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Developing and Psychometric Testing of a Questionnaire for Patient Participation in Emergency Departments

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Abstract

Aim The aim of the study was to develop and test the psychometric properties of a patient participation questionnaire in emergency departments.

Background Patient participation is an important indicator of quality of healthcare. International and national health care policy guidelines promote patient participation. While patients cared for in emergency departments generally express dissatisfaction with their care, a review of the literature fails to reveal any scientifically tested research instruments for assessing patient participation from the perspective of patients.

Methods A methodological study was conducted involving a convenience sample of 356 patients recently cared for in emergency departments in Sweden. Data was collected in 2008 and the analyses performed were tested for construct and criterion validity and also homogeneity and stability reliability.

Results A 17- item questionnaire was developed. Two separate 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. Criterion validity presented showed 9 out of 20 correlations above 0.30 and of those 3 moderate correlations of 0.62, 0.63 and 0.70. Cronbach's alpha coefficient ranged from 0.63 - 0.84 and test- retest varied between 0.59 and 0.93.

Conclusion The results signify evidence of acceptable validity and reliability and the questionnaire makes it possible to evaluate patient participation in ED caring situations. In addition it produces data which is useable by a diverse range of healthcare professionals.

Keywords: instrument development, caring, emergency department, patient participation, validity, reliability

SUMMARY STATEMENT

What is already known about this topic

International and national health care policy guidelines promote patient participation. Patients cared for in emergency departments have reason to be dissatisfied with the quality of care.

A scientifically tested research instrument for evaluating patient participation from the perspective of patients in emergency departments was not found.

What this paper adds

The ‘Patient Participation Emergency Department’ questionnaire describes the meaning of participation from the perspective of patients who have been recently cared for in emergency departments.

The final version of the questionnaire displays good psychometric properties in terms of content validity, construct validity and criterion validity and an acceptable level of homogeneity and stability reliability.

Implications for practice and/or policy

The ‘Patient Participation Emergency Department’ questionnaire makes it possible to evaluate patient participation when cared for in emergency departments and to be able to make improvements.

The questionnaire is not profession-specific and therefore may be useful to a wide range of healthcare professionals in emergency department settings.

INTRODUCTION

By definition, patient participation in nursing is described as the situation when a nurse surrenders some degree of power and control to the patient, and is manifested in the sharing of information and knowledge and through active engagement together in intellectual and/or physical activities which take place in an established relationship between nurse and patient (Sahlsten *et al* 2008). Furthermore patient participation is described as the situation when patients themselves become the unique starting point for all care actions (Eldh *et al* 2006, Larsson *et al* 2007, Tutton 2005, Frank *et al* 2009b).

Patient participation is an important indicator of the quality of healthcare (Boudreaux & O’Hea 2003, Muntlin *et al* 2006). In addition, patient participation is also a healthcare objective in several Western countries (SFS 1982, Johnson & Silburn 2000, Hostick 2005, WHO 2006) and therefore of international relevance. Studies demonstrate that patients cared for in emergency departments (EDs) have reason to be dissatisfied with the quality of care (Watson *et al* 1999, Crowley 2000, Nyström *et al* 2003, Muntlin *et al* 2006). However, patient participation is important and one of several parameters for perceiving good quality of care (Lewis & Woolside 1992, Huggins *et al* 1993, Williams 1998, Mayer & Zimmermann 1999, Baldursdottir & Jonsdottir 2002, Kihlgren *et al* 2004).

From the point of view of healthcare professionals, patient participation is described in terms of a relationship with a therapeutic approach including involvement, knowledge and information sharing (Wellard *et al* 2003, Sahlsten *et al* 2005) and according to Hostick (2005) this may indicate an ‘ideal’ representation from a normative perspective on patient

participation. However, ED healthcare professionals view patient participation in a less idealistic way and describe how it is instead as conditional from their point of view (Frank *et al* 2009a). Mutual participation is also occasionally seen, and often unexpectedly and only in the right circumstances, despite international and national guidelines (SFS 1982, WHO 2006) which lay down the requirements for patient participation.

A common attitude in nursing science is to limit the meaning of patient participation to involvement in decision making (Ciambrone 2000, Saino *et al* 2001, Saino & Lauri 2003). Decision making is not the main issue when patients describe patient participation (Eldh *et al.* 2004, Tutton 2005, Frank *et al* 2009b, Larsson *et al* 2007). Several studies have focused on the experience of patient participation from healthcare professionals' perspectives rather than that of patients (Jewell 1994, Sahlsten 2005). It is therefore valuable to focus on patient understanding of patient participation. Patients recently cared for in EDs describe how their participation is dependent on the attitude of healthcare professionals, the care environment and how the care is organised. Patient perception of what it means to participate in ED care is to be acknowledged and having a clear space which means that patients are fully entitled to personal and physical space and the ED staff's attention (Frank *et al* 2009b) which is in line with previous research (Eldh *et al* 2004, Tutton 2005, Larsson *et al* 2007). However, patients in ED perceive themselves to be participating when they have to fight to become involved, they identify themselves marginalized and have different strategies for reach contact with ED staff (Frank *et al* 2009b), a result difficult to find in participation studies from other care contexts (Eldh *et al* 2004, Tutton 2005, Larsson *et al* 2007). It is significant that patients have different needs for patient participation and therefore it is useful to investigate the extent of different perceptions in a larger sample.

There are few instruments measuring patient participation. Only one specific instrument for patient participation has been found for people with spinal cord injury in the field of disability and rehabilitation (Larsson Lund *et al* 2007). Patient participation is included as a part of the Quality Patient Perspective (QPP) instrument developed in Sweden (Wilde *et al* 1994, Wilde & Larsson 2002) and used for quality improvement work around the world (Larsson *et al* 2005). Instruments measuring patient satisfaction in patients cared for in EDs show that the strongest pre-condition for satisfaction is when patients experience interpersonal interactions with ED healthcare professionals (Boudreaux & O'Hea 2003, Cassidy Smith 2007). Furthermore, patient participation in ED is identified as one area for healthcare improvement (Boudreaux & O'Hea 2003, Muntlin *et al* 2006). For this reason it is important to develop a specific instrument for evaluating patient participation. Accordingly the aim of the study was to develop and test the psychometric properties of a patient participation questionnaire in EDs.

METHOD

The study was of methodological design with a step by step procedure. Permission to carry out the study was obtained from the Ethics Committee of the Karolinska Institute, Sweden (2008/1690-31/4) as well as from the responsible managers of the EDs involved.

Development of the Patient Participation Emergency Department (PPED) questionnaire

Step 1: Item generation: Items were constructed and related to categories developed from two qualitative studies regarding participation in patients and healthcare professionals at EDs.

(Frank *et al* 2009a, Frank *et al* 2009b). In the process of constructing the items, the results from the qualitative studies (Fig 1) have been synthesised into three categories: 'struggling for participation', 'having a common desire for participation' and to 'resign oneself to

participation'. Three patients and two nurses with ED experience worked as sources of inspiration for formulating questionnaire items within these categories. The items were aimed to be answered on a 4- point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree).

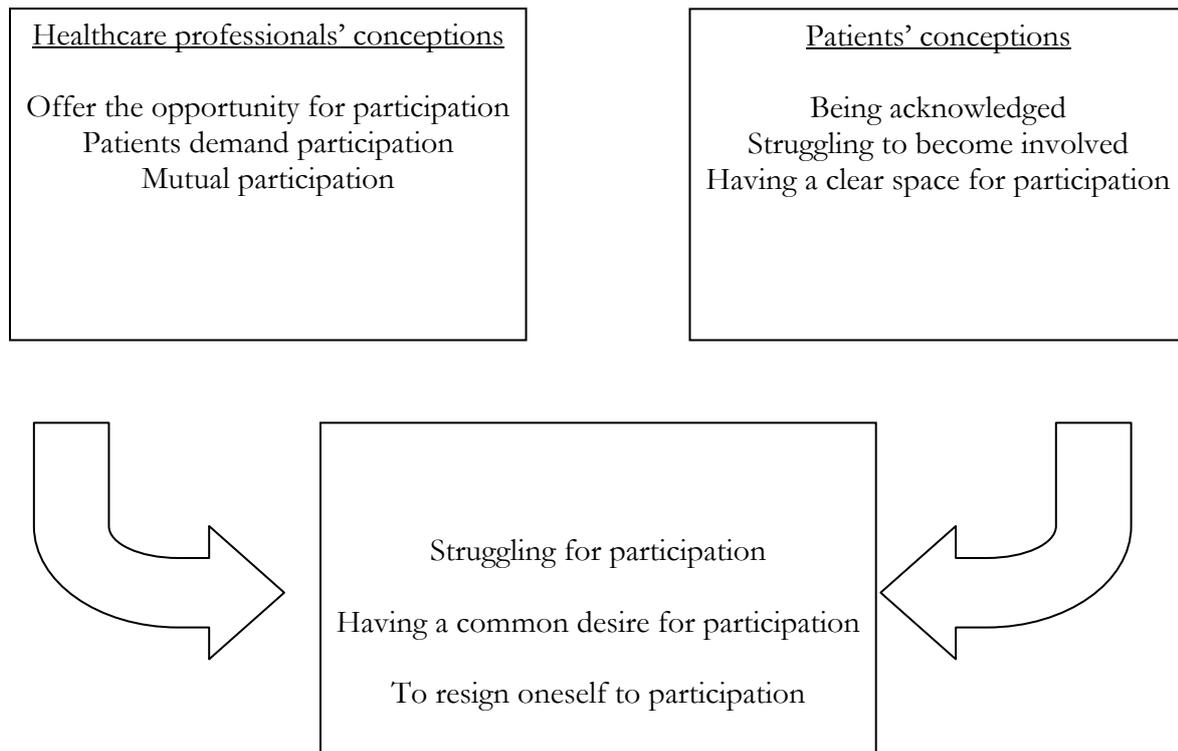


Figure 1 The process of synthesising patient participation (Frank *et al* in press, Frank *et al* 2009).

Step 2: Content validity: After the construction of the first draft of the PPEd questionnaire, content verification including face validity and think aloud took place (Streiner & Norman 2007). Face validity was carried out by six individuals: three patients recently cared for in an ED, two emergency healthcare professionals and one expert on patient participation who also had experience in instrument development. The six individuals were given the questionnaire and returned it with their written comments. The questionnaire was also scrutinised during a research seminar. Finally, one patient recently cared for in an ED tested the questionnaire with think aloud together with the first author. The face validity and think aloud resulted in adjustments of the items and changes to the language. This resulted in a total of 42 items before data analysis and reduction.

Step 3: Statistical analysis: Testing for construct validity and criterion-related validity as well as reliability for homogeneity and repeatability stability was carried out. The computer-based program SPSS 16.0 (SPSS Inc., Chicago, IL, USA) was used for all analyses.

Construct validity: In order to reduce the number of items and to emphasise apparent factors, item construct validity with explorative factor analysis was carried out with principal

component analysis through Varimax rotation with Kaiser Normalisation (Streiner & Norman 2007). Bartlett's test of Sphericity with $p < 0.05$ and the Kaiser- Meyer-Olkin Measure of sampling adequacy of ≥ 0.6 were used in performing this factor analysis. The criterion for factor extraction was an Eigenvalue ≥ 1 (Rattray & Jones, 2007).

Criterion-related validity: Criterion validity was tested with Spearman correlations by using a part of the QPP (Wilde Larsson *et al* 2002) concerning patient participation. Levels of correlation were interpreted as follows: 0.00-0.25 little if any, 0.26-0.49 low, 0.50-0.69 moderate, 0.70- 0.89 high, 0.90-1.00 very high (Hazard Munro 1997). The five chosen items were: K1: My own perception of my health problems was taken into consideration; K2: I had good opportunity to participate in decisions that applied to my medical care; K3: My medical care was determined by my own requests and needs rather than staff procedures; K4: The registered nurses and enrolled nurses seemed to understand how I experienced my situation; and K5: I received useful information on how examinations and treatments would take place.

Homogeneity reliability: This was tested with the Cronbach's alpha coefficient (Cronbach 1951). With respect to developing a new instrument, the limitation rate for alpha was chosen to be ≥ 0.70 , having compared with more established questionnaires when alpha is recommended to be ≥ 0.80 (Rattray & Jones 2007).

Repeatability stability reliability: This was tested with intra-class coefficient (ICC). After receiving completed questionnaires another identical questionnaire was sent out to 150 respondents after 5-14 days (Streiner & Norman 2007). The reasonable goal for the amount test -retests was approximately 100 answers and, due to low answer frequency, we sent out an additional 22 questionnaires. In total 91 respondents responded twice to the questionnaire.

Participants and settings

The first patients chosen were consecutively cared for in ED from 28-30 November 2008 at three hospitals (district, central and university) in central Sweden. All patients were ≥ 18 years old and were chosen in consideration of the following factors: age, sex, education, if they were admitted after treatment in ED, if they were a Swedish citizen, if they lived with a partner, if they were accompanied by relative and their length of stay at ED (Table 1). Typical examples of conditions of those for visiting ED were heart failure, stomach problems and injuries resulting from car accidents. Patients excluded were those accompanied by an interpreter and patients registered as dead during their visit at ED. Approximately 4 weeks after the time of care, a total of 780 postal questionnaires were sent to the patients. The study was carried out in accordance with common ethical principles (The Declaration of Helsinki 2004). Participants were given written information about the study, guarantee of confidentiality and the right to withdraw in order to ensure that informed consent had been obtained. Addresses were taken from the patient register in each hospital. After four reminders, the response rate was 46% ($n = 356$). In all, 211 patients chose not to participate citing reasons such as: lack of time (11%), lack of interest (17 %), did not understand the Swedish language (7%), medical reasons (20%) and other, such as loss of life for example (32 %). Finally, 214 patients did not return the questionnaire and 25 were returned because they were incorrectly addressed.

Table 1 Socio-demographic characteristics of the sample ($n= 356$)

	n	%	mean (SD)	median	range
Age	356		56 (19.6)	57	19-94
Sex					
Female	172	49			
Male	183	51			
Visit time at Ed (Hour)	328		5 (4.0)	4	0.50-24
Living with a partner	230	65			
Acompanied by relative	207	59			
Admission after ED visit	140	40			
Country of origin	329	93			
Education					
University	106	31			
High school	83	24			
Upper secondary school	89	26			
Comprehensive school	66	19			

ED: Emergency department

RESULT

Construct validity

The process of reducing the number of items was both statistically and conceptually scrutinised. The number of items was reduced from 42 to 17 in order to minimise factorial complexity and increase readability of the instrument. During the process of decreasing the number of items we kept in consideration factor loading and the meaning of the items as well as the meaning of the factor. Two examples of items which were removed are as follows:

In factor 1 item 15, 'I did not want to bother with my questions' was seen to be similar to item 21, 'I had unanswered questions after my visit', and was therefore removed.

In factor 2 item 10: 'I had possibility to ask questions to the staff' because the content is given in the other items of the factor.

The factors were labelled in accordance with statistical techniques, but also in line with the theory examining the content of the questions in each factor (Dixon 1997). The following labels were used: Factor 1: Fight for participation included five items and illustrated diverse aspects of how patients have to struggle in order to become involved in their care; Factor 2: Requirement for participation contained five items and described respect, information and time as condition for participating ; Factor 3: Mutual participation involved four items and illustrated similar aspects of two active parts in a working dialogue; Factor 4: Participating in getting basic needs satisfied included three items and illustrated how visible and invisible needs are observed and fulfilled.

Factor analysis was completed on the 17-item with principal component analysis and Varimax rotation with Kaiser Normalisation and on both occasions ($n = 356$ and $n = 91$), a four-factor solution in an apparent pattern was found. Further at both occasions the identical and same number of items loaded on each factor. The items in each factor explained a factor loading above 0.52 and showed reasonably good communality above 0.40. On the first occasion the four-factor solution had a cumulative variance of 58.3 and for the second, a cumulative variance of 63.5. Factor 1 contained five items on both occasions with an Eigenvalue of 3.44 and 4.80 which explained 23.9% and 28.2% of the variance. Factor 2 included five items on both occasions with an Eigenvalue of 4.06 and 3.22 and explained variance of 23.9% and 18.9% respectively. On both occasions, factor 3 consisted of four items with an Eigenvalue of 1.33 and 1.53 and clarified 7.8% and 9.0% of the variance. Finally factor 4 consisted of three items on both occasions, had an Eigenvalue of 1.06 and 1.24 and explained 6.3% and 7.3% of the variance.

Table 2. Construct validity, factor analysis with principal component analysis and Varimax rotation with Kaiser Normalisation.

	1 st Test (n:356)					2 nd Test (n:91)				
	CM	Factor1	Factor2	Factor3	Factor4	CM	Factor1	Factor2	Factor3	Factor4
1. Fight for participation										
I had to find out everything by myself	0.54	0.70				0.74	0.84			
I had to defend myself when I relayed acute condition	0.60	0.75				0.77	0.84			
I had to become obstinate in order to get help	0.64	0.78				0.67	0.79			
I had unanswered questions after my visit	0.55	0.69				0.60	0.71			
I need to act on my present situation	0.53	0.62				0.64	0.54			
2. Requirement for participation										
I had time to explain my acute situation	0.61		0.75			0.69		0.81		
I received information about what was going to happen during my visit	0.55		0.58			0.63		0.78		
I felt confidence in the ability of the staff	0.72		0.74			0.79		0.70		
I felt welcome	0.57		0.70			0.69		0.67		
I was treated with respect by the staff	0.75		0.85			0.70		0.63		
3. Mutual participation										
I had the possibility to say no to suggested care actions/treatment	0.44			0.57		0.56			0.72	
I was involved in the planning of my care/ treatment	0.57			0.72		0.55			0.71	
I could talk to staff in private when I needed to	0.51			0.65		0.50			0.68	
I maintained engagement through asking questions	0.47			0.64		0.40			0.59	
4. Participating in getting basic needs satisfied										
My food and drink needs were well meet	0.70				0.83	0.56				0.74
I got help when I felt pain	0.52				0.69	0.64				0.73
I got help when I was anxious	0.64				0.72	0.66				0.52
Loading^o of variance		20.3	23.9	7.8	6.3		28.2	18.9	9.0	7.3
Total variance					58.3					63.5

CM: Communalities

Criterion-related validity

The five used items from the QPP – instrument (Wilde Larsson *et al.* 2002) were: K1: My own perception of my health problems was taken into consideration; K2: I had a good opportunity to participate in decisions that applied to my medical care; K3: My medical care was determined by my own requests and needs rather than staff procedures; K4: The registered nurses and enrolled nurses seemed to understand how I experienced my situation; and K5: I received useful information on how examinations and treatments would take place. On the first occasion, there were correlations between K1- K5 and all factors except that K2 and K3 did not correlate significantly with factor 1 (fight for participation). Correlations among K1 were moderate (0.62) to factor 2, K2 showed low correlations to factor 2 (0.31) and 3 (0.41). In addition K3 demonstrated correlation at a low level to factor 3 (0.37), K4 explained moderate correlation among factor 2 (0.63) and low correlation to factor 4 (0.32). Finally K5 demonstrated strong correlation to factor 2 (0.68) and minimal correlation to factor 1 (-0.30) (Table 3).

Table 3. Association study between factors and K1-K5 with Spearman correlation.

	Factor 1	Factor 2	Factor 3	Factor 4
K1 rho =	-.30	.62	.17	.15
Sig. (2-tailed)	< .001	< .001	<.01	< .01
N	303	318	329	321
K2 rho =	.008	.31	.42	.21
Sig. (2-tailed)	.89	< .001	< .001	< .001
N	304	318	330	321
K3 rho =	.07	.27	.37	.21
Sig. (2-tailed)	.20	< .001	< .001	< .001
N	303	317	329	320
K4 rho =	-.26	.63	.16	.33
Sig. (2-tailed)	< .001	< .001	< .001	< .001
N	304	320	331	322
K5 rho =	-.31	.68	.24	.25
Sig. (2-tailed)	< .001	< .001	< .001	< .001
N	304	319	330	322

Homogeneity and stability reliability

Cronbach's alpha coefficient for the 17- item version was calculated to determine the homogeneity and ICC, the stability of each factor and the complete questionnaire. Cronbach's alpha coefficient showed 0.75 for the complete questionnaire on the first test and 0.72 for the retest. For the first factor alpha was 0.78 on the first occasion and 0.84 for the retest. For the second factor alpha was 0.82 on the first occasion and 0.83 for the retest. The third factor had an alpha of 0.63 on the first occasion and 0.66 for the retest. For the fourth factor alpha was 0.69 on the first occasion and 0.68 for the retest. The ICC varied between 0.59 and 0.93 for the test-retest reliability (Table 4).

Table 4. Homogeneity (Cronbach’s alpha coefficient) and stability (Intraclass Correlation Coefficient (ICC) reliability).

Factors and Items	n	ICC	95% CI	1st Test(n:356)	2nd Test (n:91)
				Cronbach’s alpha 0.75 (overall)	Cronbach’s alpha 0.72 (overall)
1. Fight for participation				0.78	0.84
I had to find out everything by myself	84	0.78	0.67–0.86		
I had to defend myself when I relayed acute condition	89	0.77	0.64–0.85		
I had to become obstinate in order to get help	88	0.82	0.73–0.88		
I had unanswered questions after my visit	86	0.86	0.78–0.91		
I need to act on my present situation	88	0.82	0.73–0.88		
2. Requirement for participation				0.82	0.83
I had time to explain my acute situation	87	0.71	0.56–0.81		
I received information about what’s going to happen during my visit	89	0.78	0.67–0.86		
I felt confidence in the ability of the staff	88	0.90	0.85–0.93		
I felt welcome	89	0.88	0.81–0.92		
I was treated with respect by the staff	87	0.84	0.75–0.89		
3. Mutual participation				0.63	0.66
I had the possibility to say no to suggested care actions/treatment	87	0.67	0.50–0.79		
I was involved in the planning of my care/ treatment	90	0.65	0.47–0.77		
I could talk to staff in private when I needed to	89	0.59	0.38–0.73		
I maintained engagement through asking questions	84	0.79	0.67–0.86		
4. Participating in getting basic needs satisfied				0.69	0.68
My food and drink needs were well meet	89	0.93	0.89–0.95		
I got help when I felt pain	87	0.84	0.76–0.90		
I got help when I was anxious	87	0.75	0.62–0.84		

DISCUSSION

The factors in the 17- item version of the PPED questionnaire corresponded well with the theory around the point of departure for developing an instrument (Fig 1). An advantage with a short questionnaire is that it is easy to administer, namely in terms of the number of items, which is the reason why we condensed the items in a systematic and reflective way. Construct validity through factor analysis was completed, and for both occasions a four-factor solution in a distinct model were found. On the other hand, the study has limitations such as a sample size for performing the factor analysis of 356 with the original 42 items when Pett *et al* (2003) suggest 10 to 15 subjects per item. On the other hand, our sample size appears to be appropriate according to the criteria of Hair *et al* (1998) who suggest at least five times as many observations as there are items. Furthermore the phenomenon of patient participation is well known and highlighted internationally (Johnson & Silburn 2000, Wellard *et al* 2003, Hostick 2005, Tutton 2005, Penny & Wellard 2007) but data for the present study was collected from one single country. The next stage must involve translation of the questionnaire and further studies in other countries.

Construct and Criterion validity

The factor analyses showed a four-factor solution to be the most suitable. The four factors (fight for participation, requirement for participation, mutual participation, participating in getting basic needs satisfied) included between 3-5 items and all factors over the recommended Eigenvalue ≥ 1 . With this solution we found the best cumulative variance to be 58.3% in the first and 63.5% for the second factor analysis, thereby reaching the recommended level of 60% (Rattray & Jones, 2007) with the same factor structure on both occasions. The method seemed to be adequate in providing reasonable levels of explained variance and distinct factors.

In the criterion validity analysis, the nonparametric Spearman method was appropriate for testing correlations. The result showed correlations and significance except for K2 and K3 and factor 1: Fight for participation. The content of K2 and K3 showed good opportunities for participating to be more likely factor 3, as shown by Table 2. Factor 1: fight for participation showed negative and weak correlations to K1 –K5, the factor which also is in contrast with how Eldh *et al.* (2004), Tutton (2005), Larsson *et al.* (2007) explained patient participation. The items in factor 1 (fight for participation) correspond to the theory (Fig1) on participation and are therefore adequate. Moderate to high correlations were found between factor 2 and K1 and K4 and K5 explaining that all items included were about requirement for participation.

Homogeneity and stability reliability

The reliability of the PPED can be considered sufficient due to the fact that homogeneity showed a Cronbach's alpha coefficient of 0.75 for the complete questionnaire on the first test and 0.72 for the retest. The PPED indicated acceptable to good homogeneity for this newly constructed questionnaire (Rattray & Jones, 2007). Factor 1 (0.78) and factor 2 (0.82) show good homogeneity. Factor 3 illustrates alpha of 0.63 and needs to be further developed and tested. However, if correlations were too high there would be high levels of redundancy of items about the same subject and therefore likely loss of content validity (Streiner & Norman 2007).

When studying the stability of the questionnaire over time in a 5-14 day timeframe, the ICC varied between 0.59 and 0.93 for the 17- item correspondingly. Three items were lower than

the recommended 0.70 (Terwee *et al* 2007). Hence, the items are similar and the readability might give an ambiguous response. However, the solution could be to select appropriate time intervals for testing and retesting and patients may remember their initial recall and put it down more accurately than answering the question *de novo* (Streiner & Norman 2007). The appropriate method for measuring stability on nonparametric data is Cohen's kappa coefficient. However, it is known from previous studies that analysis of ordinal data with ICC gave the same result as Cohen's kappa coefficient (Fleiss & Cohen, 1973). The ICC results were therefore acceptable, indicating that the items in each factor of the 17-item version are relevant (Rattray & Jones, 2007).

CONCLUSION

In this study, the final version of the PPEd demonstrates good psychometric properties in terms of content validity, construct validity and criterion validity and acceptable level of homogeneity and stability reliability. The ultimate international and national objective in evaluating participation is to demonstrate, via empirical studies, the added value of the various ways in which patients participate in the outcome of their healthcare. The results signify evidence of acceptable validity and reliability and the questionnaire makes it possible to evaluate patient participation in ED caring situations. In addition, the questionnaire is not profession-specific and therefore may be useful to a wide range of healthcare professionals in emergency department settings. To further develop the PPEd questionnaire, there is a need for additional studies in order to establish the construct validity with a confirmatory factor analysis. Furthermore, additional studies in other countries and settings are needed in order to enhance the homogeneity and stability reliability.

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