

Patients' quest for recognition and continuity in health care: time for a new research agenda?

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Abstract

User involvement is important in democratization of healthcare and is assumed to contribute to better and more relevant research. Despite increased requirements for user involvement in research, more studies are still needed. This study aimed at exploring what research agenda people with varied health problems consider as important, based on their own experience. The study had a phenomenological approach with a qualitative design. The sample consisted of 23 informants; nine had been critically ill and 14 were suffering from chronic muscle pain. Data were collected in five focus group interviews and one individual interview. A phenomenological approach was used in analyzing the data. Written consent was obtained from all the participants, and ethical considerations were taken throughout the entire research process. Despite various experiences among the participants, *a quest to be taken*

seriously over time by healthcare professionals emerged as a strong meaning structure in both groups. Based on these experiences, continuity across lifetime changes turned out to be an important research topic for future research. User involvement should be appreciated in all parts of the research process. A crucial prerequisite is that the users get the opportunity to bring their own experiences into the process.

Key words: user involvement, research agenda, critically ill, chronically ill, phenomenological research

Introduction

General democratization processes in the Western society have led to a less paternalistic health system where user involvement is on the health policy agenda (1). Three approaches to user involvement are identified across Europe; a consumer model with emphasis on choice, a liberation model emphasising users' voice and a participant model that regards users as co-producers (2). In Nordic countries, the democratic element has been particularly important, emphasising the value of the users' voices, both collectively and individually (3). In Norwegian health policy, this is expressed through established patient organizations, health policy documents and legislation (4).

User involvement has increasingly been emphasised in health research, and according to recommendations from the European Science Foundation (ESF) (5) patients and public should be involved throughout the research process. This is also a stated wish from the Norwegian authorities which has resulted in the development of national guidelines for user involvement in health research (6). These guidelines emphasise collective representation of user-organizations, where the overall goal is to increase relevance and quality in research by involving the users. Without the users' perspectives, in planning and conducting research, one might risk research waste, that is, producing research findings with little relevance for the patients (7).

Despite increased focus on user involvement in health care, studies on user involvement in health research are still scarce, particularly when it comes to setting the agenda of research (8). One exception however, is research in mental health, where the political slogan "Nothing about me, without me" has long been used in programmes for strengthening patients' positions, both in health care and health research (9). Also in Norway, there are networks within mental health services that explore the users' experiences of participating in research (10).

User involvement in research, regarding patients with somatic illnesses, is rare, especially related to chronic muscle pain. Some studies in rheumatology research can be found where service users have been engaged as participants throughout the research process (11 -13). These studies indicate that user involvement in research helps setting the research agenda with appropriate topics for the target group, and may facilitate mutual learning between researchers and users. Research regarding critically ill patients indicates that the priorities, in both research topics and treatment goals, are mainly defined by clinical and research experts (14, 15). A Dialogue Model has been developed for cooperation between patients and professionals in the determination of research agendas (16), where both critically and chronically ill patients have participated (17, 18). One of the case studies in the process of developing this model was related to survivors following severe burn injuries. This showed broad agreement between research priorities of both patients and health professionals. In terms of quality of care and psychosocial aftercare, however, these aspects were emphasised more by the patients, than by the professionals (19).

Knowledge about how first-person experience comes into play when patients participate in research processes seems to be lacking. Few studies have explicitly addressed what research topics are important from the patients' point of view and how this may vary between different groups of patients.

The aim of the present study was by means of focus groups interviews to explore what persons who have been critically ill and persons suffering from long-lasting chronic muscle pain, consider as important research topics, based on their own experiences of illness, and encounters with healthcare services.

Methodology and methods

As we wanted to search for research agendas emerging from the informants' first-person perspective, we chose a phenomenological lifeworld approach. Edmund Husserl, the founder of phenomenology, introduced the lifeworld concept as fundamental, both in understanding human existence and scientific activity (20).

Phenomenology has contributed to a wide range of research in various disciplines, also in the field of healthcare. For instance, within physiotherapy and nursing, research with a phenomenological perspective has had a relatively large impact (21-27). One possible reason is that phenomenological research is patient-centered and practice-oriented, in the sense that it addresses problems related to a first-person perspective. Insights into patients' experiences

have an impact on how health professionals understand, meet and care for people with diverse health problems.

Focus groups

Focus group (FG) interviews were used to collect data, a method that is particularly suitable in exploring new fields (28, 29). We chose FGs because group conversations can evoke recognition among the members and thus contribute to varied descriptions of phenomena. The aim was not to reach consensus, but rather to present phenomena in the breadth, variety and shades in the way informants have experienced them (30). During the interviews, it was crucial to elicit an open, wondering and reflective attitude (30).

Participants

The sample consists of 23 participants. The inclusion criteria were experience of challenging health problems related either to acute, critical illness or to chronic unspecific musculoskeletal pain. The critically ill should have been admitted to an intensive care unit with a life threatening illness during the last five years, and the chronically ill should have suffered muscle pain for at least one year. Aiming to explore the experiential basis for user perspectives on important research topics, we sought for illness experiences that are distinctly different in character, and considered specific diagnoses as less significant.

Nine of the participants had been suffering from different serious circulatory, respiratory or neurological diseases, while 14 suffered from fibromyalgia or similar long-term muscle pain conditions (Table 1). Variation in individual experiences within the two target groups and each focus group was emphasised. The management at two hospitals, various physiotherapy outpatient clinics and three patients' organizations were contacted. A contact person at each place helped to distribute information letters to persons who met the inclusion criteria.

Table one

Data collection and analysis

Two FG interviews and one individual interview with persons who had been critically ill, and three FG interviews with persons suffering from chronic illness, were conducted. The research team consisted of three physiotherapists and five nurses; of whom seven were senior researchers and one PhD candidate. Two of the nurses (senior researches) were respectively moderator and co-moderator of the two FGs with the persons who had been critically ill,

while all the three physiotherapists were involved either as moderator or co-moderator of the FGs with the chronically ill participants. The moderators led the group discussions, while the co-moderators supported, observed, took notes and facilitated active participation by all group members during the interviews. An interview guide was used, comprising topics that had relevance to both target groups. The main issues were experiences with being ill, encounters with healthcare professionals, and based on these experiences what they considered as important research topics. The participants were encouraged to talk as freely as possible. The moderator helped keep the conversation running and asked participants to elaborate when necessary. Despite major variation between acute and chronic conditions, we identified some core similarities which indicated saturation.

All interviews, which lasted for approximately two hours, were audio recorded and transcribed verbatim. By phenomenological reflections in analysing the data, we tried to grasp the invariant meanings across the informants' described experiences (30, 31). First, the text of each interview was reflected on to gain an understanding of the participants' experiences. Then, we searched for an understanding of the studied phenomenon across the two subgroups. Finally, an essential meaning structure arose, based on all the interviews. The final structure included significant variations in the meaning of receiving health care across being critically or chronically ill. All members of the research team were active in the analysis both within each group and across target groups.

Ethics

The study was reported to the Data Protection Official for Research, Norwegian Center for Research Data AS (NSD no. 52287). We contacted the management at the recruitment sites to ask for permission and assistance to recruit informants who met the inclusion criteria. All informants received an information letter, and written consent was obtained from all participants. Audio files and transcripts of the interviews were stored at the research server at the university.

Findings

The two patient groups had diametrically opposing experiences in the early stages of their illnesses. Those who suffered from chronic muscle pain came across as the “stepchildren” of health care, quite contrary to those who had suffered critical illness resulting in hospitalisation. In the acute phase, the latter appeared to be the “privileged” ones.

However, a strong meaning structure was identified in both patient groups: *a quest to be taken seriously over time by healthcare professionals*. Patients who had been critically ill conveyed that their acute illness had been taken very seriously. Problems following discharge from hospital however, were not followed up, and they felt left alone. Patients who had muscle pain described a long humiliating process of struggling to be taken seriously, examined properly and to find a name and help for their illness. If chronic illness finally was given a diagnosis, the situation often changed and the communication between patient and health professionals improved. Thus, the essential meaning structure across the two groups appeared with opposite timing and turning points.

A long and lonely struggle for health care

“Not to be taken seriously as a whole person by healthcare workers has perhaps been the hardest of it all.”

This quote was kernel to the accounts of living with long-lasting musculoskeletal pain. The stories portrayed experiences of disbelief, disrespect, trivialisation of ailments and longstanding struggles for proper examinations. Examination was considered crucial for explanation and diagnosis, the prerequisite to appropriate treatment. This burden, experienced from a position of powerlessness, was associated with a sense of abandonment and grief. Participants described how treatment was offered haphazardly, and a lonely struggle for helpful treatment was often experienced. What they requested was supervision, support and long-term follow-up.

Stories about feeling distrusted and struggling for being diagnosed were common. At the same time, there was a general feeling of disempowerment. For example, one woman explained how problems emerging after a car accident were ignored. Ailments had been downplayed by the GP, and it took many years before an x-ray was taken. She continues: “This is what I have said all the time. [...] Actually, it turned out that the spine was clearly lopsided [...] I have said it all the time. I have not been believed!”

To be met with suspicion, had made her mistrust her own experiences: “The main challenge has been that I really have felt treated as a hypochondriac! That suddenly stopped when I was sent to a specialist and he said: “we must take an x-ray.” When severe injury was established, she was sad, yet relieved: “I was really very glad! It was not just nonsense.” Then the doctor believed her, but to be considered a hypochondriac was a destructive experience.

Musculoskeletal pain, downplayed as psychological problems, came across as common experience. One man described how this had effected his self-respect. He used to have a very active life with family, sports, and a demanding job both physically and mentally. A knee injury with consequential back pain had led to a very constricted life with relentless prioritising. The GP did not take the pain seriously: “It must be something else, the doctor said, how is your mood?” This attitude caused frustration: “So when you are not believed ... that was a bit tough in the beginning. It is not that I want sympathy, but ... that they have some understanding.” In despair, he had gone to the Emergency Department, who sent him straight to surgery. With the discharge letter, the “proof” of his condition, he finally felt respected by his GP.

To find a cause for the problem was associated with getting a diagnosis which was prerequisite to successful treatment. One woman quoted her GP’s attitude to her request for a diagnosis: “It can wait until you claim disability benefits.” She had no intention of leaving work. When fibromyalgia was confirmed by a rheumatologist, years later, she had burst out in tears: “Finally a diagnosis! Finally, I know what is wrong with me!” The rheumatologist had asked why she cried. “Well, it is because somebody finally really ...believes me, and has given the condition a diagnosis.” She had struggled hard to find an explanation, but had been criticised for wanting to have a disease.

One woman was hardly off work, despite health problems. She had asked herself why her GP could not take her seriously. When she asked for a sick leave note, he said: “But you like to work, you like to exercise! Push on!” To feel defined as somebody who endures very little had been particularly hurtful, since her doctor knew about the major responsibilities she had endured since she was very young. The struggle to persevere work was described by several participants as a double-edged sword. Work represented a social life and self-respect, but the will to suffer pain and stay at work was often turned against them. Disappointment for lack of support on this important matter was expressed.

All described treatment of limited usefulness, and that treatment was suggested by chance. One woman illustrated: “Help is like ping pong, coincidental”. Another said: “I have been sent to one treatment after the other: acupuncture, physiotherapy, osteopathy, and chiropractor. Random referral, is the big ghost, because the doctors have nothing to offer”, she said. Search for treatment that could help was described as a lonely journey. Some had come across useful knowledge coincidentally. Some had been offered “all or nothing”, shuttling between full-time rehabilitation and nothing, full-time sick leave and full-time work, which was not considered useful. Those who described improvement emphasised that this was solely

due to their own efforts. It involved finding and trying out treatment or health-related practices, which involved perpetually working with sensing oneself and learning to recognise limitations, and to change expectations and demands on oneself. Accounts of positive treatment experiences were particularly related to experiences with psychomotor physiotherapy, described as a process of learning to comprehend ones embodied self in a therapeutic relation based in trust, where time was allowed for, according to their needs. This stood out as supportive and sustained help over time.

A quest for follow-up over time emerged in all three FGs, and a coordinator who could support them through the wilderness of healthcare was suggested. This was specifically expressed when asking participants about topics for research.

A struggle to restore life after total dependence of health care

“When I was in the emergency room, they took it all very seriously, it was just like everything I said was 100 percent true”.

When life was at stake due to critical illness, it was all about survival. Rapid and competent action from health professionals in response to their ailments was highly appreciated. It was also a confirmation of their serious condition: “I think they were very clever, efficient, everything went fast, they knew what to do.” To reach the hospital felt reassuring, as this woman expressed: “When I saw the door of the hospital, I thought, now I'm safe.”

It was comforting to be monitored and looked after: “In the intensive ward there were people nearby all the time, it was safe because my bed was next to the guardroom, they could see me through a window, and two cameras.” The informants praised the professionals: “The treatment I received was completely phenomenal. We have some amazing hospitals in this country.”

Care beyond what was expected made great impressions. After severe heart failure, one woman experienced that the doctor came to the hospital on her day off, telling her: “I'll sit here until you're safe.” Moreover, after transfer to another hospital, the same doctor called to ask how she was doing. The woman was both surprised and grateful. All the care they had received led to gratitude for being alive and made everything else subordinate.

However, the transition from hospital to home or rehabilitation facility was experienced as difficult. Being told they were healthy did not correspond with how they

experienced their altered situation. The discrepancy led to feelings of anxiousness and helplessness. Coming home meant to be confronted with a new bodily experience. Earlier activities and habits could suddenly become unfamiliar, such as climbing up on a chair and not knowing how to get down. It took time to be confident and familiar with the changed body. Not trusting oneself and insecurity could suddenly lead to being afraid of doing what they earlier used to do. A man who had used to go hiking illustrated: “Hundred meters into the forest... so ... the forest was dangerous ...in one way....because then I removed myself from people.”

Changes in capacity with regards to orientation in time and place, as well as lack of self-knowledge were typical. They searched for new ways to handle everyday situations and to compensate for their new insecurity.

A more seamless follow-up, with information and counselling, was asked for. The participants experienced that getting access to a rehabilitation facility in a timely manner was challenging. Being discharged from hospital often meant being left out in the cold: “One is completely forgotten... left to oneself... for there is no follow-up.” Systematic rehabilitation could be denied, either because they were too healthy, or too sick. One woman had asked for a stay at a rehab centre but was rejected, she said: “But now, I was too sick, they did not accept me, and I thought, is it not sick people who need this?” All groups displayed a request for professional support after discharge, which could help in their struggle for living in the best possible way with their changed bodies.

The critical illness led to fundamental changes in their life situation; grief over extensive losses and bereft everyday activities. The participants experienced losing their jobs, colleagues and social networks, as one expressed it: “Unable to have a job anymore, a great sorrow to me... losing a job I was enjoying I have lost some of my identity... “

Adapting to new ways of living had given the informants a hard time. They described periods of depressive emotions and how this came as a surprise and was associated with feelings of shame since they had been given the gift of life anew. One said:

I was so embarrassed, [...] when I had been so lucky to survive such a thing, and then, I get depressed. So, I did not dare to talk about it actually, I simply felt ashamed.

Therefore, I think it should have been mandatory being offered help [...]. Because, I believe it is hard to ask.

Having to inform their own relatives was described as challenging by the participants. There should have been a follow-up and aftercare for the relatives, as one said: “There is no one who cares for the relatives or knows how they actually cope. In many ways I think that they

have a harder time than the one who is ill”. Relatives were not prepared for the new everyday life, the challenges and losses. Training program for caregivers were lacking and requested.

Overall, having received high quality care and surviving critical illness was accompanied by a strong feeling of gratitude. Even so, the participants were unprepared for their situation post-discharge, and often felt left out in the open. Life was changed, and adapting to their new situation was a lonely struggle. Informants asked for professional health care where their next of kin could be more involved throughout the illness trajectory. They also bespoke individualised follow-up programmes. When asked for research topics, more research on follow-up treatment came up as a strong topic.

Discussion

The findings show that both patient groups in different ways emphasised a quest for being taken seriously over time by health care professionals. A general impression was that critically ill patients were the “privileged” ones in the health system, while the chronically ill may be perceived as “stepchildren”. Upon a closer examination, however, the situation might be more nuanced. Although they had all met committed healthcare providers who tried to do the best for them, a pervasive problem, however, seemed to be that the clinical encounters appeared to be fragmented. Patient care seemed to lack continuity, as all informants called for a comprehensive and long-term follow-up treatment that could make it easier to live with their health challenges in daily life.

One may ask why the informants missed continuity in care, whether they were affected by acute illness, or long-term ailments. One possible answer may be that the organisation of healthcare undermines professional cooperation. Fragmented treatment and care is acknowledged in many areas of healthcare, and different models of integrated care (IC) have been developed in attempts of improving this. One frequently cited definition says that integration is “a coherent set of methods and models on the funding, administrative, organisational, service delivery, and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors” (32, p. 3). At the political level, integration reforms are initiated to achieve more efficient and less fragmented practice, but the fact is that positive effects are difficult to document. For example, the authors of a recent systematic review of international IC related intervention studies concluded that they “identified surprisingly little evidence regarding the impact of integrated care models on patient experience of services, beyond measures of reported patient satisfaction” (33, p. 13).

The fact that IC leads to increased patient satisfaction is positive and indicates that integration is important. More substantial effects would, however, be a benefit for further implementation but the many definitions of IC and the fact that most integrative models are complex and contain many elements, makes it difficult to develop a uniform knowledge base (32).

Perhaps future policymakers, researchers and clinical professions must reflect more fully on the professions' different ideologies and theoretical underpinnings to solve some inherent contradictions. Although not explicitly stated, IC seems to be based on a rationality where values like patient centering and user involvement are important, a rationality that does not necessarily characterize current practice and research. Our findings highlight that inadequate coordination and discontinuity in health services pervaded patients' lifeworld and became obstacles to recovery. Moreover, the impact of research based on "soft data" like patients' experience and satisfaction with care, seems to be weak.

The healthcare system has arguably been anchored in a bio-medical paradigm (34-36) and the present study indicates that this still applies. In addition, it is generally assumed that market economy will contribute to a more cost effective healthcare system (37). When one attempts to implement IC in a system that is dominated by reductionism, efficiency, and market economy, conflicts are to be expected. Implementation may turn out to be difficult.

Alternative models do not appear to have gained solid acceptance in clinical practice. Qualitative health research has repeatedly showed that clinical practice does not adequately cover the experience of being ill, neither in terms of chronic nor critical illness. Several studies show for instance that patients with fibromyalgia feel left alone in their search for treatment. Furthermore, they often experience not being respected when presenting their health problems in encounters with health professionals (38- 42). A plausible interpretation is that when the presence of objective signs of disease, in medical terms, are not identified, the patients are left in an unclarified and vulnerable situation. Their illness experience do not hold 'proof', and they experience haphazard and fragmented treatment, as well as rejection. This explains why it becomes so important to get a name to these illnesses; a diagnosis. Studies have also shown that critically ill patients may struggle with psychosocial and physical problems after being discharged from an intensive care unit and have a strong need for support during rehabilitation (43- 45). These findings are in line with the current study, which unequivocally shows that, although the informants had a strong desire to be taken seriously over time, this was most often not the case.

In a phenomenological perspective, bodily expressions and illness must be understood in light of the patients' lifeworld context. When a disease affects the body, it will affect the entire human being. Body and soul are not separate parts, which can be considered separately and summed up, but constitute a whole. Hence, both a patient's lived experience and his bodily expressions are valid sources of knowledge to understand his health problems (46). This contradicts a biomedical approach which does not consider bodily expressions as relevant sources of knowledge. This also goes for the illness experience in itself, as a source of valuable knowledge, and not just as a source of identifying underlying pathophysiological causes. To be labelled as a hypochondriac when no 'objective' signs are found or to be declared cured, post discharge, without any further follow-up, is not only frustrating, but may also worsen the situation, as described by our informants.

One may further ask if user involvement in research can contribute to a more patient-centered and hence less fragmented practice. Both internationally (5) and nationally (6), active user involvement in research is emphasised as important, but inviting patients only as research "subjects" is not considered as user involvement. Although informants do not participate in the planning and conduct of this research, the aim is to bring to the fore their experience, from their angle and as openly as possible. On the other hand, organisation representatives are considered suitable to safeguard user involvement. However, representing a user organisation, does not necessarily mean that the user's own experiences will be expressed independently. These organisations often act as pressure groups and are consultative bodies in health policy issues. Hence, rather than offering personal experiences, representatives may have more of a political role. In addition, there is a requirement for training of the representatives (5), which may cause a shift from the patient role towards the researcher's perspective. In a comment to the guidelines' emphasis on representation in user involvement, Feiring et al (47) ask whether this may challenge the goal of increased democratization in research.

According to a phenomenological approach we adopted a first-person's perspective and asked the informants to recount their experiences as patients. Based on these experiences, we further asked them to reflect on what they considered as important research topics. Although some were recruited from patients' organisations, we emphasised that it was their individual experiences we were looking for. We would like to argue that such participation also is essential in the democratization process, to avoid a distance to the first-person's perspective.

Nevertheless, we cannot without reservation take the users' experiences as a basis for practical implications or health policy planning. It cannot be taken for granted that all users have similar experiences and thus speak with the same voice. However, it is important that the users perception is taken seriously and included in the development of a research agenda and that central topics that emerge will be addressed in further research.

Conclusion

Through the analysis of the present study, we came up with a meaning structure stating that both critically and chronically ill persons experienced that they were not taken seriously over time within the health care system. Furthermore, we discussed how this might be the case, even after many years of various measures to democratise health care. We suggest that part of the answer may be that clinical practice is still dominated by a biomedical paradigm with a reductionist understanding of illness. Although the two groups experienced this at different points in the illness trajectory, a reasonable interpretation may be that continuity in health care services should be placed on the research agenda, to a greater extent. We will further conclude that user involvement in all parts of the research process is important in the democratisation process, and that the users' own experiences must also be highlighted as essential in this process. The user involvement paradigm calls for taking a lifeworld perspective seriously.

Table 1: Participants

	Critical illness	Chronic illness	Critical illness FG 1	Critical illness FG 2	Chronic illness FG 1	Chronic illness FG 2	Chronic illness FG 3
Sex (male/female)	5/4	3/11	2/3	3/0	0/5	1/4	2/2
Critical illness (circulatory/respiratory/neurological)	5/1/3		3/0/2	2/1/1*			
Musculoskeletal disorder		14			5	5	4
Recruitment (patients' organisations/health care facilities)	6/3	4/10	5/0	1/2	2/3	2/3	0/4

* One participant was prevented from attending the focus group and was interviewed individually

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Conflict of Interest

The authors have stated explicitly that there are no conflicts of interest in connection with the article

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