ORIGINAL ARTICLE

Patient Experience of Neurologic Rehabilitation: A Qualitative Investigation

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ABSTRACT. Wain HR, Kneebone II, Billings J. Patient experience of neurologic rehabilitation: a qualitative investigation. Arch Phys Med Rehabil 2008;89:1366-71.

Objective: To understand the experiences of patients who had undergone neurologic rehabilitation.

Design: An interpretative phenomenological analysis of semistructured interviews.

Setting: Neurologic rehabilitation unit.

Participants: A purposive convenience sample of 8 past patients.

Interventions: Not applicable.

Main Outcome Measure: Participants' reports of neurologic rehabilitation obtained via in-depth semistructured interviews.

Results: Participants predominantly described positive experiences of rehabilitation. The superordinate theme *person-centeredness* was developed, which included 4 key themes: ownership, personal value, holistic approach, and therapeutic atmosphere. These reflected patients' perceptions of choice and control and feelings of personal respect and self-worth. These appeared to be promoted through the multidimensional benefits of the unit (eg, the understanding and friendly nature of staff and other patients, physical improvements, psychologic gains) as well as the unit's informal, relaxed environment. When present, these factors created a positive rehabilitation experience; when absent, a negative experience.

Conclusions: These findings support those from other literature, which has identified person-centered care as a core element of successful rehabilitation and linked its absence to dissatisfaction with health care. This research has increased our understanding of patients' experience of neurologic rehabilitation, and could inform the development of a patient-centered assessment instrument for neurologic rehabilitation.

Key Words: Nervous system diseases; Patient-centered care; Patient satisfaction; Rehabilitation.

PATIENT-LED HEALTH CARE has been proposed.[1] Such health care requires an in-depth understanding of patients' needs through regular assessment of their experiences and satisfaction.[2] This approach can provide great insight into the quality of care patients receive as well as highlight specific areas in need of improvement. Neurologic rehabilitation is no exception to this, and it is apparent more needs to be done to consider patient views in this area.[3,4]

Neurologic rehabilitation can be markedly different from other treatment arenas because of the diversity of services provided and the level of patient involvement required. For this reason and the fact patients may be affected by communication and cognitive difficulties, specifically designed measures should be used for this client group. Previous research has identified this gap and undertaken work to develop a measure of patient satisfaction for these services.[5,6] Wellwood et al[5] developed a semistructured interview based on previous literature and informal conversations with patients and staff. They found that 97% of patients were satisfied with the overall care they received poststroke. Unfortunately, in this study, the global satisfaction question was not a good measure of quality of service. It masked significant dissatisfaction with individual aspects of care. Nearly half of the sample was dissatisfied with at least 1 aspect of care including communication, discharge, and follow-up arrangements.

The study by Wellwood[5] highlights one of the main difficulties with patient satisfaction questionnaires. Patients will report high levels of satisfaction even when they have negative experiences of the service. It has been suggested one of the reasons for this is that such questionnaires are based on topics service providers perceive as important rather than those that tap patients' values and experiences.[7] Pound et al[6] went part of the way to address this concern by designing and testing a patient satisfaction questionnaire based on in-depth interviews with stroke patients. They found that patients' main concerns were the amount of therapy received and the amount of recovery achieved. Although this questionnaire considered patients' perspectives in its design, since their work, reservations have been raised in general terms about patient satisfaction measures.[8] It has been considered more important to look at a wider view of patient experience.[9,10]

Reservations about the validity of the concept of satisfaction have been raised. These include concerns regarding the assumption that satisfaction addresses patients' evaluations of services.[8,11] There is, in fact, little evidence that satisfaction is the result of the fulfillment of patients' expectations and needs.[11,12] Indeed, patients may not actively evaluate the care they receive, or may not use this dimension to evaluate care.[8] Qualitative research has shown that patient satisfaction is unable to account for the range of feelings and experiences patients report regarding their health care.[8,13] On this basis, it has been recommended that if service providers want to obtain

List of Abbreviations

IPA	interpretive phenomenological analysis
MS	multiple sclerosis
NHS	National Health Service

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the experience and perceptions of patients, research must first be conducted to identify the ways in which patients perceive and evaluate that service, and whether some evaluate it at all,[8] and any tools for measuring patients' views should be grounded in their everyday lives and language.

Lewinter and Mikkelsen[14] conducted a qualitative study with stroke rehabilitation patients in an attempt to gain a more comprehensive picture of patients' experiences. They were able to identify "nonphysical" benefits from rehabilitation, such as "the strength gained from being a member of a group," as an important aspect of patient care. This is something unlikely to be identified in traditional patient satisfaction surveys. To create patient-centered measures that might fully address those areas of experience and concern of most importance to patients, it is important to build on such work.

Coyle[7] undertook qualitative interviews with general medical patients who were unhappy with their health care. Although a wide range of concerns were identified, from waiting times to poor communication, these accounts were all constructed around the concept of "personal identity threat." This detailed the extent to which they felt their identity had been undermined through the processes of dehumanization, objectification, and disempowerment. Coyle and Williams[13] used this information to develop a quantitative questionnaire measure of patients' experiences of health care, grounded in patient accounts and therefore sensitive to patients' experiences. They have acknowledged that this instrument will only be meaningful in other health care environments through continued qualitative work to access each client group's perceptions and evaluations.[15]

This study aimed to explore the patient experience in depth. Qualitative methodology was used to ensure important aspects and potentially unanticipated ideas were not missed, broadening our understanding of the patient experience in neurologic rehabilitation.

METHODS

Design

Qualitative research methods were chosen for this study because they allow the experience of events to be investigated from the perspective of the individual. Such an approach addresses the complexity of meaning rather than a measure of frequency.[16] IPA was specifically chosen because it focuses on people's experiences and how these are perceived, described, and interpreted.[16] Semistructured interviews were used to collect data through a series of open-ended questions about participants' experience of neurologic rehabilitation. This technique is recommended when using IPA because it allows participants to provide a detailed account of their experiences in their own words.[17] The interviewer is then able to follow participants' interests and enter novel ideas that have originated from the respondent while maintaining some consistency in the content of the interviews.

Site

The publicly funded rehabilitation unit[4] where the study took place is situated within a small community hospital and has provided services for over 15 years. The unit provides multidisciplinary services for patients with neurologic disorders after an acute episode or exacerbation or rehabilitation management for long-term neurologic conditions. It consists of 1 mixed-sex ward with 14 beds and a purpose-built bungalow and concentrates on providing services for adults within the working-age range.

Ethics Approval

Ethics approval was sought and obtained from the local ethics committee. To ensure that all those approached had the capacity to provide informed consent, the clinical psychologist and speech-language pathologist identified all past patients who to their knowledge met this consent criterion. Participants provided informed written consent before and after the interview. The second informed consent ensured that participants were comfortable with the content of the interview once completed.

Access to Sample

Admission records for the previous 12 months were used to estimate the proportion of patients admitted to the rehabilitation unit for each illness category. This information was used to recruit participants who proportionately represented the main reasons for admission into the unit. Patients who had been discharged for at least 2 weeks and deemed to have the capacity to assent to participate were contacted via letter and invited to participate in the study. Those approached had 2 weeks to respond. After this, additional people were contacted, progressing in time since discharge. A total of 22 patients were contacted. Eight (36.4%) of these returned signed consent forms, authorizing participation. Table 1 indicates the characteristics of the sample obtained.

Data Collection

Once signed consent forms were returned, participants were contacted by the telephone, and suitable dates and times for the interview were arranged. Semistructured interviews occurred

Table 1: Participants' Demographic Information

Patient	Age	Sex	Reason for Admission	Length of Stay (wk)	Months Since Discharge	No. of Previous Admissions to the Unit
P1	63	Male	CVA: acute episode*	4	3	0
P2	47	Female	MS rehabilitation management†	2	1	23
P3	67	Male	Subarachnoid empyema acute episode*	10	2	0
P4	59	Female	CVA acute episode*	2	6	0
P5	68	Female	SAH acute episode*	21	7	0
P6	55	Female	MS rehabilitation management†	3	2	1
P7	49	Male	MS rehabilitation management†	2	8	14
P8	52	Female	MS rehabilitation management†	2	2	0

Abbreviations: CVA, cerebrovascular accident; SAH, subarachnoid hemorrhage.
**Acute episode* is admission to the unit after a specific neurologic episode.
†*Rehabilitation management* is admission to the unit for a chronic progressive condition.