PATIENT PARTICIPATION IN EMERGENCY CARE
-A PHENOMENOGRAPHIC STUDY BASED ON PATIENTS’ LIVED EXPERIENCE

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ABSTRACT International guidelines promote patient participation in health care. When
patients participate in their care they experience greater satisfaction. Studies have shown that
patients in emergency departments express dissatisfaction with their care, and it was therefore
important to study how patients understand and conceptualize their participation. The aim of
this study was to describe patients’ qualitatively different conceptions of patient participation
in their care in an emergency department. Based on a lifeworld perspective, nine interviews
were performed with patients in an emergency department. The phenomenographic analysis
shows that participation by patients means contact with the emergency department staff in
three categories of conceptions: being acknowledged; struggling to become involved; and
having a clear space. The different conceptions of patient participation give us a deeper
understanding of how patients may experience their care, and this result may provide a
foundation for developing nursing practice and the quality of health care in line with
international guidelines.

Keywords: caring, emergency department, patient, participation, lifeworld, phenomenography
INTRODUCTION

The present study is part of a larger project concerning patient participation in an emergency department (ED), where patient participation was first studied from the perspective of emergency department (ED) staffs (Frank et al., in press). The participants were assistant nurses, nurses and physicians, and the main finding was that patient participation was mainly at the conditional discretion of ED staff. Mutual participation was perceived as being occasional, and often unexpected, occurring when the right circumstances prevailed. In light of ED staff conceptions, it was of further interest to study patient participation from the patient’s point of view.

BACKGROUND

In western countries, patient participation at all levels of health care planning is considered valuable (Hostick, 2005). The international declaration made at Alma-Ata (World Health Organization WHO 1978, p.1) states: “People have the right and the duty to participate individually and collectively in the planning and implementation of their health care”. When patients are able to participate and be actively involved in their care this has an impact on their perception of satisfaction (Johansson et al. 2002, Schröder et al. 2005).
Patient participation requires that formal health carers are willing to focus on the interpersonal relationship between patients and carer, as well as having an attitude that enables patients to relate to them as subjects taking part in the care (Enehaug, 2000).

Moreover, patient participation has been studied from the patients’ view in care areas other than ED. Patients describe participation as promoting confidence and independence, and as enabling them to comprehend and maintain a sense of control in a shared and equal relationship with nurses (Eldh et al. 2004, Larsson et al. 2007, Tutton, 2005). However, patients also highlight the complexity of participation by describing difficulties in communicating with the carer (Penney and Wellard, 2007). Non-participation identifies barriers between patients and carer and is deemed by patients to demonstrate a lack of relationship, respect and information that results in failure of communication (Eldh et al. 2004, Eldh et al. 2006).

ED nurses refer to there being insufficient time to establish a relationship with the patient, and there is a tendency for ED staff to focus on instrumental behaviour rather than on psychosocial care (Lewis and Woodside, 1992, Nyström, 2002, Wiman and Wikblad, 2004).

Bruce et al. (1998) show that the level of patient satisfaction in the ED is high, but that the quality of care can improve. Studies in this area have mainly described patient satisfaction in the form of quantitative data, and while some proposed models have worked successfully, these results are restricted by a limited number of variables compared with qualitative research, and Nairn et al. (2004) suggest further qualitative research to improve the depth of areas of concern. Confounding these findings, qualitative studies show that patients in ED have reason to be dissatisfied with the care situation (Watson et al. 1999, Crowley, 2000, Nydén et al. 2003, Nyström et al. 2003). Results regarding the quality of patient care in EDs thus appear to vary and should be brought into line in order to understand better the
phenomenon of patient participation. The aim of this study was to describe patients’ qualitatively different conceptions of patient participation in their care in an emergency department.

METHODS

In this study we used phenomenography with an epistemological base in lifeworld theory, as recommended by Ashworth and Lucas (1998). The aims of phenomenography and lifeworld theory are to describe how human beings create meaning and meaningfulness in relation to their surrounding world, on the assumption that humans form thoughts concerning phenomena they encounter (Ashworth and Lucas, 1998, Dahlberg et al. 2007). Wenestam (2000) describes phenomenography as a research method grounded in describing qualitatively different ways in which people experience and conceptualize various phenomena in the world.

The phenomenon in this study is patient participation. According to Bengtsson (1998), the lifeworld is characterized by a natural attitude toward life, where one’s relation to everyday life is taken for granted. The main methodological principle supporting this study is that earlier unreflected knowledge is achieved through an openness that is sensitive to unique experiences, and is therefore different from knowledge that is taken for granted (Dahlberg et al. 2007). In addition Dahlberg et al. (2007) argue for reflective knowledge, and participants are invited during the interview to give nuance of description.

Sample
The sample consisted of nine patients who earlier had been cared for in an ED in a metropolitan district in Sweden. In accordance with the phenomenographic method, a strategic sample was taken to obtain maximal variation in description of the phenomenon among the participants (Wenestam, 2000). The selection criteria were sex, age, and patients from different sections of the ED (medical, infectious diseases, orthopaedic, surgical and ear, nose and throat sections). The inclusion criteria for participants were ability to speak a language that could be understood by the interviewer. The nine participants were four women and five men, and were aged between 26 and 73 years. Before the interviews began the participants were guaranteed confidentiality. Participants were informed in writing and verbally that participation was voluntary and that they were free to withdraw at any time. The study was approved by the ethics committee of the Karolinska Institute, Sweden (490/03) as well as by the heads of the EDs.

Data collection

Data were collected during 2006 and the interviews were conducted by the first-named author in the form of a dialogue. The interview questions were open-ended in order to let the participant choose the dimensions of the question they wished to address (Marton, 1994, Dahlberg et al. 2007). The first question posed to each participant was to describe how they experienced their visit to the ED. The audio-taped interviews lasted between 25 and 90 minutes and were transcribed verbatim.

Analysing process
Data consisting of transcribed interviews concerning patient participation were scrutinized in order to perceive each participant’s way of understanding them (Wenestam, 2000). Following this strategy, the transcripts were then carefully read until close acquaintance with the material was established. The repeated reading of the transcripts was conducted with openness, immediacy, and with a unique approach to each in order to allow sensitivity to the nuances of meaning (Dahlberg et al. 2007).

When familiarity with the text material had been achieved the following question was asked: “What is patient participation?” The answers to the question were then extracted to create meaning units concerning the phenomenon. The meaning units contained the patients’ expressions of patient participation. After further reading with a focus on differences and similarities, a pattern emerged consisting of twelve preliminary categories of description. Further comparisons between the preliminary categories were carried out to find sources of variation or agreement in order to constitute comprehensive, conceptive descriptions (Wenestam, 2000). After further revision of the categories three qualitatively different categories describing the patients’ conceptions of patient participation in an ED emerged.

RESULTS

The patients’ conceptions of patient participation can be described in three qualitatively different descriptive categories: being acknowledged; struggling to become involved; and having a clear space.

Being acknowledged
In this category, patients perceive that they are acknowledged when they experience a limited contact with the ED staff. It is the ED staffs who take the initiative in establishing contact with the patient. The basis of contact is focused on the medical aspects of illness rather than on the patient as a person. Being acknowledged means being noticed through eye and/or verbal contact when the patient’s condition so demands. Patients say that they would be satisfied if they could just have a meagre amount of contact with ED staff. Depending upon patients’ previous experience of care in EDs they have low expectations and adapt to the situation. However, it is the ED staff who lay down the conditions for when and how that participation will take place and in what form. The conceptions include it being the technical medical aspects of the patient’s condition that prompts the ED staff’s perceptions. Care actions appropriate to the condition or illness are then administered, and information and advice are given to the patient concerning the situation. The following quote illustrates how a patient perceives contact with the carer on technical medical issues:

“The only contact I had with her was when she came with huge needles. Again, they do not observe other needs, when they come to me it’s when they have to do something to me, give me a jab or take me somewhere.” (woman, aged 42)

Patient participation means being acknowledged again and again over time. This form of participation is considered to be less important, and it is the contact between patient and ED staff that is central. However, such limited connection leads patients to perceive that they participate in their own caring situation. For the patient, the contact may just as well involve day-to-day matters as medical information. It is when ED staff observe the patients’ body language and offer help that patients say that they are participating.
Patients consider themselves to be participating when ED staff give them information relevant to their circumstances and about what is going on around them. ED staff decide what type of information to give without asking the patient what they would like to know. Brief contact occurs in these situations in which information is given, normally of a medical nature. Patients attending the ED adjust themselves to the existing care culture as they have heard from others or learnt from earlier experience. When patients arrive at the emergency care unit they explain their problem in detail. Afterwards, they wait quietly for someone to attend to them and hope to participate. By waiting in silence, patients show their understanding of the ED staffs’ work situation.

Struggling to become involved

In this category patients perceive that they are marginalized, that they do not have the contact they would like with ED staff and that they are frustrated. Patient participation means that patients refuse to subordinate themselves to the existing care culture. In this case, it is the patients who take the initiative to participate. When patients make their voices heard it is to call attention to their presence.

Patients have different strategies’ for participating in their own care process. One strategy is when patients themselves call repeatedly for contact with ED staff. Communication between the patient and ED staff has not yet been established, the patient strives to achieve contact through repeated attempts at participation. Patients can be insistent and persistent in their attempts to create contact with their ED staff. In other cases, patients wish to find out more about their situation, and by asking about and calling into question the information they are given by the ED staff they feel as if they are participating. Patients who are more aware of what will happen create a sense of control for themselves. However, in cases when patients
have read up on their condition, are knowledgeable or ask for information about medical examinations or treatments, they consider themselves to be met with a dismissive attitude on the part of ED staff. The following quote illustrates different strategies for how patients can present their criticisms about care in ED:

“Ordinary people who complain are regarded as something to be ignored. You have incredibly little chance of influencing things as a patient. You can file a complaint under the Health and Medical Services Act and so on and contact the public medical service, but on the whole they rarely listen to you as a patient.” (man, aged 50)

Another strategy is when patients perceive that relatives can provide support in the struggle to become involved. If patients themselves are unable to apply sufficient pressure, relatives can help to gain ED staff’s attention. The relatives and/or patients can try to monitor and listen to conversations between carers, in order to gain information that may be relevant to their situation.

A third strategy for patient participation is more drastic, such as shouting out loud, becoming unpleasant or even aggressive in attempts to ensure that they have not been forgotten. Patients say that it cannot always be taken for granted that ED staff are willing to listen to them and they consider themselves to be of low priority within the emergency ward organization. When ED staff members do not listen, patients use various methods to gain attention. Patients consider the situation to be a power struggle, with themselves as underdogs. After lengthy attempts to make contact with ED staff, patients behave in a disagreeable way. Patients find themselves in an impossible situation, they are in pain and
worried, and yet are unable to make a connection with the ED staff, who they perceive must have other important things to do.

A fourth strategy for struggling to become involved is to see possible ways of using other means to lodge criticism, either using a complaints box, formally registering a complaint or taking part in health care surveys. Patients wish to convey negative criticism of their care. However, patients consider it difficult to make their protest heard when the ED staff are, they feel, blinded by feelings of superiority and not interested in listening to complaints.

Having a clear space

In this category, patients perceive that they do not have to do anything; they are fully entitled to personal and physical space and the ED staff’s attention. This category differs from the others in that the initiator of patient participation is of secondary importance. Patient and ED staff establish a relationship in which patients considers themselves to be experts on their own care situation: patients consider themselves to be respected and acknowledged as individuals and not reduced to medical diagnoses. A dialogue is created that transcends the professional technicalities of caring.

Having a clear space means that ED staff are at hand, and listen to and understand patients’ concerns about matters other than purely medical issues. Patients can explain what disturbs or worries them, and irrespective of what they say or ask, ED staffs treat them respectfully. Both parties interact in a dialogue where patients note a response and have their questions answered.

The dialogues do not require a long period of time when ED staffs focus on what is important to patients. When ED staff address the person and not the medical condition it means that they are concerned with what the patient considers essential. Having a clear space means when the
ED staff take stock of the patients’ whole life situation. The following quote illustrates an ED staff member taking stock of the patient’s life situation:

“Yes, she was gentle and kind and asked questions; she asked me things. Yes, she understood that I had been in considerable pain and then of course I was also a little concerned for the children, who I had left with a neighbour in the middle of the night. I didn’t feel good about that, I can imagine that there are many people who are in the same situation, having to leave their children like that.” (woman, aged 35)

Having a clear space means being treated courteously, without indifference and scepticism on the part of ED staff. Participation is considered to be welcomed when ED staff express interest and ask open-ended questions in a language that patients understand. Questions presuppose that there will be time and opportunity for the patient to reply. ED staff members who act in an overbearing manner and/or use language that patients do not understand create a barrier to the patient’s participation.

Participation occurs in situations where ED staff are regarded as sensitive to patients’ feelings, fear, insecurities and anxiety. A shared dialogue between partners means that ED staff respect and show understanding for a patient’s need for everyday care and attention. Having a clear space also means that the ED staff show understanding for common needs that change over time. Patients’ perceptions of clear space are dependent upon the ED staff’s work situation and/or their willingness to participate. Patients say that it is a matter of chance whether they are going to be able to participate, because it will depend on how many patients are waiting for treatment, the time an ED staff member can allocate to them, and their priority amongst all the other patients. When ED staff give patients a moment of commitment it
means that they can talk to each other in peace and quiet without feeling stressed. It may also
be important to the patient that ED staff members are recognizable, because this creates a
feeling of trust. This trust is built on the continuity created by dealing with the same ED staff
and a relationship over the time spent at the hospital. Patients perceive that they are important
when ED staff express the need for and value the continuity that has been created. It was
when patients conceptualized that ED staff considered them important that they felt
themselves to be truly participating. To have a clear space presupposes that patients know
something about their condition, that they have courage to ask questions or express their
wishes. Patients make demands on themselves in this dialogue by taking on responsibility for
communicating their concerns.

DISCUSSION

Method

We have tried to describe the process of analysis as carefully as possible and validity can
therefore be achieved in these results, built on lifeworld theory (Dahlberg et al. 2007). The
results may have important implications for other EDs. Data were, however, collected in
Sweden and their transferability to other contexts, e.g. other countries, is therefore uncertain.
Data in the present study were collected from nine participants cared for in one ED, and it is
uncertain how varying states of health and willingness or ability to participate may have
influenced the recruitment of informants. However, interviews were conducted following a
lifeworld perspective with openness to otherness as a main feature, and patients were
couraged to include all previous experiences of being cared for in an ED.
Results

Our results describe patients’ qualitatively different conceptions about their participation in three categories: being acknowledged; struggling to become involved; and having a clear space. They might have some important implications for practice and include essential information for staff working in an ED. Patients cannot be treated as a single homogeneous group of people, due to their different needs for participation. They explicitly state that they need to be cared for individually. Our results show that patient participation in a working relationship does not necessarily need a large amount of time, in contrast to other studies examining the ED staff’s point of view (Lewis and Woodside, 1992, Nyström, 2002). Accordingly, there are instances of participation requiring more time, but participation and recognition could also be attained by one or other brief moments of contact. Patient participation does not demand extended therapy-like conversations, as some nurses working in wards have described (Sahlsten et al. 2005). In the first category, our results acknowledge a sense of participation when patients receive even a small moment of contact when ED staff give attention to technical medical issues. In these short technical encounters, patients perceive a sense of satisfaction, which can relate to the need to be seen as a medical diagnosis. It could, however, also mean that patients have adapted to the existing, non-participatory culture in the ED. In these settings, patients do not have high expectations for the level of care, in line with Cassidy-Smith et al. (2007), who show that patients’ experience of satisfaction is dependent upon the patient’s level of expectation. According to this result patients are regarded merely as medical conditions, and other studies show that nurses and assistant nurses working in emergency care departments may find it difficult to anything beyond the biological body. Nyström (2002) has described this as a lack of holistic perspective that is dependent on various obstacles such as time and presence. In the
hierarchy of care, nurses are not the obvious organizers of care because of their subordinate position. There may consequently be less focus on holism and individual-centred care, which further complicates patient participation (Jewell, 1996).

Our findings suggest that patient participation means a struggle to be involved and a refusal to subordinate oneself to the existing culture. However, patients describe themselves as being in the hands of ED staff, and trying to engage in self-confident behaviour in relation to their own care situation, but state that this is difficult. Patients tend to feel dissatisfaction after waiting a long time in the ED and sometimes conceptualize themselves as marginalized. The organization of care and of priorities is complex and almost impossible to understand for patients. According to Nyström et al. (2003), patients attending the ED are ranked in a system of medical priority and non-urgent patients are expected to wait for several hours. Patients, on the other hand, perceive themselves as being ill and in need of immediate help. Even if their care is deemed to be non-urgent from the ED staff’s point of view, they still require confirmation (Eriksson and Svedlund, 2007), as well as corroboration, regarding the importance of their circumstances.

Our results support previous findings (Enhaug, 2000, Schuster, 2006) that patients may experience an attitude from nurses as though they have exclusive knowledge of what it means to be a patient. Nurses in this asymmetric relationship may carry images of how they can meet all patient needs with common knowledge. Surprisingly, the concept of caring assumes patient needs as a point of departure, but perceptions of holding exclusive knowledge serve only to maintain an asymmetric relation (Schuster, 2006).

Patients pointed out the importance of being viewed as humans, as well as being the starting point for care actions, in the category of having a clear space. Our findings agree with recent studies showing how participants perceive themselves as participating in a self-confident,
shared and identical relationship with the carer (Eldh et al. 2004, Tutton, 2005, Larsson, 2007, Penney and Wellard, 2007). Patient participation means gaining the understanding of ED staff for their entire life situation. Nurses’ encounters with suffering humans are not only about solving problems, they are also concerned with being present and engaged (Shuster, 2006). According to Hughes (2003) and Eldh et al. (2006), patient participation assumes that patients are appreciated as experts in their own experience. Our findings categorically support this finding and show that patients also conceptualize carers’ willingness to understand. ED staff may in these situations also be perceived as being motivated to recognize more existential needs among patients. In a previous study (Nyström, 2002), staff working in ED describes care as actions relating only to practical matters, and consider that patients do not need nursing care and are just waiting for the medical examination. Our findings highlight the importance of ED staff listening closely to patients. Patient participation is considered when the patient’s voice is heard; the patients are shown respect for their self-determination as being able to understand their life and suffering, and a balance of power is experienced. Understanding and respect for the patient’s feelings are important since patients describe themselves as being frightened and anxious in a new, scary environment. In such a valued position, the patient is given a new sense of status when they are recognized by the professional carer (Schuster, 2006).

CONCLUSION

Patients conceptualize patient participation as contact with ED staff from three different perspectives, depending on the ED staff members’ attitude and the care setting in the ED. For clinical implications it is significant that patients can have different needs for participation and therefore it is important that the patient is the starting point for all care actions. Patient
participation does not require extended time in therapy-like conversations and even if the
organisation of care in ED regards patients as non-urgent they nevertheless desire to be cared
for.

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