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Patient Participation in the Emergency Department: an evaluation using a specific instrument to measure patient participation (PPED)

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Aim: This study aimed at evaluating patient participation from the perspective of patients who received care in emergency departments, with a separate examination of the relationship between participation and age, sex, education and priority level.

Background: International and national guidelines encourage patient participation. High patient participation is required to ensure a high quality of care. No studies evaluating patient participation at an emergency department have been published.

Methods: An evaluating study, with the Patient Participation Emergency Department questionnaire, was conducted at emergency departments in Sweden. A consecutive sample of 356 patients participated. Data was collected in 2008: participants were 49% women and with an average age of 56 years. The statistical methods used were Student's t-test, one-way ANOVA and Spearman correlation.

Results: The results revealed that patients experienced good requirement such as time and information for participation. Mutual participation demonstrated a reasonable level but patient participation is low in two dimensions (Fight for participation, Participation in getting basic needs satisfied). Young and well-educated patients fought more to participate in their care and gained less attention for basic needs than older and less well-educated patients.

Conclusions: Patient participation in a mutual care situation between patients and healthcare professionals requires further improvement to ensure that patients are satisfied and do not have to struggle and fight in order to participate in their care.

Keywords: questionnaire, caring, emergency department, patient participation, evaluation, patient perspective, nursing

SUMMARY STATEMENT

What is already known about this topic

- Patients perceive that the quality of care is acceptable when they are given the opportunity to participate.
- Patient participation has been identified as an area for improvement in emergency departments.
- An evaluation of patient participation from the perspective of patients in emergency departments has not been published.

What this paper adds

- Patients believe that the requirements for participating in their care are good.
- Mutual participation and participation in getting basic needs satisfied need further improvement.
- Patients have to fight sometimes in order to achieve participation.

Implications for practice and/or policy

- It will be valuable to identify areas for patient participation in emergency departments, and this will promote further development and improvement.
- The results can be used to gain useful knowledge for healthcare professionals and contribute towards changing attitudes in caring situations, in order to facilitate patient participation.

INTRODUCTION

Patient participation is an important factor to consider when measuring the quality of care (QoC) (Boudreaux and O'Hea 2004, Muntlin et al. 2006) and it is, of course, important when the patient is the unique starting point for all care actions (Tutton 2005, Eldh et al. 2006b, Larsson et al. 2007, Frank et al. 2009b). Patient participation in nursing is defined as the nurse relinquishing a certain amount of power and control to the patient: it is demonstrated in the sharing of information and knowledge between nurse and patient, and through active engagement in intellectual and/or physical activities that take place in the relationship that is established between them (Sahlsten et al. 2008). Several nursing theorists include participation implicitly (Watson 1979, Paterson 1988, King 1989) or explicitly (Peplau 1992) in their work, stating that nurses have a responsibility to help patients improve at participating in solving problems, rather than simply providing solutions. Patient participation is a healthcare objective in several Western countries (SFS 1982, Johnson and Silburn 2000,

Hostick et al. 2005, WHO 2006) and it is therefore of international relevance. The Swedish government has expressed this explicitly in the Health and Medical Services Act (SFS 1982). Patient participation in the emergency department (ED) requires organisation and time, since patients are almost always in need of urgent attention when they arrive, and there are considerable variations in patient flow (Frank et al. 2009a, Frank et al. 2009b). When the pace of work increases at the ED, healthcare professionals give less attention to the needs of each individual patient (Frank et al. 2009a, Frank et al. 2009b). This leads to patients not always being satisfied with the care received in EDs (Watson et al. 1999, Crowely 2000, Nyström 2003, Muntlin et al. 2006). Patient satisfaction with the ED is lower among patients who are considered to be non-urgent patients than it is among those who are categorised as immediate and urgent patients (Hansagi 1992), and men and women experience their hospital visits differently (Foss and Hofoss 2004). Patients visiting EDs tend to be older and often have multiple illnesses. However, little attention is paid to the special needs of older patients in EDs in Sweden (Nydén 2003). Well-educated patients also expect a higher QoC (Franzén et al. 2006), and such patients experience lack of respect from healthcare professionals as indicative of lower QoC (Muntlin et al. 2008). The perception is that there is not enough time available for creating a participating relationship with the patient, and there is a tendency for ED healthcare professionals to focus on instrumental behaviour rather than

on psychosocial care (Lewis and Woodside 1992, Nyström 2002, Wiman and Wikblad 2004). However, patients point out that participation does not necessarily require a great deal of time: it is more a matter of the approach of healthcare professionals in caring situations (Frank et al. 2009b). Consequently, there are many different ways in which both patients and healthcare professionals perceive patient participation (Frank et al. 2009a, Frank et al. 2009b), and the degree of patient participation that takes place in a caring situation depends on the individual nurse involved (Sahlsten et al. 2005a). There is no specific strategy in place at the ED for ensuring patient participation (Frank et al. 2009a), even though an increase in patient participation is recognised as being an aspect of improvements in the care provided by EDs (Boudreaux and O'Hea 2004, Muntlin et al. 2006). The Swedish Health and Medical Services Act (SFS 1982) states that patients require participation in their care, and there is an increased demand for adequate knowledge among healthcare professionals who are preparing to meet an active patient (Cahill 1998). No studies have been published that specifically examine patient participation from the perspective of patients at an emergency department.

THE STUDY

Aim

The aim was to evaluate patient participation from the perspective of patients who received care in emergency departments, with a separate examination of the relationship between participation and age, sex, education and priority level.

Design

A cross-sectional design was used.

Participants

The sample consisted of 780 consecutive patients who received care in an ED between 28 and 30 November 2008 at one of three hospitals (district, central and university) in central Sweden. No formal priority system was used at the hospitals. Patients under the age of 18, those accompanied by an interpreter and those pronounced dead during their visit to the ED were excluded from the sample.

Data collection

A questionnaire was sent by post to all 780 patients included in the study about four weeks after their visit in 2008. Addresses were taken from the patient register in each hospital. An additional three reminders were sent out at two-week intervals to the patients' homes with a request to complete and return the

questionnaire in a preaddressed envelope. The response rate after the initial distribution and three reminders was 46% ($n= 356$). Patients stated their reasons for drop-out on a separate form. These reasons included lack of time (13%), lack of interest (19%), insufficient mastery of the Swedish language (8%), medical reasons (23%), and other reasons (36%). Forty-seven percent of the dropouts were women, and the mean age of the dropouts was 55. Finally, 212 patients did not return the questionnaire and 25 questionnaires were returned because they were incorrectly addressed.

The questionnaire

A newly developed 17-item questionnaire, the Patient Participation at the Emergency Department questionnaire (PPED), was used (Frank et al. in press). Patients responded to statements by giving a rating on an ordinal 4-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree), i.e. the higher the values, the stronger the dimension of participation. The questionnaire has been tested for construct and concurrent validity as well as homogeneity and reliability. For construct validity two separate explorative factor analyses revealed a distinct four-factor solution which was labelled: fight for participation, requirement for participation, mutual participation and participating in getting basic needs satisfied. Concurrent validity showed 9 out of 20 correlations above 0.30, three of which had moderate correlations of 0.62,

0.63 and 0.70. Cronbach's alpha coefficient ranged from 0.63 to 0.84 and test-retest reliability ranged from 0.59 to 0.93 (Frank et al. in press).

The questionnaire included four dimensions of patient participation: Fight for participation (5 items, min-max value 5–20); Requirement for participation (5, 5–20); Mutual participation (4, 4–16); and Participation in getting basic needs satisfied (3, 3–12).

Ethical considerations

Approval was obtained from the research ethics committee at the Swedish university involved (2008/1690-31/4) and from the managers of the EDs involved. The study was carried out in accordance with common ethical principles (The Declaration of Helsinki 2004). Participants were given written information about the study, promised confidentiality and the right to withdraw.

Power of the study

The expected effect size of the study was set at 15%. The premise was based on expected effect on empirical experience of the study outcome. According to our assessment, a hypothetical effect of 10% (difference 5%) might be of clinical significance. With regard to an alpha value of 0.05 and a beta value of 0.20 (power=0.80), approximately 316 patients were needed to give a significant result for the study outcome.

Data analysis

The data analysis was carried out with appropriate parametric and non-parametric tests, based on scale level and sample size for each dimension. Descriptive statistics were used to describe the four dimensions of patient participation. Student's t-test (sex, priority level), one-way ANOVA (education) and the Spearman correlation (age) were used to compare subgroups of patients. The Bonferroni correction was taken in account to reduce reporting multiple-significance in the one-way ANOVA analysis. Otherwise the level of significance was set at 5% for all tests. SPSS version 16.0 was used to analyse the data (SPSS Inc., Chicago, IL., USA).

RESULTS

Descriptive data

A total of 356 persons (46% of the potential participants) participated in the study. Their mean age was 56 years (range 19-94), 49% were women and 93% were Swedish citizens. Sixty-five percent lived with a partner, while 31% had more than twelve years of education, 24% had twelve years of education, 26% nine years of education and 19% six years of education. The mean duration of care in the ED was 5 hours (range 0.50-24) including waiting time and 48% of participants had been given a high priority diagnosis. In the questionnaire the participants presented reasons for visiting ED, which were then divided by two emergency nurses into high and low priority. High priority patients were, for

example, those with heart failure or injuries resulting from a road traffic accident, while low priority patients were those with knee problems or throat infections, for example.

The median value of the *Fight for participation* dimension was 6.00 (IQR: 4-11), which corresponds to a low level of activity for participation in their care. A higher value of fight for participation was correlated with low age, while there were no differences with regard to sex or education (Tables 1 and 2).

The median value of the *Requirement for participation* dimension was 16 (IQR: 13-19) which corresponds to high levels of the conditions required for participation, such as time, respect and information. Higher values of the prerequisites for participation were correlated with low age, while there were no differences with regard to sex, education or priority (Tables 1 and 2).

The median value of the *Mutual participation* dimension was 8 (IQR: 4-10), which shows that patients took an active part in caring situations. There were no differences with regard to age, sex, education or priority (Tables 1 and 2).

The median value of the *Participation in getting basic needs satisfied* was 5 (IQR: 3-8), corresponding to a low level of satisfying such basic needs as pain

relief, anxiety relief and food supply. A high level of participation in getting basic needs satisfied was correlated with six years of education, while those with twelve years of education or more had lower scores. Further, high priority patients experienced a higher degree of participation in getting basic needs satisfied than low priority patients, while there were no differences with respect to age or sex (Tables 1 and 2).

-----Insert Tables 1 and 2 about here-----

DISCUSSION

The patients included in the study were of different ages and they were equally divided between the sexes. This ensured an adequate spread among the patients studied. However, the sample was limited to Swedish-speaking patients, and the inclusion of patients who could not speak Swedish would have contributed valuable information. It is difficult to get patients to complete a postal questionnaire, and the response rate was only 46% after three reminders. The response rate has been low also in other studies concerning patients' care experiences in EDs (Holden and Smart 1999, O'Regan and Ryan 2009, Brunero et al. 2009). The expected response rate for mailed surveys is 40%, which rises to 60% after intensive follow-up (Eaker et al. 1998). Personal surveys and

telephone surveys achieve greater response rates (Yu and Cooper 1983).

However, the sample of 356 patients satisfied the goal determined by the power calculation. Another method of analysing the effect of each factor would have been to enter the factors using multiple regression to control for the effects of any interaction between variables (Afifi 1990). We chose instead to look at each factor separately, using Bonferroni corrections to allow for multiple testing and risks of Type 1 errors in the one-way ANOVA analysis. This is an acceptable method when comparing subgroups of patients (Kirkwood and Sterne 2003).

The results have important implications for Swedish EDs, but it is unclear whether they are relevant for other countries. We suggest that the newly constructed questionnaire should be translated and developed further in order to ensure its international relevance.

The results of patients self - report show that patient participation is low in two dimensions (*Fight for participation* and *Participation in getting basic needs satisfied*), it is reasonable in one dimension (*Mutual participation*), and it is high in one dimension (*Requirement for participation*). We conclude that patient participation needs to be improved in ED care. There were equal numbers of male and female patients in the study and there are no significant differences between men and women in any dimension of patient participation. Sex bias, however, may account for the disparities in prioritising cases between women and men (O'Donnell et al. 2005). The median value on the *Requirement for*

participation dimension was 16, which corresponds to 25% of the patients agreeing strongly with the statements, a result that shows that patients participate in gaining respect, confidence, time and information from healthcare professionals. This result shows that healthcare professionals meet the patients' expectations of *Requirement for participation* to a high degree. Twenty-five percent of the patients in this study were over 69 years old, and such patients rated the *Requirement for participation* dimension higher than younger patients. This result agrees with the finding that older patients perceive themselves more satisfied and less critical (Nerney et al. 2001) when faced with illness and age (Richardson et al. 2007). Younger patients in this study experience fewer requirements for participation to be satisfactory, and they are more critical of the QoC in EDs, as has been shown previously by several studies (Sun et al. 2000, Foss and Hofoss, 2004, Muntlin et al. 2008). Twenty-five percent of patients strongly disagreed with the statements in the *Mutual participation* dimension, showing that participation perceives low in care planning for patients. The Swedish Health and Medical Services Act (SFS 1982) states that patients have the right to be involved in the planning of their care and treatment, and we are thus led to pose the question of why patients participate less in the *Mutual participation* dimension, when it is clear that participation here is a right. Healthcare professionals lack conscious strategies for patient participation in ED settings (Frank et al. 2009a), which might be due to a lack of knowledge about

what such participation is and how to ensure that it is achieved. However, nurses working on medical wards have established strategies for optimising patient participation and the goal is to find patients own inherent knowledge, values, motivation and linking these to actions (Sahlsten et al. 2009). Twenty-five percent of patients disagreed strongly with the statements in the *Participation in getting basic needs satisfied* dimension that concerned obtaining help with pain and anxiety. This result makes it clear that not all patients obtain help from healthcare professionals in basic care, which supports the conclusions of Muntlin et al. (2006). Patients in our study who have more than twelve years of education perceive themselves as participating less in getting basic needs satisfied than those with lower levels of education, which can be explained by such patients being more highly critical and having higher demands for basic care (Franzén et al. 2006, Muntlin et al. 2008). Urgent patients in this study experience a higher degree of participation in getting their basic needs satisfied. However, urgent patients are more satisfied with their care in ED than non-urgent patients (Hansagi 1992, Franzén et al. 2006), and nurses provide more verbal and non-verbal communication to urgent patients than they do to non-urgent patients (Wiman and Wikblad 2004). Patient participation in the *Fight for participation* dimension perceives low, and nearly half of patients strongly disagreed with the statements that measured this dimension. Thus, the patients' activity is low in situations in which they are forced to take responsibility for

their situation at the ED for obtaining help from, and contact with, healthcare professionals. Younger patients score more highly on the *Fight for participation* dimension. Such patients, characterised as being active, taking responsibility and “never giving up”, are what Cahill (1998) describes as the future active participating patient (Cahill 1998). Studies of professional healthcare in other care contexts than the ED do not often consider *Fight for participation* as a dimension of patient participation (Sahlsten et al. 2005b, Eldh et al. 2006a).

CONCLUSIONS

Participation in a mutual care situation between patients and healthcare professionals requires further improvement to ensure that patients are satisfied and do not have to struggle and fight to participate in their care. Young and well-educated patients in particular perceive that they need to fight more to participate in their care and that they gain less attention for basic needs than older and less well-educated patients. The differences between the ways in which various groups participate in their care may be due to a lack of knowledge in how to encourage patients to participate. It is therefore important to identify areas in which patient participation can be improved, in order to know where to take action. The results facilitate the work of healthcare professionals with changing attitudes in caring, changes that are needed to improve patient

participation in care in the ED. We recommend, however, that further studies be carried out in various ED settings, in order to ensure that the results are relevant internationally.

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Table 1: Descriptive statistics for the four dimensions and their associated items of patient participation for patients receiving care in emergency departments, PPED (Frank et al in press).

	n	Mean (SD)	Median (IQR)	Min–Max
Fight for participation	305	7.48	6.00	0 – 20
I had to find out everything by myself		(4.47)	(4.00 – 11.00)	
I had to justify my attendance at the ED				
I had to become obstinate in order to get help				
I had unanswered questions after my visit				
I need to act on my present situation				
Requirement for participation	323	15.49	16.00	0 – 20
I had time to tell about my acute situation		(4.07)	(13.00 – 19.00)	
I received information about what was going to happen during my visit				
I felt confidence for staff				
I felt myself welcomed				
I was treated with respect by the staff				
Mutual participation	333	7.64	8.00	0 – 16
I had the possibility to say “No” to suggested care actions/treatment		(4.21)	(4.00 – 10.00)	
I was involved in the planning of my care/treatment				
I could talk to staff in private when I had the need				
I maintained contact through asking questions				

Participation in getting basic needs satisfied	325	5.49	5.00	0 – 12
My need for food and drink were well meet		(3.81)	(3.00 –	
I received help when I felt pain			8.00)	
I received help when I was anxious				

SD: Standard deviation ; IQR: Interquartile Range.

Table 2: A comparison between patient participation and age, sex, education and priority level for patients receiving care in an emergency department.

	Age*	Sex***	Education**	Priority level***
Fight for Participation ☐	n = 305	n = 305	n = 311	n = 289
	<i>p</i> = 0.027	n.s.	n.s.	n.s.
Requirement for participation ☐	n = 323	n = 323	n = 296	n = 305
	<i>p</i> = 0.003	n.s.	n.s.	n.s.
Mutual Participation ☐	n = 333	n = 333	n = 320	n = 314
	n.s.	n.s.	n.s.	n.s.
Participating in getting basic needs satisfied ☐	n = 325	n = 325	n = 314	n = 308
	n.s.	n.s.	n.s.	CI = 0.09 – 1.78

*Spearman correlation; **Analysis of variances (ANOVA); ***Student's t-test

☐ Higher values the stronger dimension of participation. CI = Confidence interval; n.s. = Not significant.

