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# Incorporating Patient and Carer Concerns in Discharge Plans: The Development of a Practical Patient-Centred Checklist

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### Abstract

Discharge plans should include prompts for patients and their families to identify key concerns regarding their ability to undertake practical activities of daily living post-discharge. During a six month series of post-discharge interviews, elderly recently ill patients and their carers identified concerns about managing on leaving the hospital, encompassing transport home from hospital, gaining entry to their home, having appropriate food and effective heating or cooling available immediately post-discharge, obtaining assistance in managing their home and family responsibilities, navigating around their house, accessing their General Medical Practitioner, going shopping, paying bills and regaining social contacts. Few of these concerns were addressed in formal discharge plans made by hospital staff for patients in our study. This paper outlines the development of a patient-centred checklist generated from patient and carer concerns related to being prepared for discharge.

### Background

Discharge planning has been defined as the systematic identification and organisation of services and supports to assist patients to manage in the community post-discharge.<sup>1,2</sup> Under this definition, hospital staff who are involved in discharging patients (nurses, medical, and allied health staff) understand and interpret patient and carer needs from patients' and carers' perspectives, within the constraints of local post-discharge service organisation and availability. This definition also assumes that these hospital staffs appreciate patients' home environments and social supports, as well as patients' ability to recuperate once they have left hospital; and that they can match actual patient need with organisation of available and appropriate community supports. The importance of involving patients and their families in planning for discharge from hospital is documented in recent systematic reviews; however, there are few published mechanisms by which this could consistently occur within the hospital setting.<sup>3-5</sup>

The literature is sparse on processes by which hospital staffs involved in planning for discharge can efficiently and accurately identify genuine patient need in a manner that takes account of patients' usual living arrangements. It is also sparse on how hospital staff can encompass this information into appropriate and realistic discharge plans. High quality discharge planning activities should be timely, proactive and patient centred, and they should address key factors that could compromise patients' health and safety post-discharge.<sup>1-5</sup> However decreasing lengths of stay in hospital for older patients generally constrain discharge planning to arranging referrals to formal community services and contacting patients' general medical practitioners (GPs).<sup>1,2,6-8</sup>

This paper outlines the development of a patient-centric tool that could increase the engagement of patients and their families in planning for their discharge from the hospital.

## Method

*Ethics approval:* Ethics approval was obtained from the Human Research Ethics Committees of the researchers' universities and the participating hospitals. Before discharge from hospital, or at the first post-discharge contact, subjects provided written informed consent to participate, and verbally reconfirmed this consent at each subsequent contact.

*Design:* A longitudinal observational study collected qualitative and quantitative data from patients and their primary carers. The first contact was one week following discharge from hospital, followed by monthly post-discharge contacts for six months. These follow-up intervals allowed charting and comparison of patients' and carers' experiences over time regarding recovery from illness, or caring for an ill person. Current systematic reviews of discharge planning literature describe the most common follow-up period to evaluate the effectiveness of discharge planning initiatives as one to two weeks.<sup>1-5,6-8</sup> These reviews also highlight how little is known about the effectiveness on longer-term recuperation of discharge plans made whilst the patient was hospitalised. We recently published the quantitative and qualitative data from this study describing the six-month post-discharge period from patient and carer perspectives which provides rare insights into the dilemmas faced by carers, and by patients whose health status has changed irrevocably as a result of illness.<sup>9,10</sup>

*Subjects:* Between February and July 2000, eligible patients were recruited for this study from the medical wards of four hospitals (one large metropolitan, three medium sized regional centres (all situated within three – five hours drive of a capital city)). Eligible patients were over 60 years of age, English-literate, and had been admitted to hospital for the first event of a medical condition which could challenge their ability to live independently (for instance heart disorders, strokes, falls etc). Patients with co-morbidities of depression and anxiety were eligible to participate, however patients with dementia, or primary or secondary diagnoses of malignancy were excluded. There were no other specified diagnostic criteria. Potential participants were approached whilst in hospital until a sample size of 100 patient respondents had been accumulated. This number was chosen on pragmatic grounds to reflect the range and distribution of common post-discharge experiences.

*Data collection:* This paper reports on aspects of the qualitative data collected from patients within a grounded theory paradigm using semi-structured interviews. A concept or question was introduced by one interviewer (JF) (who undertook all interviews), and patients expanded upon it, if it was relevant to their circumstances. There was minimal prompting by the interviewer, whose purpose was mainly to focus and progress the interview.<sup>11</sup>

*Data management and analysis:* Transcripts of all interviews were independently analysed by two researchers for emergent and continuing key themes, and their frequency of occurrence. Patient-specific examples relative to key themes were identified, for use as illustrations of core issues. Key themes were collated at each of the interview time frames, allowing identification of continuity or change in key themes at each time period of the study.

This paper reports on a synthesis of patient reflections in the first month after discharge, regarding practical issues of daily living which concerned them on their immediate return to the community. Patients perceived that had they been alerted to these issues whilst in hospital, immediate post-discharge experiences might have been improved.

## Results

*Subjects:* 107 eligible patients were approached to participate, with 100 patients consenting to do so. Over the study period, five patients died and six withdrew, with reasons for withdrawal being respondent burden (2), moving to residential care (1), and new illness (3). The average age of participating patients was 74.2 years (SD 7.1; age range 61 to 91 years). Patients presented with a range of primary diagnoses such as failing balance mechanisms, stroke, heart, digestive and respiratory conditions, inflammatory and degenerative joint conditions. In all instances the index hospital admission had been unplanned, thus ruling out opportunities for pre-admission consideration of patients' post-discharge needs.

Patients were almost universally appreciative of the efforts that hospital staff had made on their behalf, and usually recognised the workload constraints under which staff operated. Nevertheless, as consumers, many were able to take a constructively critical stance, identifying ways in which they could have worked better with hospital staff to consider issues that were important to them, and which would impact on their safe and sustainable return to the community.

*Timing of need and service provision:* The first two weeks post-discharge have been highlighted in our work and others' as the time of greatest concern for many patients and their families.<sup>1-5,7-10</sup> This seems to be the time period when patients are at their most vulnerable, learning new skills, and adapting to significant physical and emotional changes. Less than 20% of patients in our study were provided with formal health and support services during the first two weeks after discharge, with the median waiting period for organised services being eight working days (25% percentile 4.5).<sup>9</sup> Thus, it seemed that patients were left with little alternative but to develop their own strategies in the first few days out of hospital, when they were most vulnerable in health status and in confidence.

This paper provides a summary of patient concerns relevant to the construction of a patient-centric checklist that identifies key issues relevant to patients regarding their safe discharge plans. Supporting statements (extracts) from patient quotations relevant to the key themes synthesised in this paper are reported in earlier publications from this study.<sup>9, 10</sup>

**Reflections on discharge plans:** Patient reflections on what they understood of the plans that had been made for them in hospital suggested that few discharge plans took account of their usual routines or their concerns, or considered practical ways to ease transition from illness to wellness. Few patients reported being involved in making discharge plans, and most discharge plans appeared to focus on the organisation of formal health and support services to assist with hygiene, wound and medication management, meal provision and home modifications. Moreover, few patients reported having been given information in hospital which could assist them in the practicalities of coping at home in the early post-discharge period, or to support them to take control in this difficult time. Patients reflected that whilst they were in hospital, few formal opportunities were made by hospital staff for discussions about how patients perceived that they would manage at home, or what concerns they had. Thus, for many patients and carers, the practical realities of daily living after hospitalisation only seemed to occur to them once they had left the safety of the hospital bed.

**Formal service provision:** Patient ownership of the hospital discharge process appeared to be minimal. It seemed to many patients that staff involved in discharge planning almost universally used measures of patient performance that did not reflect their real life needs, basing discharge plans on their own perceptions of patient need rather than on information from patients themselves (or carers) about actual needs and concerns. It thus seemed to a number of our patients that discharge plans often had the outcome of engendering dependence on external, formal service providers, rather than assisting patients to develop specific coping strategies that could be exercised in the absence of formal service provision.

### ***Realities of returning to the community***

A range of issues was identified by patients after discharge that they believed had constrained their safe and confident return to the independence in the community.

*Safe transport from hospital to home* was often overlooked by hospital staff and patients. For instance the realities of independent mobility after alighting without assistance from a taxi (or public transport) at the front gate, were a revelation to many patients, particularly if they were not in possession of the house keys. *Unpaid bills* whilst in

hospital meant that some patients living alone returned to homes where the electricity or water had been disconnected. Having access to *ready cash* to pay for pharmaceuticals or home deliveries in the first few days home was overlooked by a large number of our patients, and over 75% of our patients reported surprise at *significantly reduced post-discharge mobility*. A common patient response was the increased energy required to move around their house in the immediate post-discharge period. Whilst in hospital many patients had been given aids (walking frames, wheelchair, stick etc) with the aim of assisting their post-discharge mobility. A number of patients found that this actually decreased their mobility because of incompatibility with carpets, stairs or narrow passageways. This highlighted differences between perceived patient need (by hospital staff, in the absence of patient input) and the reality of living independently living within the context of the home environment.

Difficulties with *obtaining and preparing food* were commonly raised in our interviews in the first month after discharge. Patients whose capacity to drive a car had been constrained post-discharge by their illness, found that they needed to organise food to be delivered to their home, or to rely on others to obtain it for them. Patients who had previously regularly caught public transport to shop found that reduced mobility and/or energy levels constrained their independence as well as the amount of shopping they could carry.

Effective management of *short-term home responsibilities* appeared integral to patients' confidence in remaining in their own home. This included caring for other people, pets and the home/ garden. A number of our patients had to resume usual 'caring' activities for an ill spouse or child on the day of discharge (for instance caring for a disabled adult dependent at home, or looking after grandchildren on a regular basis). For several patients, caring for pets presented a dilemma, as whilst they relied on their pet for companionship, providing the pet with adequate care was beyond their physical capabilities (for instance, taking the dog for a walk). In several instances patients made decisions in the immediate post-discharge period about giving away their pets because they perceived that they could not care for them, and yet regretted the decision later when they were in better health. The emotional loss of separating from a pet under these circumstances was enough for patients to seriously consider permanent residential care.

Accessing *medical care* in the immediate post-discharge period posed problems for many patients, particularly when their GP or pharmacist did not make house calls. Patients thus needed to rely on others for transport, with some reporting going without medication for some days until they could arrange for someone to collect it from their

pharmacist.

*Collated concerns:* This study provided a rare opportunity to improve cohesion between hospital staff discharge planning activities and patients' own efforts to prepare for their transition from illness to independent living in the community. Joint discharge planning involving hospital staff, patients and families could be enhanced by a process

which recognised and addressed patient need whilst in hospital, and which provided a platform for discussion of patient concerns about returning to the community. To this end, we synthesised key themes of the practical elements of returning home that patients believed they should (could) have considered whilst in hospital that might have improved their transition from illness to wellness (see Table 1).

**Table 1.** Common patient concerns

<b>Immediate post-discharge concerns</b>	<b>Longer term post-discharge concerns</b>
<ul style="list-style-type: none"> <li>➤ How would they travel home?</li> <li>➤ Could they get into their house readily (physical access via stairs, keys etc)?</li> <li>➤ Was fresh food available?</li> <li>➤ Would they be able to prepare and eat food?</li> <li>➤ Was the house clean?</li> <li>➤ Who knew that they had been in hospital, and/ or that they were coming home?</li> <li>➤ How would they manage with sleeping, and moving around the house at night?</li> <li>➤ Would they be able to get to and from the toilet easily?</li> <li>➤ Who had been caring for their pets, and could they manage to care for them?</li> <li>➤ Were there any bills that needed to be paid? Were all utilities still connected?</li> <li>➤ Did they have enough medication?</li> <li>➤ Did they understand enough about them?</li> <li>➤ Was their doctor aware of their admission to hospital?</li> </ul>	<ul style="list-style-type: none"> <li>➤ How would they shop?</li> <li>➤ Who could help them to pay bills?</li> <li>➤ How would they travel to medical appointments?</li> <li>➤ Who could assist them to manage their house and garden chores?</li> <li>➤ How long would they be feeling unwell?</li> <li>➤ Should they consider nursing home placement?</li> <li>➤ Should they worry about their health?</li> </ul>

*Constructing a patient-centred checklist:* From the themes presented in Table 1, we drafted a Discharge Planning Checklist that could be used by patients and their families whilst in hospital, as a prompt for assisting them to make plans for their own discharge. For instance, if patients had not considered how they would travel home from hospital, being alerted to this could prompt organisation of safe transport home prior to discharge, leaving no opportunity for misadventure. Being alerted to the need to obtain food in the immediate discharge period could provide the opportunity for a family member or friend to organise food in the house prior to discharge, or to arrange home deliveries. Availability of ready cash could be organised prior to discharge so that the patient could leave the hospital equipped with sufficient money for the immediate post-discharge period. Recognition of the importance of contacting the patient's GP and pharmacist for post-discharge attention could result in pre-discharge contact by hospital staff or family or friends (on behalf of the patient), ensuring a smooth transition from hospital care to

community health care.

By overtly involving the patient and family in recognising post-discharge needs, health and support services organised by hospital staff to deal with hygiene, wound, medication and meal management could occur in conjunction with solutions arrived at by patients and their families (with advice, as required, from hospital staff) to address the practical environment-specific immediate issues of returning to the community. Patient ownership of discharge plans would increase, assisting patients to be better adjusted for the transition from hospital care to independent community living.

Early versions of the draft checklist were circulated to the participating patients in this study for comment and revision, resulting in a number of subsequent modifications to wording, checklist layout and organisation. The final version of the Discharge Planning Checklist is provided in Figure 1.

**Figure 1:** Proposed discharge planning checklist (printed in A5 brochure format)**DISCHARGE PLANNING CHECKLIST FOR PATIENT & CARER**

This checklist is to prompt you (patient) and your carer, family and friends to consider a range of practical aspects about your return home after being in hospital. It is very important that, in the time you are in hospital, you consider and discuss each of the elements on this list to make sure that you are prepared for discharge. Hospital staff can advise you if you are not sure about anything, and can help you make plans. The items on this list have been identified by other patients like you, as things that worried them after they had been discharged from hospital, and that they wished had been brought to their attention before discharge. Being safe and confident after leaving hospital will happen if you consider the practical aspects of managing at home when you are not feeling the best. This checklist will get you started. Not all the concerns on this checklist may be relevant to you, and there may be other things that we have not mentioned that are important. Please write these down and sort them out before going home. Remember, if there are any issues that worry you about going home, make sure that you have worked out a solution with hospital staff before you leave hospital! Don't leave the problems to sort themselves out!

HOME CONSIDERATIONS	If this is a problem, how can it be solved?
1. Do you, or your family, have the keys to your home?	
2. Does your home need to be cleaned before you get out of hospital?	
If Yes, who can do this for you?	
3. Are there fresh groceries at home in preparation for discharge (e.g.	
.fresh bread, milk, fruit, meat and vegetables)?	
If No, is there anyone who can organise these for you?	
4. Do you feel confident about preparing and eating food when you	
go home?	
5. Pets? What arrangements have been made for your pets while you	
are in hospital, and after you go home?	
Are you worried about managing your pets when you go home?	
6. Do you think you can manage the house and garden after	
discharge?	
If No, what jobs are urgent?	
Do you know of anyone who can assist you?	
If No, do you know who to contact for assistance?	
7. Do you have adequate heating/cooling immediately you get home?	
Do you need to pay any urgent electricity, gas or telephone bills in	
the first few days after going home?	
8. Who might help you to do this?	
9. Is there anyone who can give you a phone call every day for the	
first few weeks that you are home?	
10. Do you have adequate lighting in your house, particularly over	
steps, in the bathroom and toilet?	
If No, can you organise short term solutions?	
11. Do family/friends need to be contacted to advise them that you are	
going home?	
If Yes, who will do this?	
12. Does anything worry you about going home or managing once you	
are at home?	
13. Would you like to take home a brochure or information about	
personal alarms, or other services?	
14. How will you get home from hospital?	
15. Do you have sufficient money for the first few days out of	
hospital?	
If No, can you arrange to have money available?	

### SERVICES

16. Were you receiving community health or support services before you were admitted to hospital?  
Do these services know you are in hospital?  
Do these services know the date when you will be discharged?  
Are you expecting these services to be available for you as soon as you are discharged?  
Do you know if new community health or support services have been arranged for you?
17. Do you have their details so you can follow them up?

### CARERS

18. Do you have a carer (someone who can assist you with aspects of daily living after you leave hospital)?  
If No, do you need assistance at home?  
If Yes, see next two questions.  
Have you discussed with this person what they might need to do for you, and how often this will happen?  
Are you and your carer confident that you can both manage every day?  
If No, you will both need to discuss this with hospital staff and work out a solution.
19. Do you regularly care for someone else (an ill spouse, child, friend, neighbour or grandchild)?  
What arrangements have been made whilst you are in hospital for this person?  
What arrangements need to be made to assist you both when you go home?

### GENERAL MEDICAL PRACTITIONER

20. Do you have a regular GP?  
Do you see more than one GP?  
Which GP needs to be told about your stay in hospital?  
Does he/she do home visits?  
Who will let him/her know that you are coming home from hospital?

### MEDICATIONS

21. Do you feel you need more education and/ or assistance with your medication before you leave hospital?
22. Do you understand about how any new medications work in the presence of the ones you were taking previously?
23. Are you taking any herbal / naturopathic remedies?  
If Yes, make sure you tell hospital staff about these as some can react with your medications.
22. Do you have enough medication to last for the first few days after discharge?  
If No, how will you obtain your medications?  
Within the next few days, you will need to plan a GP visit (for prescriptions) and transport to a Pharmacy to have the script filled – how will you do this?

EQUIPMENT	
23.	<p>Do you feel you need any equipment to help you manage in your house? (i.e. walking frame, stick, rails etc)</p> <p>If you already have equipment, do you think you will still use it?</p> <p>If you have been given equipment whilst in hospital, are you confident that you can use it properly at home?</p>
DRIVING/TRANSPORT	
24.	<p>Do you drive a car?</p> <p>If Yes, have you discussed with staff whether you are still well enough to do this?</p> <p>Make sure that you ask hospital staff before you leave, when you might expect to return to driving.</p> <p>If you are unable to drive, what alternatives are available to you for transport?</p> <p>How many times do you currently go out to shop, etc, each week?</p> <p>Do you think this will change if you can no longer use a car?</p>
THINGS TO DO BEFORE YOU GO HOME	
25.	<p>Speak to at least one hospital staff member about how long it might be before you will be feeling better and can expect to resume usual activities.</p> <p>If your physical abilities have changed as a result of your illness, make sure you understand what you can and cannot do when you go home. Ask questions!!!!</p> <p>Discuss how you will cope if you feel anxious, lonely, or blue.</p> <p>Ask staff questions about what has happened to you, and what changes you can expect in your health and daily activities once you return home. Make sure that your carer is confident about helping you at home, before you leave hospital.</p>

### Conclusion

The immediate post-discharge concerns outlined by patients in our research have been reported by others as has the importance of involving patients in planning for discharge.<sup>1,3,5,7,8</sup> However no standard approach has been proposed in the literature by which patient involvement in discharge plans can be sought in order to identify and address the specific issues that may confront them post-discharge. Anyone who has returned home after a period of absence will identify with the need for ready entry to the dwelling, heating and power to run household appliances, clean living environment and bed linen, availability of adequate food and payment of pressing bills. Thus the checklist we outline in this paper is no more than any long-distance traveler might identify as essential for transition from one abode to another.

The items on the checklist highlight the potential gap between formal health services provided post-discharge and genuine patient need, particularly relevant in the immediate post-discharge period. We contend that, for many elderly patients, the effectiveness of health and support services provided post-discharge could be improved by practical advice provided whilst in hospital, regarding effective methods of solving common problems

that could compromise immediate post-discharge health and safety.

We are currently reporting on our research findings regarding the practical application and effectiveness of the checklist with respect to the quality of discharge planning.

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