councils and community providers have traditionally been very successful in negotiating with retail providers regarding planning and service provision to help elderly people with shopping. However our study identified that in all study populations there still existed issues for older people regarding shopping centre design and access.

Obtaining food in the country was frequently more difficult and costly than in the city, where often there was a local corner store that could be readily accessed. A number of country participants recalled how, the early days post discharge, bread and milk cost around \$15 when taxi fares were taken into account. Costs were not only financial - where the carer had previously relied on the patient not only to drive but also to assist with lifting groceries, carers now had to shop more regularly so as to carry less each trip.

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Many of our participants reported overwhelming physical constraints when undertaking extended clothing or gift shopping following their illness. Such shopping often required use of mobility aids (frames or scooters), and frequent use of benches for rest periods. Some shopping centres had a limited number of walking aids available for customers, but this required patients and carers to prioritise if they both required assistance with mobility at the one time. Our participants reported curtailing shopping trips because of fatigue, difficulties of access to shops, lack of courtesy of shop assistants, frustration with not finding what they wanted while they were still 'fresh', and lack of availability of benches for resting.

The role of the general practitioner

For many of our participants, their general medical practitioner was the key person within their health system.

We found repeated evidence that perceived inflexibility of appointment scheduling in general medical practitioners' practices often constrained full disclosure by patients of their concerns at any one appointment. Patients frequently reported being bothered by multiple health and / or social issues at the time of any one medical appointment, yet they consciously prioritised their problems so that the general medical practitioner could deal with one or two issues within the scheduled appointment.

The enhanced primary health care initiative did not feature to a large extent in this study. This was not surprising because care planning is generally undertaken for patients who are recognised as having chronic conditions. Our participants were on the 'cusp of chronicity' and therefore may not have been identified by their general practitioner as yet requiring care planning. We identified several issues as requiring further investigation:

- ◆ Training for general medical practitioners in identifying patients who require care planning, developing appropriate care plans, ensuring the implementation of such plans, and evaluating their outcome
- ◆ The skills and resources required for general medical practitioners to identify patient need, match need with appropriate services, broker services and evaluate service success
- ◆ The funding and incentives required for other health practitioners to participate in case conferencing and care planning

The older person in the community

Our participants identified opportunities that could be addressed at low cost, which would make a large difference to the way elderly, recently ill people function in the community. Again, these are issues which, to be adequately addressed, will largely involve cooperation with transport and local council providers. They include:

- ◆ Healthy and able bodied older people being encouraged to offer assistance to less healthy older people (home visiting, assistance with household chores, reading the newspaper, writing letters etc)
- ◆ More well placed street lighting and better designed footpaths
- ◆ Longer "walk" lights across busy streets, to allow more time to cross the road when there is traffic
- ◆ More vertical community integration strategies that recognise the worth of older people within the community

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Rehabilitation

The length of stay in hospital is mostly too short to allow sufficient time for patients' health status to stabilise, for them to reach an acceptance of their changed state, or for staff to find the right opportunity to address with patients and their carers the issue of transition from being previously well to being permanently impaired. We found that delivery for community services such as allied health or nursing was too patchy, and too variable in timeliness, to be responsible for counselling once the patient had returned to the community. While general medical practitioners are probably the most consistent service providers, they indicated repeatedly in this study that they often feel inadequate to address patients' emotional, nursing, rehabilitation and social needs.

Solutions

One of our main findings from the study was that elderly people are very capable of identifying their own needs and the ways in which these needs can be met. Involvement of elderly people in future policy development would be especially valuable in identifying existing gaps in service provision, and suggesting ways in which these deficiencies could be addressed. The following are suggestions derived from our interviews with older people that could help address some of the areas identified in the Moving Ahead Strategic Plan for older people, particularly in the directions of access to information and support, addressing specific service gaps, developing entry processes to link acute care and community support systems, and integrating acute care with pre and post acute services.

Support groups

Support groups could help improve elderly patient's, and their carer's access to information and support. They could be arranged by the acute hospital, and operated at little cost as an outpatient service. The support groups would provide a forum for patients and carers to express their concerns, learn from each other, reduce feelings of isolation and obtain information about service availability and access.

Checklist for going home

This, in combination with the next solution, could help integrate acute care with post acute services. We propose the use of a checklist whilst the patient is still in hospital to flag practical and potential constraints for safe return to the community. We provide a draft checklist in this report that addresses practical and common issues described by many of our participants as essential for them to feel in control, and safe, in the first few days post discharge. It is of interest that few of these issues reflected the actual supply of community services.

Assistance with going home

A risk assessment tool could be implemented by hospital staff to identify people who are likely to have problems on transition from hospital to home, and then be used to pair the patient with a 'friend' (an appropriately trained and resourced volunteer) who could smooth the transition to living back in the community.

Executive Summary for clinicians

This report outlines the methods and findings of a longitudinal study that followed a group of elderly patients, and their carers, for six months following the patients' discharge from an acute hospital. The Strategic Policy and Planning Division of SA

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Department of Human Services, and the SA Office for the Ageing jointly funded this study.

Our overall aim was to describe and analyse community supports used by elderly patients and their carers following discharge from the acute hospital setting. The focus was to identify strategies and services that were most useful, flexible and sensitive to change, which could be implemented in a timely and cost effective manner, and would empower patients and their carers to make decisions that supported independent and successful return to the community after hospitalisation.

This report collates several different aspects of our research.

- ◆ We undertook a critical appraisal of the research literature regarding discharge planning and community supports for recently ill, elderly people.
- ◆ Extensive pre-project interviews were conducted with prominent systems personnel in Government and non-Government organisations, and representative service providers.
- ◆ Longitudinal information was sought on how elderly patients coped after hospitalisation following a significant change in health status. This was done using quantitative analysis of results obtained from the PREPARED instrument immediately after discharge, and SF-36 and SF-12 questionnaires over six months post discharge. In depth semi-structured interviews were also done to explore our subjects' experiences and concerns
- ◆ The report concludes with discussion of a range of issues identified in the results sections, and recommendations for practical strategies that could be implemented in hospitals and communities to address the issues pertinent to elderly people who are coping with significant changes to health and community status.

Key findings

Carers

The need to consider carer health was highlighted by the length of time over which many of our patients required active caring (many for five to six months post discharge) and by the diminishing mental health status of many of our carers as time went on. Deeming the patient to have a 'carer' may not actually indicate that they have a useful support mechanism. In many instances the presence of a carer post discharge produced more stress for both the patient and carer, than was experienced by patients managing alone.

We found that the role of the carer was frequently unrecognised by members of the health system until major problems occurred that necessitated emergency action, often at high cost (such as hospital re-admission for the patient, or carer illness).

Systems issues

In the country we encountered instances where personality issues impacted on the provision of appropriate services. For example, hospital staff had often known the patient and / or carer for years and frequently did not seem to take the time to talk with them about their actual or changed needs for service. Services were thus provided (or not) on historical perception of need. We also found several instances

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where patients or carers were perceived to be 'difficult' and services were not offered appropriately. We found that in the country (more than the city) health providers frequently knew about the patient's family and social support network and thus assumed that children or friends 'ought to' provide care for elderly patients, based on local knowledge rather than a professional assessment of their ability and willingness to undertake this role.

Metropolitan versus country patient and carer attributes

On the whole, country patients and carers were more resilient and adaptable than metropolitan patients and carers. They seemed more adept at drawing on existing networks and adapting old methods of doing things to deal with changed health circumstances.

The role of the general practitioner

For many of our participants, their general medical practitioner was the key person within their health system. In many instances (particularly in the country) the patient and carer had known the doctor for many years. The advantages of this were that the patient's and carer's medical and social histories were well known to the doctor, and there was openness in discussion of 'where to from here'. The disadvantages occurred when the doctor assumed prior knowledge (without a full reassessment of the patient or carer in light of changed health status), thus potentially missing vital clues as to patient and carer ability to maintain their independence in the community. Country patients were more likely to be distressed by changing general medical practitioners than city patients, and city patients were more at ease with seeing multiple doctors. When country doctors left the district (for retirement, or holidays), their patients were often reluctant to commence a new relationship with another doctor for some time. We found extremes of satisfaction with the performance of the general practitioner, from patients not relating at all to their doctor and making health decisions largely uncounselled, to patients being maintained independently in the community mostly because of the strong relationship they had with their doctor. The most successful strategies used by general medical practitioners were telephone calls to recently discharged patients to check on their progress, and regular home visits to patients who found it difficult to get to the surgery. When the general medical practitioner made a home visit, patients and carers appeared to find it easier to discuss difficult issues, such as dealing with pain or grief, worry about managing at home or concern over the health of a spouse.

We found repeated evidence that perceived inflexibility of appointment scheduling in general medical practitioners' practices often constrained full disclosure by patients of their concerns at any one appointment. Patients frequently reported being bothered by multiple health and / or social issues at the time of any one medical appointment, yet they consciously prioritised their problems so that the general medical practitioner could deal with one or two issues within the scheduled appointment. Issues that were most difficult for patients to discuss, or for their general medical practitioner to deal with, were pain, fear and anxiety, loss of confidence or mobility, lack of social supports, carer concerns and grieving for lost health and social roles.

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We found surprising resistance by our participants to the use of computers in the doctor's consulting room. Our participants told us that they often perceived this as a barrier to good communication with the doctor, and a waste of part of their consultation time, particularly if the doctor was not computer literate.

We identified several issues as requiring further investigation:

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Condition effect

It was the physical ramifications of the recent illness that frequently constrained patients and their carers post discharge, not the nature of the illness. Preparation for discharge differed marginally with respect to diagnosis, with common issues being medication, community equipment and services, specific education related to changed physical functioning, or dietary requirements.

Rehabilitation

We found delivery for community services such as allied health or nursing was too patchy, and too variable in timeliness, to be responsible for counselling. While general medical practitioners are probably the most consistent service providers, they indicated repeatedly in this study that they often feel inadequate to address patients' emotional, nursing, rehabilitation and social needs.

Solutions

Support groups

Support groups for recently discharged people could be arranged by the acute hospital, and operated at little cost as an outpatient service. The support groups would provide a forum for patients and carers to express their concerns, learn from each other, reduce feelings of isolation and obtain information about service availability and access.

Checklist for going home

We propose the use of a checklist whilst the patient is still in hospital to flag practical and potential constraints for safe return to the community. We provide a draft checklist in this report that addresses practical and common issues described by many of our participants as essential for them to feel in control, and safe, in the first few days post discharge. It is of interest that few of these issues reflected the actual supply of community services.

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