

## OLDER PEOPLE

# Exploration of patients' needs for information on arrival at a geriatric and rehabilitation unit

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**Exploration of patients' needs for information on arrival at a geriatric and rehabilitation unit**

**Aim.** The aim of this study was to gather information about patients' needs prior to transferring from an acute care facility to a rehabilitation setting that could assist patients to engage actively in rehabilitation activities upon entering the unit.

**Background.** The provision of information is an important aspect of health care as it assists patients to become informed and actively participate in this care. Improved recovery has been associated with patients' adherence to care regimes. **Method.** Semi-structured interviews were undertaken with a convenient sample of nine patients shortly after admission/transfer to a rehabilitation unit and with four of these patients after discharge. The intent was to learn what information patients receive prior to admission to the rehabilitation unit, whether this information is useful and whether different information would be more useful to facilitate patients' engagement in the activities central to rehabilitation treatment. **Results.** Interviews revealed that, generally, patients received very little information about what to expect on admission to the rehabilitation unit and patients' engagement was more dependent on perceptions about rehabilitation. Thematic analysis identified that, in general, rehabilitation was perceived as 'a ticket out' and 'a good thing'. In relation to provision of information of

participants identified that 'doesn't matter that I don't know'; 'information is not always meaningful' and 'I will adjust in my own time'.

**Relevance to clinical practice.** Health professionals need to recognize that patients are often compliant with decisions made while they are inpatients of the current health care system. Even though patients may 'actively participate' in rehabilitation processes it is often still as a passive recipient of health care.

**Key words:** geriatric, information needs, nursing, patient, rehabilitation, transfer

## Introduction

The provision of information is an important aspect of health care as it assists patients to become informed and actively participate in their care (Entwistle *et al.* 1998). Improved recovery has been associated with patients' adherence to care regimes (Wiles *et al.* 1998).

Unfortunately, research indicates that overall information given to patients is poor; as inpatients (Rodgers *et al.* 2001), and also on discharge from hospital (Clare & Hofmeyer 1998, Henderson & Zernike 2001, Atwal 2002). Audit findings suggest that, for the majority of patients, their needs are not discussed prior to discharge (McBride 1995); therefore there is little evidence to suggest that the provision of information to patients prior to transferring to a rehabilitation setting would be significantly different. This is reaffirmed by the paucity of literature about appropriate information that prepares rehabilitation patients for transfer, from an area where patients have been passive, to an area where patients are required to be actively engaged in their treatment regimes.

The provision of information is an important component of quality health care. However, given the existing evidence that information is not readily provided, it is prudent that the need for information is investigated to assist in the best use of limited resources. Consideration needs to be given to why the information is necessary and what it is going to achieve (Entwistle *et al.* 1997). The difficulty is that specific content and the preferred mode of delivery as they pertain to patients' health problems are not always so clearly delineated (Hanger *et al.* 1998).

While there is a paucity of literature about rehabilitation in general, there is some evidence about patients' desire for information following stroke, where rehabilitation is often a significant aspect of their care. Content areas that patients initially identify as important relate to recovery, treatment and prognosis; namely: the nature of stroke, fear of recurrence and degree of stroke (Hanger *et al.* 1998, Wiles *et al.* 1998). While factual information is sought, information pertaining to the provision of services, for example, rehabilitation, is generally not actively sought. Alternatively,

patients will spontaneously offer compliments and complaints (in approximately balanced numbers) about the hospital service (Hanger *et al.* 1998).

Tertiary referral rehabilitation units accommodate patients with a broad range of diagnoses and consequently treatments and prognoses. Information given by staff is often based on what health professionals want patients to know and what they perceive as patients' needs, without direct knowledge of what is most important to patients (Rodgers *et al.* 2001). It is necessary and, in some ways, seems logical and appropriate to ascertain the information of concern to patients to maximize the usefulness and applicability of the time spent on the provision of information within the clinical setting. Differences have already been established in the priorities of patients and nurses: nurses have ranked subject areas such as psychological support (in surgery patients) and resumption of sexual activity in postmyocardial infarction patients much higher than that ranked by patients (Fox 1998, Turton 1998).

The need for information for patients moving into rehabilitation settings has been highlighted by Grenenger (2003) who identifies that relocation to new settings can be accompanied by many changes in physiological and psychological status. Older patients who express satisfaction with existing care arrangements can express concerns about transfer (Dickinson 1996). The provision of individually tailored information based on patients' expressed concerns can be successful in alleviating some of these concerns (Dickinson 1996). Understanding what patients identify as questions and concerns early in rehabilitation can assist in the provision of relevant information to the patient (McLennan *et al.* 1996). It is important that the provision of information is appropriately pitched as too much information may induce anxiety or depression (Gillies & Baldwin 2001).

## Aim

The aim of the study was to gather information about patients' needs prior to transferring from an acute care facility to a rehabilitation setting that could assist patients to engage actively, that is, purposely participate in rehabilitation activities upon entering the unit.

## Rationale

The multidisciplinary team in the Geriatric and Rehabilitation unit were keen to identify if prospective patients were informed about what to expect from rehabilitation. This concern arose from the observation that many patients were not purposely participating and thereby not maximizing their opportunities during rehabilitation sessions. While a patient leaflet was proposed, the team were aware that measurable differences in patient outcomes are generally not achievable through just the provision of information through the written medium. Rather, when information is provided, improved knowledge retention has been associated with tailoring the information to the individual (Zernike & Henderson 1998). Furthermore however, participation in rehabilitation largely pertains to other considerations, for example, motivation (Clark *et al.* 2002). Extensive resources were not available to the staff in the rehabilitation unit to introduce broad scale changes to enhance motivation and create unique programmes. The team therefore elected to undertake an exploratory study to identify clearly the specific issues that may possibly have an impact on patients' desire to participate and accordingly facilitate targeted interventions that were most likely to bring about change.

## Method

Semi-structured interviews were undertaken with a convenient sample of nine patients shortly after admission/transfer to a rehabilitation unit. Four of these patients were interviewed again after discharge.

## Setting

The study was conducted in a 26-bed rehabilitation unit in a modern tertiary referral hospital with diverse acute and rehabilitation facilities.

## Ethical considerations

Ethical approval was obtained from the hospital ethics committee. All eligible patients were invited to participate in the study. Patients were reassured that their decision to participate or not to participate in the study would not affect their care.

## Subjects

Subjects were patients admitted to the rehabilitation unit during the two-month period of the study, April 2003 and May

2003. Nine patients admitted fulfilled the criteria and consented to take part in the study. Criteria for participation was an ability to articulate needs clearly and communicate these in English. Patients were excluded on the following basis:

- Diagnosis of dementia.
- A psychiatric co-morbidity.
- A current acute illness.
- Aphasia.
- An mini-mental score (MMSE) of below 24. A score of below 24 is currently used as a benchmark to suggest that cognition may be impaired [the MMSE is a simplified, scored form of cognitive mental status. It takes only five to ten minutes to administer and focuses on cognition. It does not include questions such as mood or abnormal thought processes (Folstein *et al.* 1975)].

Six patients admitted during the study period were excluded because of cognitive/mental health issues. No patients who fulfilled the criteria refused to participate in the study.

The sample comprised eight females and one male. The age range was 54–93 years with a mean of 74.9 years. Four participants were diagnosed with fractures, two with CVAs, one had a prosthesis removal, one with Guillian Barre and another was diagnosed with syncope. These diagnoses were typical of the admissions to this particular rehabilitation unit.

## Data collection

Potential participants were approached as soon as practicable after admission to the rehabilitation unit. Nine patients consented to take part in the study. Five of these patients were interviewed once and four were interviewed twice. The first interview was conducted shortly after admission and the second interview, when it was undertaken, after discharge.

All nine patients were interviewed as soon as practicable after their admission. The timing of the first interview varied depending on the health status of the patient and the availability of the researcher. Because of week-end admissions and several public holidays (affecting the availability of the researcher) and one patient's cognitive status deteriorating after admission, the maximum period before the first interview was undertaken was seven days after admission. This was the situation for one patient. However, in all other situations the first interview was undertaken within three to four days. Consent was obtained immediately prior to the first interview being conducted.

### *The first interview*

At the first face-to-face interview the researcher introduced herself, explained the purpose of the study and proceeded to discuss with the participant information relevant to their

needs. The research questions that guided the interview were as follows.

- 1 What were your expectations of the geriatric and rehabilitation unit before your admission?
- 2 What information did you receive before your admission?
- 3 Did you find this helpful?
- 4 What did coming to the rehabilitation unit mean to you?
- 5 What was unexpected or took you by surprise when you were admitted to the rehabilitation unit?
- 6 What would have been helpful before your admission to the geriatric and rehabilitation unit?

#### *The second interview*

A second telephone interview was conducted with four of the nine participants within a week of their discharge home. At the second interview the researcher discussed with the participants the information that they shared at the first interview. The participants were then asked whether there were any further events or situations that they would have preferred information about prior to admission to the unit. They were also asked whether there was any specific information that they believe other patients admitted to the unit should know prior to admission. As these interviews were quite short and did not reveal any further information relevant to the aims of the study, it was decided not to continue these interviews with the remaining patients.

One member of the multidisciplinary team undertook the interviews. At the time of the interview she was not required to be engaged in her regular clinical work. As there were no simultaneous demands on the interviewer considerable time was spent in exploring the intended meanings in the participants' responses. The issues that emerged were fairly consistent. After only five interviews the major themes were identified. Despite, a further four interviews being conducted no new themes emerged. No further interviews were undertaken.

#### **Data analysis**

The taped interviews were transcribed verbatim by an administrative officer. The printed versions of the interviews were then cross checked with the tapes by the interviewer. When the printed versions were deemed to be an accurate account by the interviewer the transcriptions were then distributed among all the other researchers. Members of a multidisciplinary team read and reviewed the transcripts and independently identified issues. The data were tabulated according to the issues and then, through discussion by the team, collectively coded from the issues identified by the individual research members. The language

of the patients was used when the data were coded. The statements grouped together in codes were then discussed, again, by all the researchers to explore possible meanings (Miles & Huberman 1994). From these meanings the themes emerged.

#### **Results**

Overall, the interviews revealed that generally participants received very little information about what to expect on admission to the rehabilitation unit. Participants did not receive a formal explanation prior to admission to rehabilitation explaining the intent of the unit, how it operated, or what staff expected from them. Rather, the information that participants received after they were informed that they were being transferred to a rehabilitation unit was from questions they directed mostly to nurses and other allied health professionals and sometimes to doctors. Those participants who did not raise any questions about the transfer received very little if any information about their changed situation.

However, while most participants only had a vague understanding about what they would encounter in the unit because of the small amount of information provided, none of the participants viewed this as being problematic. A number of themes emerged that indicated satisfaction and acceptance of being admitted to the rehabilitation unit. In particular the themes that rehabilitation was 'a ticket out', and 'a good thing'. In relation to provision of information participants identified that 'doesn't matter that I don't know'; 'information is not always meaningful' and 'I will adjust in my own time'.

#### **'A ticket out'**

Rehabilitation was perceived as a 'ticket out of hospital' or 'a step in the right direction'. In relation to the question 'what were your expectations', information was sought about the care participants thought they would be receiving. Five participants (over half) responded that they had 'no idea'. While these participants had not formed any definite expectations about the particulars of their stay in the unit, for example, their daily routine or provision of care, they seemed to have developed some general expectations about what rehabilitation meant. Evidence as to some general assumptions underlying admission were apparent through comments such as: 'it's a step on the way out'; 'I have to do it to get home'; it will 'sort me out' and 'thought I might get better'. Of interest, was that this predominant theme was perceived positively by all except one of the participants. This particular participant felt coerced to participate actively, that is, if

she 'didn't do it ... she needed to stay longer'. Consistent with the other participants, this participant believed that transfer to rehabilitation meant earlier discharge.

Despite most participants receiving very little information prior to their admission to the rehabilitation unit, one gentleman received very detailed information. This gentleman, admitted from another hospital, explained how he *had* been informed in detail about what to expect; for example, he reiterated the description of how the rehabilitation unit would be more like his own home environment.

#### **'Doesn't matter that I don't know'**

Overall, as previously mentioned, participants received very little information about what would happen to them. This was evident when asked 'what information did you receive prior to your admission?'. In response to this question most participants said 'nothing' or 'not much'. However, they did not deem it necessary to obtain information.

It became apparent that, if information was given to participants, it was unstructured. Most often it was the doctor who told them that they were to be transferred to the rehabilitation unit. This information was usually in the form of a statement accompanied by very little explanation. Invariably it was a nurse on the ward or a family member who provided more information informally through conversation once the participant had been told by the doctor. Allied health staff were also identified as informative – participants identified that allied health staff informed them that similar staff would also be in the rehabilitation unit. In particular, participants who were told that they were going to be transferred and then moved fairly soon afterwards, for example, later the same day, arrived in the rehabilitation unit still very unsure about what to expect. It became evident that 'just a statement' was insufficient as an explanation as participants had little understanding of the practicalities associated with rehabilitation, in particular, changes to their care regimes.

Overall, the impression was that the lack of information was not terribly problematic: one patient mentioned she was initially dubious but was quite happy and settled by the time of the first interview (only a few days later). The little information that people did receive from extraneous sources was positive such as 'it is quite good'. One participant did comment that 'the way it was set up was different – it took her by surprise' but this did not appear to alarm her or impede her involvement in rehabilitation activities. Neither did she have any recommendations as to how to avert this 'surprise' for others.

#### **'Information was not always useful'**

For those participants who did receive more than just a statement the information was variable in its usefulness. One participant, a transfer from another hospital rather than from within the hospital, explained that she felt she had received a full explanation and felt fully informed. This explanation was along the lines of she would 'get more movement' and she would need to do things for herself. Alternatively, another participant replied that although she was told 'it would help her a lot', that she would need to get dressed and would receive more physiotherapy and occupational therapy; she felt she was no better informed about what to expect.

#### **'Being here is a good thing'**

Overall, the rehabilitation process was perceived positively. Of significance, is that participants' responses about their expectations seemed positive. This could reflect more on patients' knowledge or belief in the 'system' of care; for example, comments such as it will help 'sort me out' are consistent with the general perception that hospitals are designed to assist people in the recovery process, that is, the 'right thing will be done for them'.

#### **'I will adjust in my own time'**

In relation to the question about what information would have been helpful, one participant was quite adamant that although she had not received information there was no value in her receiving it. She was quite clear in saying that she was 'not ready' for the information. On reflection, she stated that it took her a couple of days before she could accept where she was and that she was required to participate actively.

### **Discussion**

The value of semi-structured interviews in exploring patients' needs for information, on arrival at a rehabilitation unit, provided for the identification of information already imparted, or previously learnt, through direct or indirect experience with the health care system. Awareness of prior knowledge enabled recognition of patients' preconceived ideas and possible misconceptions. Such interviews, therefore, assisted in the identification of any gaps between current understanding and desired level of understanding. The use of interviews was perceived as more appropriate than a questionnaire as interviews permitted exploration of comments such as 'not much'. It also facilitated exploration of the

limitations in patient understanding and beliefs that would not otherwise have been possible.

The finding that participants were poorly prepared with respect to information is consistent with existing trends in the literature. Patients' information needs prior to discharge from a health facility are generally inadequate for patients to care for themselves at home (McBride 1995, Clare & Hofmeyer 1998, Henderson & Zernike 2001).

Patients did not perceive lack of information as a problem. From the interviews it became apparent that there was a prevailing sense of acceptance rather than any sense of disquiet or complaint about the lack of information about rehabilitation. This is possibly suggestive of a sense of trust of the system where doctors' knowledge and practice are valued most highly and where opportunities for active patient participation in decisions are often limited to specific contexts and situations. Patients' lack of discriminatory power could be related to the belief that they will receive appropriate care (Avis *et al.* 1995).

The findings suggest that patients actively engage, albeit slowly in some cases, in their rehabilitation programmes, whether or not they receive information prior to relocation to a rehabilitation unit. For the participants interviewed, the lack of information did not appear to have had a major negative impact on either patients' progress or patients' length of stay.

Of particular significance was the comment about 'adjusting in my own time'. There is increasing evidence about the timeliness of information, that is, patients' information needs are largely dependent on their stage along the continuum of care (Henderson & Chien 2004). Given the importance and individual nature of 'patient readiness' it may be more appropriate to learn the subtle 'signs' of readiness rather than trying to create them in our patients.

Patient participation is a rapidly emerging consideration in health care (Cahill 1998). Most of the patients were older patients, which may have contributed to their absence in any discussion about choices available to them (Thompson *et al.* 1993). Throughout the interviews, except for one, where the participant clearly stated that she felt 'if she didn't do it she had to stay longer', there was very little indication that individuals felt coerced. Neither, however, did participants give the impression that they had choices. The provision of information possibly needs to consider the patients' readiness to receive this information and how this information can be useful to them.

### Recommendations for health care practice

While the intent of the provision of information about rehabilitation is to encourage patients to engage in the

programme, this is still as an active participant in a programme that is fully controlled by the health system and its medical, nursing and other allied health staff members. Health professionals need to be aware that participants' motivation to partake in the programme is possibly influenced more by attitudes, beliefs, perceptions than provision of information about their participation. While such perceptions may be founded on the information that is provided to patients, they are more likely to be inherent in the organizational culture; namely these perceptions reflect more on patients' beliefs in the value of the organization to maintain their health and well-being. It is therefore appropriate for health professionals to explore perceptions and ascertain patients' willingness or, rather, readiness to engage in rehabilitation prior to commencement of a programme. The value of providing information to patients prior to transfer to a rehabilitation unit may be limited in maximizing their readiness for engagement in their rehabilitation programmes. It may be of greater benefit in the current system to explore other factors such as psycho-social concerns to gauge patients' involvement in the rehabilitation process.

### Conclusion

The semi-structured interviews with the participants identified that, in general and in the current health system, the value of the provision of information to prospective rehabilitation patients is limited. Participants' beliefs are that they were not given explicit details about rehabilitation care but rather were told something general, such as, 'something would be done'. It seems that a belief that a transfer to rehabilitation is 'a step on the way out' was a significant motivator for these participants and that more explicit information about rehabilitation may not significantly alter the desire to partake in the rehabilitation programmes on offer.

There are a number of issues and questions raised by these findings that have implications for health professionals. Primarily, health professionals need to recognize that patients are often compliant with decisions made while they are inpatients of the current health care system. The philosophy and practices of this system could be reviewed to examine how patients, as valuable partners in the system, are actively engaged in their own programme planning. Secondly, health professionals need to be cognisant of the perceived power differential in the current health care system between them and their patients and therefore the potential for patients to accept the direction of their care without question. Thirdly, health professionals need to recognize patients' perceptions of 'earlier discharge' as a motivator regarding compliance in current health care transfers.

## Contributions

Study design: AH, SMcK, SK, SD, LK, KA; data collection and analysis: SMcK, AH, SK, SD, LK; manuscript preparation: AH, SMcK.

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