

Existential struggle and self-reported needs of patients in rehabilitation

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Abstract

Title. Existential struggle and self-reported needs of patients in rehabilitation

Aim. This paper is a report of a study to increase understanding of patients' experience of rehabilitation and their self-reported needs in that context.

Background. Nurses need to be able to recognize patient needs to plan effective and individualized care. Needs-led nursing care is emphasized in the nursing literature, but few studies in rehabilitation have explored needs from the patient's perspective.

Method. The sample of this phenomenological study was purposively selected and the data consisted of 16 in-depth interviews with 12 people aged between 26 and 85 years. The data were collected in 2005.

Findings. The findings showed that being a patient in rehabilitation involves existential struggling, as the reason behind patients' rehabilitation, accident or illness usually leads to trying to cope with existential changes while needing to adapt to new characteristics of life and self. This makes patients vulnerable and their self-reported needs include individualized caring and emotional support from family, peers and staff. Participants also reported a need for a sense of security in a stable and homelike environment, with assistance, help and presence. Finally, they reported needing goal-oriented and progressive care in which realistic and achievable goals were established. Individualized patient education enhanced their independence and empowered them towards a new and progressive lifestyle.

Conclusion. A new emphasis is needed in rehabilitation nursing, involving assessment of existential well-being of patients by means of skilful interpersonal relationship based on individualized caring and emotional support and recognition of each patient's own hierarchy of needs.

Keywords: empirical research report, interviews, multidisciplinary teamwork, nursing, phenomenology, patients' needs, rehabilitation

Introduction

Regardless how nursing is defined, it is clear that nurses need to be able to recognize patient needs to plan effective care for each patient (Meleis 2006). The concept of need is widely discussed in healthcare literature, but definitions have been

problematic. The only consensus to be found in the literature is that *no* consensus has been reached about the definitions (Asadi-Lari *et al.* 2004). Attempts have been made to develop comprehensive assessments of needs. The National Health Services (NHS) and Community Care Act (1990) were established in the united kingdom (UK) with the aim of

forming a cornerstone for quality care. To assist the authorities to fulfil their statutory obligations under the Act, comprehensive needs assessment was established. The latter is widely used in the mental health services, for example the Camberwell Assessment of Needs (Phelan *et al.* 1995), but an equivalent tool was not found in the rehabilitation literature. To date, most studies of needs have been grounded in the positivistic paradigm (Parry-Jones & Soulsby 2001), which posits that objective accounts can be given of the world (Denzin & Lincoln 1998). Little is known about patients' needs in rehabilitation but, because of the complexity of rehabilitation as a multidisciplinary practice, and as questionnaires cannot allow respondents to describe their responses in context, it is doubted that they can reveal patients' needs from their own perspective (Campbell *et al.* 2003, DeMarco *et al.* 2004). Even if qualitative research is recognized as increasing richness and depth in health care, and quality is itself a priority of the practical work (Sandelowski 1997), only few qualitative studies have explored patients' perspectives on their needs in rehabilitation (Pâquet *et al.* 2005).

Background

Rehabilitation

Traditionally, rehabilitation is seen as a health-seeking effort on the part of patients, based on the attitude that recovery is possible (Jacobson & Greenley 2001). Rehabilitation has been defined as 'the process of restoring a person's ability to live and work as normally as possible after a disabling injury or illness' (Miller & Keane 1983, p.968). For us, in addition, the concept of rehabilitation means a holistic, teamwork-oriented approach, where patients and their needs are at the centre of the interdisciplinary teamwork.

Interdisciplinary teamwork

An interdisciplinary team work approach was described by Dowd (1999) as a climate that nurtures open interdisciplinary communication and trust, positive interdependence, individual accountability, social interactive skills and group reflexivity, where the contribution of all professions in the team is equally important. In a literature review, Kirkevold (1997) reasoned that nursing is a valuable input in the rehabilitation team; we agree with this and claim that the nurse's unique function in the team originates in the holistic philosophy of nursing, which focuses simultaneously on patients' basic needs and the whole picture of their rehabilitation experience.

Needs

For many years, Maslow's hierarchy of needs was one of the cornerstones in nursing education (Lauri *et al.* 1997, Boree 1998). It has, however, been criticized for a lack of flexibility as people's needs are highly variable (Boree 1998). The Merriam-Webster on line dictionary 2007 defines 'need' as: (a) a lack of something requisite, desirable or useful; (b) a physiological or psychological requirement for well-being and (c) a condition requiring supply or relief.

In a grounded theory study aimed at exploring the efficacy of the NHS and Community Care Act (1990), Parry-Jones and Soulsby (2001) found that needs were diffusely identified and that guidelines seemed to be lacking about how to deal with unmet needs. Holistic assessments were more likely to be needs-led, and multidisciplinary practice was found to facilitate assessment. A case can be made that it might be timely to change the ontological focus concerning needs towards exploring the outcomes that patients want and how they perceive their needs have been met (Egan 1999, Hallström & Elander 2001).

The study

Aim

The aim of this study was to increase understanding of patients' experiences of rehabilitation with emphasis on their self-reported needs in that context.

Methodology

This study was guided by the Vancouver School of Doing Phenomenology (Halldorsdottir 2000). The epistemology of phenomenology aims to explain meaning and increase understanding of human phenomena (Van der Zalm & Bergum 2000). It is a holistic and humanistic methodology, which claims that people's sense of reality is subject to each individual's interpretation of their own experience and environment (Koch 2000). The main strength of the Vancouver School, and the reason we used this approach, is that each participant is treated as a separate 'case'. Therefore, each participant is seen as co-researcher, in their own context. There is 'individual case construction', then each 'case' is systematically compared with other 'cases', and there is meta-analysis of all the case constructions. This method is, therefore, ideal when two or more researchers are working together. Furthermore, the Vancouver School is strongly influenced by constructivism, which is as an additional strength in that the findings are seen as mutual construction

Table 1 The 12 basic steps of the Vancouver School as followed in the study

Steps	Action
Step 1	Selecting dialogue partners (the sample). 12 former rehabilitation patients.
Step 2	Silence (before entering a dialogue). Reflection on preconceived ideas.
Step 3	Participating in a dialogue (data collection). 16 dialogues in all.
Step 4	Sharpened awareness of words (data analysis). Listening, reading, reflecting.
Step 5	Beginning consideration of essences (coding). Trying repeatedly to answer the question: what is the essence of what this former patient is saying?
Step 6	Constructing the essential structure of the phenomenon from each case. From one to two dialogues with each former patient.
Step 7	Verifying each case construction with the relevant co-researchers. This was carried out with all participants.
Step 8	Constructing the essential structure of the phenomenon from all the cases. (Meta-synthesis of all the different case constructions).
Step 9	Comparing the essential structure of the phenomenon with the data. Reading all the transcripts again.
Step 10	Identifying the overriding theme which describes the phenomenon: the essential structure of patients' experience of rehabilitation and their self-reported needs in that context.
Step 11	Verifying the essential structure with some research participants. Two participants were contacted, as they were considered key-informants. Same as in step 7, instead more time was used to compare the essential structure with the data repeatedly and from different angles.
Step 12	Writing up the findings (multivoiced).

of researcher(s) and participant(s) as co-researcher(s), which more strongly presents patients' perspectives. An overview of the Vancouver School is presented in Table 1.

Participants

The authorities of the three biggest rehabilitation clinics in Iceland were contacted and they all agreed to give access for the study. Possible participants were identified and contacted by head nurses at the clinics. The study population consisted of people who had experienced rehabilitation therapy because of acute or chronic illness in 2004 or 2005, were likely to be able to tolerate a conversation for 60–90 minutes and agreed to participate in the study. The sample was thus purposefully selected (Morse 1998) and consisted of seven men and five women aged 26–85 years (Table 2). Most had

Table 2 Overview of study participants

Sex	Age (years)	Type of problem	Type of rehabilitation
Female	26–45	Acute	24 hours/7 days
Male	26–45	Chronic	24 hours/7 days
Male	26–45	Acute	24 hours/5 days
Male	26–45	Acute	24 hours/7 days
Female	46–65	Chronic	24 hours/6 days
Female	46–65	Acute	24 hours/5 days
Female	46–65	Chronic	24 hours/5 days
Male	46–65	Chronic	8 hours/5 days
Female	46–65	Chronic	< 8 hours/2–4 days
Male	46–65	Acute	24 hours/5 days
Male	66–85	Acute	24 hours/5 days
Male	66–85	Chronic	24 hours/6 days
Female	26–45	Acute	24 hours/7 days

completed a 4–6 weeks' inpatient rehabilitation programme, two were in day-care, but three were severely physically injured and had been inpatients in rehabilitation for several months.

Data collection

Data collection took place from April to June 2005, through 16 unstructured interviews or dialogues with the participants which took place in locations of the participants' choice, most often their own homes. Four participants were interviewed twice to increase the depth of data collection. Not only was a description of interviewees' experiences sought, but also the meanings attributed to it in relation to their experiences of rehabilitation and self-reported needs in that context.

Ethical considerations

The UK Royal College of Nursing's guidelines and ethical principles for nursing studies were followed explicitly (RCN, 2004). The study was approved by the Icelandic National Bioethics Committee, head nurses and physicians-in-chief at the participating clinics. As required, the Icelandic Data Protection Authority was notified and no one was included in the study without giving written informed consent. The freedom to withdraw from participation at any time was stressed.

Data analysis

In accordance with the Vancouver School, data collection, literature review and data analysis were carried out simultaneously and new themes constructed during the study led to simultaneous literature searching and analysis.

Rigour

Rigour was established by using methods intended to increase trustworthiness, such as continuous questioning and critical assessment of the quality of data collection, analysis and presentation. For credibility, the participants are represented as clearly as possible and direct quotations are used in the text to enable readers to judge this for themselves (Lincoln & Guba 1985). Confirmability was sought by consulting with the participants in the analytical process (Fleming *et al.* 2003). As Halldorsdottir (2000) recommends, a reflective diary was kept and provided an audit trail of the data analysis process. Vocal intonation, gestures and physical expressions were noted, as well as researcher’s thoughts and reflections after each dialogue.

Findings

Existential struggling and vulnerability of rehabilitation patients

The findings clearly indicate that being a patient in rehabilitation involves *existential struggling*. The reason behind patients’ rehabilitation, accident or illness, usually meant that they were facing considerable *existential changes*. Being suddenly knocked down in an accident has more than physical implications. Participants’ existential struggles were many-sided. Some described how they were trying to tackle two paradoxical processes at the same time: the need to adapt to a change in self-identity and holding on to aspects of the old life and self:

The staff tended to look on my handicap as the main problem and emphasize the plan of exercise and then perhaps my work in relation to that. My view was the complete opposite. I wanted to keep my job and adapt my exercises and assistance that I needed because of my handicap to that.

This existential struggle made the average patient *vulnerable* and they felt more easily sent off balance.

Patients’ self-reported needs in rehabilitation

Six clusters of needs in the context of rehabilitation were constructed in the study. Firstly, participants needed to be able to cope with the impact of their acute or chronic problems. They felt that their ability to cope was strongly tied to their own personal traits, their earlier experiences and preconceptions, knowing the source of their suffering; they also needed to experience a balance between sleep, rest and activity while in rehabilitation. Secondly, they needed to adapt to new characteristics of the self, as their accident or illness usually involved considerable changes. In the midst of these changes, they felt that they needed to be able to sustain a personal role and needed faith, hope and optimism to succeed. Thirdly, they needed individualized caring where they needed to be ‘I’ and not just ‘the patient’: they needed to be listened to and heard in a caring relationship where their need for privacy, when needed, was respected. Fourthly, participants needed emotional support from family, peers and staff. Furthermore, they needed a sense of security in a stable, safe and homelike environment with available assistance, help and presence. Finally, they needed goal-oriented and progressive care, where realistic and achievable goals were established and patient education enhanced their independence and empowered them into a new and progressive lifestyle. Table 3 gives an overview of the essential structure of the interviewees’ self-reported needs in the context of rehabilitation.

Need to be able to cope

All participants felt that their ability to cope was strongly tied to their own personal traits and earlier experiences and

Table 3 The essential structure of the former patients’ self reported needs in the context of rehabilitation

Need to be able to cope	Need to adapt to a new life and self	Need for individualized caring	Need for emotional support	Need for a sense of security	Need for a goal-oriented and progressive care
Personal traits	Adapting to new characteristics of self	Being ‘I’, not just ‘the patient’	Emotional support from family or significant others	Available assistance, help and presence	Establishing realistic and achievable goals
Earlier experiences and preconceptions	Sustaining a personal role	Being listened to and heard	Emotional support from peers or group	Safe environment	Patient centred education
Knowing the source of suffering	Faith, hope and optimism	A caring relationship	Emotional support from staff	Stability	Being empowered into a new lifestyle
Balance between sleep, rest and activity		Respect for privacy		To feel at home in rehabilitation	

preconceptions, as well as knowing the source of their suffering. Most mentioned that the results depended on themselves. One man put this as the 'mentality that you are going to do something about it, for yourself'. Another important element was to sustain the waiting to get better, and some found it hard to cope when their condition improved very slowly. Patients' ways of dealing with problems were various and some used pure will-power to cope. Their preconceptions were important, as well as knowing the source of suffering. It was of basic concern to them to have the time they needed, and professional assistance to find out the roots of their problems. Finally, a balance between sleep, rest and activity facilitated their ability to cope.

Need to adapt to new characteristics of life and self

Most often participants had been struggling to adapt to new characteristics of self, and new life situations caused by their acute or chronic problems. This could be problematic, first to "accept the fact that I was ill...to be 'a patient'" and then adapting to a new self when the disease had perhaps led to some long-lasting or permanent changes. One man explained: 'I have certain limitations that I didn't have before'. Another initially regarded it as a major setback if he needed help once in the day, and felt that it ruined his day. Later, he took another stance, seeing it as rational to accept help with certain things, even if he could do them himself, as it was more important for him to save time to be able to work.

Participants expressed a need to be allowed to maintain their personal role and integrity, even though they had to put up with new characteristics that emerged from the accident or their disease, and in some instances to accept help with the smallest things. Their need for faith, hope and optimism seemed to be an essential aspect of adapting to a new self and getting through the difficulties involved: '...one didn't know what the future would be... and to me there is no question that it was my faith that carried me through it'. The rehabilitation experience and recovery could bring about some new and unexpected possibilities, as experienced by one woman. Having regretfully left her career, she went to a music school which she enjoyed very much. She stated: 'There I can go at my own pace, although I am taking the studies seriously. But if I am unable to attend, the studies wait for me'.

In addition, participants saw rehabilitation as a phase on the way to better health after a hospital stay or in chronic illness. However, many were worried about finances and rigidity in their work environment concerning their endeavours to adapt to a new self and adjust their work to their physical conditions. Finally, the social security system was found neither supportive nor encouraging for people who

were testing their ability to work after an accident or period of illness. Those who tried returning to work found that they were penalized by deductions from their disability pension, and the system was too rigid, depriving them of the stimulus to try to return to work.

Need for individualized caring

It was important for participants to be 'not just some patient or invalid or whatever, simply to be allowed to be myself'. They appreciated it when the rehabilitation staff considered their individualistic needs: 'How do you sleep? Is the pillow OK? Bed? Not go on exercising until you feel pain'. Moreover, it was important to be allowed to state their needs: 'I feel so bad if it's windy and cold. I was allowed to walk inside if I asked to'. Participants regarded it as important to be listened to and heard by professionals who had a caring relationship with them based on mutual acceptance: 'The staff accepts me as I am. If I say it's a good day then they are happy for me, and if it's a bad day then that's all right too'.

Even if participants were in general happy with their rehabilitation experience, there were some examples of negative encounters with staff, e.g. being spoken down to, or not being listened to. Such encounters made them feel uncomfortable and not cared for. In a group session, a physician refused to believe on woman's experience of bad dreams as a side-effect of a drug. She explained: 'He was standing there right in front of me saying scornfully, "Why don't you share your dreams with the group?"'. The memory still made her upset and it was evident that she had been offended and made to feel uncomfortable. One woman, who had been affected by difficult life events both physically and mentally, had visited her GP often but claimed that only her physical problems were dealt with and not her difficult life events or their consequences. She managed, however, to turn her focus away from bad experiences, into restoring her own health with the help of a nurse in rehabilitation. Individualized caring also meant respect for participants' privacy when needed.

Need for emotional support

All participants agreed that emotional support was invaluable. Most regarded their family as their primary supporters, but friends, peers and healthcare staff were also mentioned. A man stated: 'My wife came to me almost every day and my children also, and going home every weekend for a short holiday also made it all a bit easier'. It was important that the family had good access to the healthcare staff at the

rehabilitation clinics. Many reported having been supported by peers, wither individually or as a group. One man was accompanied by another 'lad' from [his hometown] 'and we...were in this all together and kind of motivated each other'.

Need for a sense of security

Participants reported having had a need for a sense of security and for stability in staff and environment. Having to move a great deal between rooms could be hard, although they understood that this might be necessary: 'I found it very bad and nerve-racking to be required to move around so often. It was like being torn up by the roots and always having to get used to a new place'. Person-centred care and continuity in staffing was mentioned by some as contributing to their feeling of stability: 'On the ward there were always the same nurses, the same care assistants... so one got to know the staff very well, not only as professionals but also as human beings'. Feeling at home in the rehabilitation clinic contributed to participants' sense of security, for example 'The attitude there, it is all just somehow so warm in there. You feel well when you enter the clinic; everyone is smiling, all ready to help' and 'I know everyone at the ward. You come in and greet everyone and you know them all. It is different when you know the staff'. Some explained that the reason why they wanted a 24-hour service rather than just during the day was the sense of security. A woman stated: 'It is naturally this safety – that if something goes wrong then there are experts all around you'. A man explained: 'It was vital to have access to these (professional) people to be able to go through this mentally, because that is not the least important part of it'. A safe environment was important, and most participants mentioned good facilities (swimming pool, gymnasium and walkways) as important. The participants noticed the team orientation in the approach by staff and were gratefully aware of being monitored which gave feelings of security. A man recounted: 'While one is doing the exercises, it is just very good to have a person nearby who you trust is looking after you. They know what you can manage'. A woman said: 'I noticed that when I had been to the physical therapy class the physical therapist had talked to the nurses and then they asked me if I was too tired. They always checked up on me'. It was seen as important for healthcare staff to step in if needed, and to follow up on care.

Need for goal-oriented and progressive care

Establishing realistic and achievable goals with the help of professionals was important for participants when they were

patients; rehabilitation representing *stepping stones* on the way to better health. One woman experienced systematic and effective use of goal-setting in physical therapy and occupational therapy, but less in nursing:

In physical and occupational therapy there was regular reconsideration of my goals. [But in nursing] (hesitantly) to be able to pee, to be self-sufficient in going to the toilet - it was in a way never revisited specifically. I could not pee for some time. It was what the nursing staff was concerned with. There is, as a matter of fact, very little that can be done about it. It is something that either gets better, or not.

Most participants referred to patient education as an important aspect of their rehabilitation experience, which they used to build on for their future. They learnt methods that were supplementary to familiar training strategies, and some ways to handle a new and possibly permanently altered physical condition. A man said: 'Almost all I have learnt to cope, I think I learnt at the rehabilitation clinic' and a woman said 'Although I was disappointed with my (physical) results from the rehabilitation therapy, I was discharged with a lot of hints that helped me to go on'. Another woman, however, questioned what she called 'too-inclusive lectures'. She stated: 'It (the coverage) was a little non-specific. I was waiting for what related to me. I would have preferred just a talk about [my] side, that it was a smaller group'.

Participants felt that they needed to be empowered into a new lifestyle by rehabilitation professionals and helped to take an active stance concerning their disease or handicap – an active turn which some saw a special chance to tackle in the setting of rehabilitation, because: 'In your own home, surrounded by your family, there is a certain habit. You are in a given frame. There is nothing that pressures you to change anything'. All participants felt that their lives were different after rehabilitation, and most mentioned assuming more responsibility for their health than they had before. A part of adapting to normal life again was to assume a new lifestyle, which involved taking care of themselves in a responsible way 'because this is what I have to do and what I am going to do'. One woman put it this way: 'I go to water-gymnastics, bought walking sticks and I just walk out of here...eat healthy foods. Now I feel like a queen...just taking care of myself'.

Discussion

One of the main findings of the study was that being a patient in rehabilitation can involve existential struggling and vulnerability. Writers in the rehabilitation literature have paid little attention to this existential struggling and vulnerability. Our findings indicate that careful assessment of

existential wellbeing of patients in rehabilitation needs to be emphasized. Hagren *et al.* (2005) explored the experiences of 41 chronically ill patients and concluded that they indirectly expressed an existential struggle, which was not always identified by caregivers. Furthermore, in a phenomenological-hermeneutic study of 18 patients' experiences of life with chronic illness, Delmar *et al.* (2005) identified the vulnerability that is derived from being a patient. Similar findings were also reported by Halldorsdottir (1996) from several studies about the experience of being a patient.

Six clusters of needs were identified in our study: to be able to cope; to adapt to new characteristics of life and self; individualized caring; emotional support; a sense of security; and goal-oriented and progressive care.

According to participants, existential struggling and vulnerability are stressful and they felt that they were now more easily sent off balance, making it harder for them to cope. From findings from psychoneuroimmunology we know that stress depresses the immune system severely (Glaser & Kiecolt-Glaser 2005, Vitetta *et al.* 2005) and that negative emotions can intensify a variety of health threats and contribute to sustained pro-inflammatory cytokine production (Kiecolt-Glaser *et al.* 2002). Furthermore, cognitive states such as perceived control, views of the self, and views of the future have been associated with immune parameters and health (Brosschot *et al.* 1998).

The reason behind patients' rehabilitation, accident or illness usually leads to trying to cope with existential changes, while adapting to new characteristics of life and self. Our participants described how they tried to tackle two paradoxical processes at the same time: the need to adapt to a change in self identity and holding on to aspects of the old life and self. Their notion of rehabilitation as a stepping stone is an important finding, as well as the long-term positive outcome of rehabilitation, the importance of getting many hints for a better lifestyle, as well as mastery of new technique of various kinds, such as getting dressed, walking with sticks, relaxation and focusing on themselves. Nätterlund and Ahlström (1999) also report the need for adjustments in daily life as a result of rehabilitation. Our findings indicated that the social security system was unresponsive to participants' needs to adapt to new characteristics of life and self. This suggests that measures to increase participation in the labour market need to be developed.

Another important finding was that the participants reported their need for individualized caring, including a caring relationship with rehabilitation professionals. Until recently, the concept of caring has been almost ignored in the rehabilitation literature. The need for caring is, however, supported by empirical evidence such as Halldorsdottir and

Hamrin's (1997) phenomenological study with nine participants, most of whom had experienced multiple hospitalizations, indicating that they needed a caring relationship, sense of solidarity and mutual respect. Our participants also reported a need for respect as persons not only as patients; this is further supported by Schmidt (2003), who found that patients wanted to be treated as individuals, to be known by more than their diagnosis and to be treated as persons. As one of the perceived effects of a caring encounter is a feeling of empowerment (Halldorsdottir 1996), it can be surmized that by being caring the staff can fulfil this need and help patients in their existential struggling and in maintaining a better sense of control and positive self-image in spite of their challenging circumstances. Nurses have the mandate to meet patients at their own level to establish a therapeutic relationship that becomes the baseline for effective nursing care (Peplau 1991). Therefore, uncaring attitudes towards patients, as experienced by some participants, who were spoken down to or not listened to, is contrary to the expressed goals of nursing. Such encounters made participants feel uncomfortable and not cared-for and were not likely to empower them to be able to cope. The findings reveal that task-oriented nursing, focussing on written medical instructions rather than a professional nursing evaluation of participants' needs, was perceived as unprofessional and indicating an unsuccessful interpersonal relationship.

All participants reported needing emotional support in their own context from family, healthcare staff and peers. Just being able to talk about their difficulties helped them a great deal. Being able to share their meanings, hopes and expectations with nurses, significant others and companions in rehabilitation can be an important aspect in patients' coping. Research on emotional expression or disclosure suggests that emotional expression generates balance in the neuropeptide-receptor network and a functional healing system. Emotional expression is also a marker for 'psycho-spiritual vitalization' (Bergsma 1994). Finally, support is labelled as a 'stress buffer' (Maier & Watkins 1998), and perception of high quality support (including spouse, intimate friends and healthcare professionals) correlates statistically significantly with a higher level of natural killer cell activity (Levy *et al.* 1990).

Our participants' self-reported need for a sense of security might come from their existential struggling, as many were dealing with a new and unfamiliar health condition. It might also be caused by the sense of vulnerability and might reflect rehabilitation patients' perceived uncertainty in unfamiliar circumstances. Our participants reported experiencing a sense of security when they were certain that someone was

What is already known about this topic

- Holistic assessments are more likely to be needs-led and multidisciplinary practice has been found to facilitate needs assessment.
- Adjustments in daily life have been recognized as a result of rehabilitation.
- The rehabilitation literature has not focused on patients' self-reported need for caring.

What this paper adds

- Being a patient in rehabilitation involves existential struggling, as the reason behind patients' rehabilitation leads to having to cope with existential changes while having to adapt to new characteristics of life and self.
- The self-reported needs of patients in rehabilitation include being able to cope, individualized caring, emotional support, a sense of security and a goal-oriented and progressive care.
- Nursing care needs to be clearly goal-oriented in cooperation with rehabilitation patients themselves, as well as in collaboration with other members of the rehabilitation team.

there watching over them and present to respond to possible happenings, e.g. when exercising.

Participants' need for goal-oriented and progressive care was sometimes not fulfilled, and some experienced lack of clarity in goal-setting by nurses. If nursing is to be a valuable input in the rehabilitation team in the way that Kirkevold (1997) suggests, it is important that nursing care is clearly goal-oriented, both towards patients as well as other members of the rehabilitation team. We suggest that such goal-directed care, where the patient and their needs are at the centre, could be truly progressive.

Study limitations

Although a gate-keeper bias is a well-known concomitant of a purposeful sample selection, it may be a weakness of this study because the optimism that characterized most, if not all, participants' narratives is not characteristic of all patients in rehabilitation. It may be that the nurses who established the contacts with their former patients, without being aware of their bias, tended to contact those who had been positive, active and made some progress in the rehabilitation period. Therefore, silent, inactive and not so positive rehabilitation patients need to be represented in a purposeful way in further

studies. In addition, it would be interesting to study the experiences of various groups of patients within rehabilitation, such as those with pulmonary, neurological and psychiatric diseases. Our findings are not generalizable, as each and every person's experience is unique. However, they offer a much needed perspective on patients' experiences self-reported needs in rehabilitation.

Conclusion

Rehabilitation teams need to confront the existential struggling of patients and the fact that they may feel insecure and vulnerable when they embark on their rehabilitation, and we call for further research into these important aspects. We advocate the assessment of patients' existential well-being within a framework of holistic needs assessment. The findings suggest that the focus of nurse education needs to be sharpened concerning establishing a therapeutic relationship with patients within a needs-led approach and in goal-setting with patients. A unified hierarchy of self-reported needs could not be constructed from our findings, which in a way supports critics of Maslow's hierarchy of needs. The findings indicate, however, that each and every person has their special hierarchy of needs, and this has to be identified for each individual. We recommend that rehabilitation professionals acknowledge patients' self-reported needs in the context of their illness experience. Rehabilitation nurses play a pivotal role in that important task.

Author contributions

JS and SH were responsible for the study conception and design and JS was responsible for the drafting of the manuscript. JS performed the data collection and JS and SH performed the data analysis. JS and SH obtained funding. SH made critical revisions to the paper. SH supervised the study.

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