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1 PATIENT PARTICIPATION IN EMERGENCY CARE
2 -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

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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).

1 Patient participation requires that formal health carers are willing to focus on the interpersonal
2 relationship between patients and carer, as well as having an attitude that enables patients to
3 relate to them as subjects taking part in the care (Enehaug, 2000)
4
5 Moreover, patient participation has been studied from the patients' view in care areas other
6 than ED. Patients describe participation as promoting confidence and independence, and as
7 enabling them to comprehend and maintain a sense of control in a shared and equal
8 relationship with nurses (Eldh et al. 2004, Larsson et al. 2007, Tutton, 2005). However,
9 patients also highlight the complexity of participation by describing difficulties in
10 communicating with the carer (Penney and Wellard, 2007). Non-participation identifies
11 barriers between patients and carer and is deemed by patients to demonstrate a lack of
12 relationship, respect and information that results in failure of communication (Eldh et al.
13 2004, Eldh et al. 2006).

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

17 Bruce et al. (1998) show that the level of patient satisfaction in the ED is high, but that the
18 quality of care can improve. Studies in this area have mainly described patient satisfaction in
19 the form of quantitative data, and while some proposed models have worked successfully,
20 these results are restricted by a limited number of variables compared with qualitative
21 research, and Nairn et al. (2004) suggest further qualitative research to improve the depth of
22 areas of concern. Confounding these findings, qualitative studies show that patients in ED
23 have reason to be dissatisfied with the care situation (Watson et al. 1999, Crowley, 2000,
24 Nydén et al. 2003, Nyström et al. 2003). Results regarding the quality of patient care in EDs
25 thus appear to vary and should be brought into line in order to understand better the

1 phenomenon of patient participation. The aim of this study was to describe patients'
2 qualitatively different conceptions of patient participation in their care in an emergency
3 department.

4

5

METHODS

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7 In this study we used phenomenography with an epistemological base in lifeworld theory, as
8 recommended by Ashworth and Lucas (1998). The aims of phenomenography and lifeworld
9 theory are to describe how human beings create meaning and meaningfulness in relation to
10 their surrounding world, on the assumption that humans form thoughts concerning
11 phenomena they encounter (Ashworth and Lucas, 1998, Dahlberg et al. 2007). Wenestam
12 (2000) describes phenomenography as a research method grounded in describing qualitatively
13 different ways in which people experience and conceptualize various phenomena in the world.

14

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

22

23 Sample

24

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

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15 Data collection

16

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

23

24 Analysing process

25

1 Data consisting of transcribed interviews concerning patient participation were scrutinized in
2 order to perceive each participant's way of understanding them (Wenestam, 2000). Following
3 this strategy, the transcripts were then carefully read until close acquaintance with the
4 material was established. The repeated reading of the transcripts was conducted with
5 openness, immediacy, and with a unique approach to each in order to allow sensitivity to the
6 nuances of meaning (Dahlberg et al. 2007).
7 When familiarity with the text material had been achieved the following question was asked:
8 "What is patient participation?" The answers to the question were then extracted to create
9 meaning units concerning the phenomenon. The meaning units contained the patients'
10 expressions of patient participation. After further reading with a focus on differences and
11 similarities, a pattern emerged consisting of twelve preliminary categories of description.
12 Further comparisons between the preliminary categories were carried out to find sources of
13 variation or agreement in order to constitute comprehensive, conceptive descriptions
14 (Wenestam, 2000). After further revision of the categories three qualitatively different
15 categories describing the patients' conceptions of patient participation in an ED emerged.

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RESULTS

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

22

23 Being acknowledged

24

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

14

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

18

19

20 Patient participation means being acknowledged again and again over time. This form of
21 participation is considered to be less important, and it is the contact between patient and ED
22 staff that is central. However, such limited connection leads patients to perceive that they
23 participate in their own caring situation. For the patient, the contact may just as well involve
24 day-to-day matters as medical information. It is when ED staff observe the patients' body
25 language and offer help that patients say that they are participating.

1 Patients consider themselves to be participating when ED staff give them information
2 relevant to their circumstances and about what is going on around them. ED staff decide what
3 type of information to give without asking the patient what they would like to know. Brief
4 contact occurs in these situations in which information is given, normally of a medical nature.
5 Patients attending the ED adjust themselves to the existing care culture as they have heard
6 from others or learnt from earlier experience. When patients arrive at the emergency care unit
7 they explain their problem in detail. Afterwards, they wait quietly for someone to attend to
8 them and hope to participate. By waiting in silence, patients show their understanding of the
9 ED staffs' work situation.

10

11 Struggling to become involved

12

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

18 Patients have different strategies' for participating in their own care process. One strategy is
19 when patients themselves call repeatedly for contact with ED staff. Communication between
20 the patient and ED staff has not yet been established, the patient strives to achieve contact
21 through repeated attempts at participation. Patients can be insistent and persistent in their
22 attempts to create contact with their ED staff. In other cases, patients wish to find out more
23 about their situation, and by asking about and calling into question the information they are
24 given by the ED staff they feel as if they are participating. Patients who are more aware of
25 what will happen create a sense of control for themselves. However, in cases when patients

1 have read up on their condition, are knowledgeable or ask for information about medical
2 examinations or treatments, they consider themselves to be met with a dismissive attitude on
3 the part of ED staff. The following quote illustrates different strategies for how patients can
4 present their criticisms about care in ED:

5

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

10

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

16

17 A third strategy for patient participation is more drastic, such as shouting out loud, becoming
18 unpleasant or even aggressive in attempts to ensure that they have not been forgotten.

19 Patients say that it cannot always be taken for granted that ED staff are willing to listen to
20 them and they consider themselves to be of low priority within the emergency ward
21 organization. When ED staff members do not listen, patients use various methods to gain
22 attention. Patients consider the situation to be a power struggle, with themselves as
23 underdogs. After lengthy attempts to make contact with ED staff, patients behave in a
24 disagreeable way. Patients find themselves in an impossible situation, they are in pain and

1 worried, and yet are unable to make a connection with the ED staff, who they perceive must
2 have other important things to do.

3 A fourth strategy for struggling to become involved is to see possible ways of using other
4 means to lodge criticism, either using a complaints box, formally registering a complaint or
5 taking part in health care surveys. Patients wish to convey negative criticism of their care.

6 However, patients consider it difficult to make their protest heard when the ED staff are, they
7 feel, blinded by feelings of superiority and not interested in listening to complaints.

8 Having a clear space

9
10 In this category, patients perceive that they do not have to do anything; they are fully entitled
11 to personal and physical space and the ED staff's attention. This category differs from the
12 others in that the initiator of patient participation is of secondary importance. Patient and ED
13 staff establish a relationship in which patients considers themselves to be experts on their own
14 care situation: patients consider themselves to be respected and acknowledged as individuals
15 and not reduced to medical diagnoses. A dialogue is created that transcends the professional
16 technicalities of caring.

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

22 The dialogues do not require a long period of time when ED staffs focus on what is important
23 to patients. When ED staff address the person and not the medical condition it means that they
24 are concerned with what the patient considers essential. Having a clear space means when the

1 ED staff take stock of the patients' whole life situation. The following quote illustrates an ED
2 staff member taking stock of the patient's life situation:

3

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

9

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

16

17 Participation occurs in situations where ED staff are regarded as sensitive to patients'
18 feelings, fear, insecurities and anxiety. A shared dialogue between partners means that ED
19 staff respect and show understanding for a patient's need for everyday care and attention.

20 Having a clear space also means that the ED staff show understanding for common needs that
21 change over time. Patients' perceptions of clear space are dependent upon the ED staff's work
22 situation and/or their willingness to participate. Patients say that it is a matter of chance
23 whether they are going to be able to participate, because it will depend on how many patients
24 are waiting for treatment, the time an ED staff member can allocate to them, and their priority
25 amongst all the other patients. When ED staff give patients a moment of commitment it

1 means that they can talk to each other in peace and quiet without feeling stressed. It may also
2 be important to the patient that ED staff members are recognizable, because this creates a
3 feeling of trust. This trust is built on the continuity created by dealing with the same ED staff
4 and a relationship over the time spent at the hospital. Patients perceive that they are important
5 when ED staff express the need for and value the continuity that has been created. It was
6 when patients conceptualized that ED staff considered them important that they felt
7 themselves to be truly participating. To have a clear space presupposes that patients know
8 something about their condition, that they have courage to ask questions or express their
9 wishes. Patients make demands on themselves in this dialogue by taking on responsibility for
10 communicating their concerns.

11

12 DISCUSSION

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14 Method

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

25

1 Results

2

3 Our results describe patients' qualitatively different conceptions about their participation in
4 three categories: being acknowledged; struggling to become involved; and having a clear
5 space. They might have some important implications for practice and include essential
6 information for staff working in an ED. Patients cannot be treated as a single homogeneous
7 group of people, due to their different needs for participation. They explicitly state that they
8 need to be cared for individually. Our results show that patient participation in a working
9 relationship does not necessarily need a large amount of time, in contrast to other studies
10 examining the ED staff's point of view (Lewis and Woodside, 1992, Nyström, 2002).

11 Accordingly, there are instances of participation requiring more time, but participation and
12 recognition could also be attained by one or other brief moments of contact. Patient
13 participation does not demand extended therapy-like conversations, as some nurses working
14 in wards have described (Sahlsten et al. 2005). In the first category, our results acknowledge a
15 sense of participation when patients receive even a small moment of contact when ED staff
16 give attention to technical medical issues. In these short technical encounters, patients
17 perceive a sense of satisfaction, which can relate to the need to be seen as a medical diagnosis.
18 It could, however, also mean that patients have adapted to the existing, non-participatory
19 culture in the ED. In these settings, patients do not have high expectations for the level of
20 care, in line with Cassidy-Smith et al. (2007), who show that patients' experience of
21 satisfaction is dependent upon the patient's level of expectation.

22 According to this result patients are regarded merely as medical conditions, and other studies
23 show that nurses and assistant nurses working in emergency care departments may find it
24 difficult to anything beyond the biological body. Nyström (2002) has described this as a lack
25 of holistic perspective that is dependent on various obstacles such as time and presence. In the

1 hierarchy of care, nurses are not the obvious organizers of care because of their subordinate
2 position. There may consequently be less focus on holism and individual-centred care, which
3 further complicates patient participation (Jewell, 1996).

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

16

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

23 Patients pointed out the importance of being viewed as humans, as well as being the starting
24 point for care actions, in the category of having a clear space. Our findings agree with recent
25 studies showing how participants perceive themselves as participating in a self-confident,

1 shared and identical relationship with the carer (Eldh et al. 2004, Tutton, 2005, Larsson, 2007,
2 Penney and Wellard, 2007). Patient participation means gaining the understanding of ED
3 staff for their entire life situation. Nurses' encounters with suffering humans are not only
4 about solving problems, they are also concerned with being present and engaged (Shuster,
5 2006). According to Hughes (2003) and Eldh et al. (2006), patient participation assumes that
6 patients are appreciated as experts in their own experience. Our findings categorically support
7 this finding and show that patients also conceptualize carers' willingness to understand. ED
8 staff may in these situations also be perceived as being motivated to recognize more
9 existential needs among patients. In a previous study (Nyström, 2002), staff working in ED
10 describes care as actions relating only to practical matters, and consider that patients do not
11 need nursing care and are just waiting for the medical examination. Our findings highlight the
12 importance of ED staff listening closely to patients. Patient participation is considered when
13 the patient's voice is heard; the patients are shown respect for their self-determination as
14 being able to understand their life and suffering, and a balance of power is experienced.
15 Understanding and respect for the patient's feelings are important since patients describe
16 themselves as being frightened and anxious in a new, scary environment. In such a valued
17 position, the patient is given a new sense of status when they are recognized by the
18 professional carer (Schuster, 2006).

19

20

CONCLUSION

21

22 Patients conceptualize patient participation as contact with ED staff from three different
23 perspectives, depending on the ED staff members' attitude and the care setting in the ED. For
24 clinical implications it is significant that patients can have different needs for participation
25 and therefore it is important that the patient is the starting point for all care actions. Patient

1 participation does not require extended time in therapy-like conversations and even if the
2 organisation of care in ED regards patients as non-urgent they nevertheless desire to be cared
3 for.

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