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ORIGINAL ARTICLE

Development and Validation of a Questionnaire to Measure Patient's Experiences of Health Care in Pulmonary Arterial Hypertension Outpatient Clinics

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Background Measuring the patients' experience of care at an outpatient clinic can provide feedback about the quality of health care and if needed, can be support for quality improvements. To date, there is no patient reported experience measurement (PREM) developed targeting patients at the pulmonary arterial hypertension (PAH) outpatient clinics. Therefore, the aim was to develop and evaluate the psychometric properties of a PREM scale to be used for patients at PAH-outpatient clinics.

Methods The development and psychometric evaluation of the PREM for patients at PAH outpatient clinics followed two stages: (I) development of the PAH Clinic PREM (PAHC-PREM) scale based on interviews with patients; and (II) psychometric evaluation of the PAHC-PREM scale including data quality, factor structure (construct validity), criterion validity and internal consistency.

Results A sample of 156 patients at PAH outpatient clinics completed the PAHC-PREM scale (median age 69 years, 57% women). Unidimensionality of the PAHC-PREM scale was supported by parallel analysis. A single factor explained 67% of the variance. Inter-item and item-total correlations were satisfactory (0.46–0.88 and 0.64–0.91, respectively). Internal consistency reliability with ordinal coefficient alpha was good (0.93).

Conclusions The PAHC-PREM scale was demonstrated to have good psychometric properties and is now ready to be used to measure quality of health care experience from patients at PAH-outpatient clinics.

Keywords Pulmonary arterial hypertension • Patient reported experience measurement • Chronic disease • Quality of health care

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Introduction

Pulmonary arterial hypertension (PAH) is a progressive and severe disease where patients are cared for at PAH specialist clinics [1]. The estimated prevalence of PAH in Sweden is 25 cases per million adults and the median age is 67 (inter quartile range 22) years [2]. PAH outpatient clinics assume a central role in the evaluation, treatment and follow-up care for patients with PAH or other conditions with increased pulmonary artery pressure requiring PAH-specific treatments [1]. The clinics are responsible for planning and offering a good quality care service to address the needs of the patients with PAH [1].

The patient's experience of their health care is one of the central pillars in health care quality and therefore an important measurement perspective of health care quality [3–7]. Good health care experiences are known to lead to higher levels of adherence to prevention and treatment, better clinical outcomes, and fewer hospitalisations and hospital readmissions [4,8–11]. Patient reported experience measurement (PREM) questionnaires bring important knowledge to the health care system about how patients experience their contact with it e.g. the time in the waiting room, relevance of the received information or was the communication with the health care staff satisfying [3]. The use of PREM in health care is increasing [3,4,12] and there are established patient surveys measuring the quality of care, e.g. The Consumer Assessment of Health Providers and Systems [13], and a PREM for use by older people in community services [14]. However, none of the available PREMs are developed and evaluated for use for patients at PAH outpatient clinics.

Each patient visiting a PAH outpatient clinic should receive the highest quality of care and, therefore, the aim of this study was to develop and evaluate the psychometric properties of a PREM scale to be used for patients at PAH-outpatient clinics.

Methods

Design

A sequential transformative mixed methods design was used to develop and validate a PREM scale for use at PAH-outpatient clinics [15].

Research Team

All authors in the study have their specialty in cardiovascular disease and a PhD (five nurses [NW, TJ, BI, AS, KÅ] and one biomedical analyst [BK]). Four (4) hold a position as professors (TJ, AS, KÅ) or associate professor (BI). The main occupations of the authors are researcher and university lecturer. Within the team there is significant experience and training in conducting studies with both qualitative and quantitative methods. Three authors have a specialty in qualitative methods (BI, TJ, AS) and one in psychometrics evaluation of self-rating scales (KÅ). One author with training in qualitative methods (with no pre-understanding of the patient group's experiences of health care) conducted the interviews (NW). None of the authors are connected with the PAH clinics. Authors in this study have worked together previously in other projects.

Settings and Patients

Pulmonary arterial hypertension clinics in Sweden are specialist clinics that evaluate, diagnose, treat and follow patients with PAH, chronic thromboembolic pulmonary hypertension (CTEPH) and other forms of pulmonary hypertension that require treatment with PAH-specific drugs [2]. The multi-disciplinary teams at the clinics generally include nurses, physicians, and physiotherapists who work in close collaboration with other professionals, such as psychologists, dietitians, and social workers. After diagnosis, all patients with the diagnosis are called regularly for follow-up visits to the PAH outpatient clinic, commonly every 6-12 months (Swedish Pulmonary Artery Hypertension Registry [SPAHR], annual report, 2015) [16].

Inclusion criteria for participation in the study were adult patients registered in SPAHR and who visited a PAH outpatient clinic in the preceding 3-4 months. Exclusion criteria were severe mental or medical issues and/or problems communicating in Swedish, preventing the patients filling out the questionnaires. Six (6) of the seven university hospitals in Sweden have a PAH outpatient clinic that participated in the study. The Regional Ethical Review Board in Lund, Sweden, approved the study (No. 2015/825), which complied with the Declaration of Helsinki. All patients provided signed informed consent to participate in the study.

Procedures

The PREM was developed and evaluated in two stages (Figure 1). In Stage I the PREM was developed in three steps: 1 – interviewing patients to collect data on health care experiences; 2 – ranking statements on health care experiences and; 3 – merging statements into items. In Stage II, a psychometric evaluation was performed.

Stage I: Development of PREM

Stage I aimed to generate a questionnaire with items for measurement of important health care experiences for patients visiting a PAH outpatient clinic.

Step 1: Thirty-two (32) patients, five to six from each PAH-clinic, were invited for interviews. Four (4) of them declined participation and three could not be reached. Twenty-five (25) patients (median age 67 years [q1-q3 = 53-74], 52% women) were interviewed by telephone to collect data about what health care experiences they found most important. One (1) researcher interviewed all patients. The interviews were set up as a dialogue using a semi-structured interview guide. The guide was tested in the first four interviews, leading to minor adjustments in the order of questions. The interview questions were: "*Could you please tell me . . . What is important to you when you visit the PAH clinic?*", "*Are*

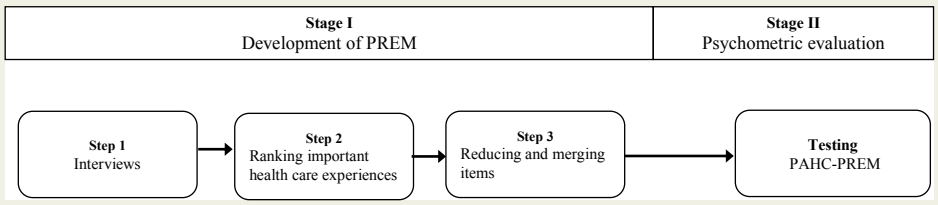

Figure 1 The process of development of the patient reported experience measurement.
Abbreviations: PREM, patient reported experience measurement; PAHC-PREM, pulmonary arterial hypertension clinic-patient reported experience measurement

you pleased with something in the health-care at the PAH clinic that is important to you?", "*Are you disappointed with something in the health-care at the PAH clinic that is important to you?*", "*What do you think could be improved in the health-care at the PAH clinic that is important to you?*" All patients were encouraged to freely express their health care experiences from their PAH outpatient clinic visit and to consider both positive and negative aspects. The interviewer transcribed the answers during the interview. The interviews were analysed using a content analysis approach [17]. An interview lasted for a median of 25 minutes (range 10–70 minutes). The interviews resulted in 29 statements about health care experiences of visiting a PAH outpatient clinic.

Step 2: The 25 patients from Step 1 were invited to participate and 21 accepted (median age 66 years [51-72], 62% women). A list with the 29 statements about health care experiences was mailed to the patients who were asked to rank the 10, three and one most important statements.

Step 3: The 18 statements ranked the highest by patients were selected. The research group then reduced the 18 statements into 11 items by merging equivalent statements (Figure 2). The 11-item questionnaire was named PAH Clinic PREM (PAHC-PREM).

For the eight items PAHC-PREM scale a three-point Likert type response scale was used: "No, not at all" (1 score), "Partially" (2 score), and "Yes, totally" (score 3). For one of the three general items, patient's overall experience of the health care visit, the answer options were "poor", "good", and "very good". For the other two items, the possibility for the patient to meet the same physician or nurse, the answer options were "no", "no request" and "yes".

Stage II: Psychometric Evaluation

The psychometric evaluation included an analysis of the factor structure of the PAHC-PREM scale and of the association between the general question about overall health care experience of the health care visit and the PAHC-PREM scale. Homogeneity and internal consistency were also tested.

For inclusion, the PAH outpatient clinics provided a list of all patients who had visited the clinic in the preceding 3-4 months and who met the inclusion/exclusion criteria. An invitation including the PAHC-PREM and questions about socio-demographic information were sent to all patients on the lists. One reminder letter was sent if a patient had not responded within 4 weeks.

The socio-demographic questions included gender, age, time since diagnosis, employed and working or retired, education and length of transportation. Information about diagnosis and PAH-specific treatment was obtained from the PAH-clinics. Only information from patients who respond was included in the study.

Data Analysis

Descriptive statistics were used to characterise socio-demographic data and are presented as number (%) or median (first and third quartile). For the psychometric analyses, items in the PAHC-PREM scale were treated as ordinal data and analysed with non-parametric statistics. Of the 11 items in the PAHC-PREM the answer options for three items (the possibility for the patient to meet the same physician or nurse, and patient's overall experience of the health care visit) differed from the other eight items in the scale, and were, therefore, not included in the psychometric evaluation. Data quality was evaluated regarding item and score distribution as well as missing data patterns. For this, descriptive statistics (median, quartiles and frequencies), standardised normal probability plot, normal quantile plot and and D'Agostino test of normality were used.

An exploratory factor analysis was performed to evaluate the factor structure of the eight items (construct validity). The analysis was based on a polychoric data matrix and the unweighted least squares (ULS) method was used to extract factors. The exploratory factor analysis was justified by the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and the Bartlett's test of sphericity [18]. A parallel analysis, based on 500 replications, was conducted to determine the number of factors of significance [19].

For evaluation of criterion validity, the association between the general question about the overall health care experience of the visit at the PAH outpatient clinic and the health care quality experience as assessed with PAHC-PREM scale total score, were evaluated with a polyserial correlation coefficient (rho). Our hypothesis was that higher ratings on the general question about the overall health care experience should correlate moderately to strongly (rho 0.3-0.8) to support criterion validity.

With regard to estimation of homogeneity and internal consistency reliability, inter-item and item-total correlations were calculated, as well as an ordinal version of coefficient alpha [20] for the PAHC-PREM scale, all analyses were based

Figure 2 The 18 statements ranked most important by the patients were merged into 11 items by the researchers in the study. Abbreviations: PAH, pulmonary arterial hypertension

on polychoric or polyserial correlations (rho). Inter-item and item-total correlations ≥0.3 and ordinal alpha ≥0.70 were used as criteria for satisfactory homogeneity and internal consistency respectively [21].

The analyses were conducted with SPSS statistics 23 (IBM Corp., Armonk, NY, USA), FACTOR 10.3.01 (Rovira i Virgili University, Tarragona, Spain) and R 3.3.2 (the R Foundation for Statistical Computing, Vienna Austria).

Results

Patients

The questionnaire was mailed to 202 patients (between 32-37 patients from each PAH clinic), of whom 156 (77%) returned the completed questionnaires, with an equal response rate between the clinics. The median (first and third quartile [q]) age of those who responded was 69 (q1-q3 = 57-75) years and 57% were women (Table 1). A majority of the patients (69%) were diagnosed more than 2 years ago and 83% received a PAH-specific treatment. They spent a median of 2 hours (1-4) on transport and almost half of the study sample travelled more than 100 km to get to their PAH-clinic (Table 1).

The PAHC-PREM Scale and Data Quality

The eight items comprised issues such as if the patients were given the opportunity to discuss symptoms and treatment, being involved in decisions about their care, the availability

Table 1 Patient characteristics.

Variable	N = 156
Age (years), Mdn (q1-q3)	69 (57-75)
Women, n (%)	89 (57)
Diagnosis	
PAH, n (%)	77 (49)
CTEPH, n (%)	50 (32)
Other, n (%)	20 (13)
Missing, n (%)	9 (6)
PAH-specific treatment*, n (%)	129 (83)
Time since diagnose	
<6 months, n (%)	7 (5)
6 months - 2 years, n (%)	41 (26)
>2 years, n (%)	108 (69)
Transport to PAH clinic	
Car, private, n (%)	78 (50)
Public transport, n (%)	31 (20)
Transportation service, n (%)	26 (17)
Other, n (%)	21 (13)
Distance to PAH clinic	
<10 km, n (%)	22 (14)
11 - 100 km, n (%)	65 (42)
>100 km, n (%)	69 (44)
Transport time back/forth to PAH clinic (h), Mdn (q1-q3)	2 (1-4)
Education	
Primary school, n (%)	53 (34)
High school, n (%)	59 (38)
University, n (%)	44 (28)
Occupation	
Employed, n (%)	27 (17)
Retired, n (%)	112 (72)
Sick leave, n (%)	12 (8)
Student/other, n (%)	5 (3)
Living alone, n (%)	34 (22)

Abbreviations: PAH, pulmonary arterial hypertension; CTEPH, chronic thromboembolic pulmonary hypertension.

*PAH-specific = treatment endothelin receptor antagonists, and phosfodiesteras-5-inhibitors.

of the clinic, and obtaining information about illness and self-care behaviour (Table 2).

Few patients used the response category ''No, not at all'' and for item 8, this alternative was not used at all (Table 2). There was no missing data. The PAHC-PREM scale demonstrated a negative skewed distribution (median = 19.5, q1-q3 = 17-21, skewness -1.3) that deviated significantly from a normal distribution, graphically (normal probability and quantile plots) and statistically ($\chi^2(2) = 28.7$, $p < 0.001$).

Homogeneity

The homogeneity among items was satisfactory. The inter-item correlations varied between rho 0.46 and 0.88, mean 0.62 (Table 3). The item-total correlations, adjusted for overlaps, ranged between rho 0.64 (item 7) and 0.91 (item 2) and were all above the recommended value of rho 0.30 (Table 3).

Factor Structure

The sampling adequacy was good, evaluated with the KMO measure of sampling adequacy (0.86), and the Bartlett's test of sphericity was significant (<0.001). The eigenvalues were 5.37 for the first factor and 0.68 for the second factor, i.e., supported a one-factor model. The parallel analysis confirmed the one-factor model with corrected eigenvalues of 5.01 for the first factor and 0.23 for the second factor. No communality value was below the critical level of 0.3, with a range between 0.46 and 0.86 (Table 4). The factor loadings varied between 0.68 and 0.92. This one-factor model explained 67% of the variance of the PAHC-PREM scale.

Criterion Validity

The overall experience of the visit at the PAH-outpatient clinic correlated strongly, as hypothesised, with the total score for PAHC-PREM scale (rho = 0.76), which supported criterion validity.

Reliability

The PAHC-PREM scale demonstrated good reliability in terms of internal consistency of the total scale according to both ordinal and traditional Cronbach's alpha, 0.93 and 0.81 respectively. No item reduced the internal consistency reliability according to the test of ordinal alpha if the item was deleted (Table 4).

Discussion

To our knowledge, this is the first validated PAHC-PREM scale developed for patients who visit a PAH outpatient clinic. It measures PAH outpatients' experiences associated with health care quality and can be used to improve those aspects of health care delivery at the clinics. The PAHC-PREM scale is brief and yet a valid and reliable instrument to measure the PAH outpatient patients' health care experience.

Results from the present study indicate that the tested PAHC-PREM scale is a unidimensional measure of health care quality experience for patients visiting a PAH outpatient clinic. The unidimensionality implies that the items in the scale measure a single underlying construct for these patients. The contribution of each item ranged between moderate to high. The item-total correlations were all above the recommended value of $r = \geq 0.30$, meaning that each item correlated well with the overall scale [18]. The internal consistency (alpha value 0.93) provides further support of the reliability and confirms that each of the eight items was valuable [18,21].

The items in the scale were all derived from the patients' own experiences of their care. Based on Beattie's model, there is a general understanding of what health care quality should include [5,6]. The model suggests that care should be timely,

Table 2 Data quality of the items in the PAHC-PREM scale (n = 156).

	Items	Skewness*	Score distribution, n (%)		
			No, not at all	Partially	Yes, totally
1	Did you get the opportunity to discuss how you feel, your symptoms and your treatment?	-2.087	4 (2)	26 (17)	126 (81)
2	Did the physician listen to you?	-2.510	4 (2)	20 (13)	132 (85)
3	Did you feel involved in decisions about your care and treatment, as much as you wished?	-1.873	6 (4)	29 (19)	121 (77)
4	Did you get information about your illness, as much as you wished?	-1.153	5 (3)	47 (30)	104 (67)
5	Did you get information about what you should/can do yourself to feel good or better?	-0.633	23 (15)	56 (36)	77 (49)
6	Do you feel confident with the coordination between different care units concerning your care?	-1.304	11 (7)	40 (26)	105 (67)
7	Was the availability of the PAH outpatient clinic during office hours good?	-1.979	1 (1)	26 (17)	129 (83)
8	Was the time in the waiting room at the PAH outpatient clinic acceptable?	-3.196	0 (0)	12 (8)	144 (92)

Abbreviations: PAH, pulmonary arterial hypertension.
*Values close to 0 indicate a symmetric distribution.

Table 3 Homogeneity in terms of item-total and inter-item correlations.

	Items	Item-total correlations	Ordinal Alpha if item deleted	1	2	3	4	5	6	7	8
1	Did you get the opportunity to discuss how you feel, your symptoms and your treatment?	0.86	0.91	1.0							
2	Did the physician listen to you?	0.91	0.91	0.88	1.0						
3	Did you feel involved in decisions about your care and treatment, as much as you wished?	0.84	0.92	0.77	0.81	1.0					
4	Did you get information about your illness, as much as you wished?	0.80	0.92	0.69	0.69	0.60	1.0				
5	Did you get information about what you should/can do yourself to feel good or better?	0.75	0.92	0.65	0.67	0.56	0.68	1.0			
6	Do you feel confident with the coordination between different care units concerning your care?	0.71	0.93	0.52	0.61	0.69	0.54	0.57	1.0		
7	Do you agree that the availability of the PAH outpatient clinic during office hours is good?	0.64	0.93	0.54	0.58	0.55	0.49	0.46	0.50	1.0	
8	Was the time in the waiting room at the PAH outpatient clinic acceptable?	0.82	0.92	0.63	0.71	0.60	0.65	0.48	0.53	0.63	1.0

Item-total correlation based on polyserial correlations.
Inter-item correlations based on polychoric correlations.
Abbreviations: PAH, pulmonary arterial hypertension.

Table 4 Factor loadings of the one-factor model of the PAHC-PREM scale.

Item	Abbreviated item label	Factor loading	Communalities
1	Discuss feelings, symptoms, treatment	0.87	0.75
2	Physician listening	0.92	0.86
3	Involved in decisions	0.84	0.71
4	Information about illness	0.78	0.61
5	Information what to do yourself	0.73	0.54
6	Confidence with coordination	0.70	0.50
7	Availability of PAH outpatient clinic	0.68	0.46
8	Waiting time at the PAH outpatient clinic	0.77	0.60

Unweighted Least Squares as factor extraction method; Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy = 0.861; Bartlett's test $\chi^2(28) = 498.8$, $p < 0.001$.
Abbreviations: PAH, pulmonary arterial hypertension.

safe, effective and enable system navigation [5,22]. The items derived from the patients' experiences in the present study included the aspect of timeliness in item #8, as it measured waiting or delay within the health care system [22]. Effectiveness is about communication, health care professionals' technical skills, and bringing the science together with the care given [5]. Items #1, #2, #4 and #5 reflect this aspect of communication in terms of listening, informing, and discussing. System navigation is about ensuring accessibility and efficient arrangements of those entering and navigating the health care system [5,6]. This aspect is congruent with items #6 and #7 about coordination of the care units the patient will have contact with and about the availability of the PAH outpatient clinic. Even though the aspect of safety, described as the ability of health care to provide accurate and reliable service, was not considered an important aspect among the PAH patients interviewed in the present study, many of the items cover the safety aspect.

The health care quality should also include foundational domains, that is caring and patient-centredness [5]. All of the items in the PAHC-PREM scale are based on respect to caring for the patient and the perspective of patient-centredness. Caring is central to health care quality and establishing caring relationships are essential for many patients [5]. Patient-centred care is respectful of an individual's preferences, needs and values and incorporates the notion of 'nothing about me without me' [22]. In the present PAHC-PREM scale, item #3 concerns patient participation, congruent with the perspective of patient-centredness, where the patient is feeling involved in decisions about care and treatment.

The study sample of 156 patients comprised almost 80% of the patients who visited one of six Swedish PAH outpatient clinics during the 3 months preceding the study. The study population, accounting for 25% of patients in SPAHR registry that were alive in 2015 [16], was a good representation of patients included in SPAHR, with regard to gender (women in study 57% vs. SPAHR 60%), and patients diagnosed with CTEPH (32% vs. 28%). Patients in the study were slightly older (median 69 [57-75] years vs. 64 [45-72]), and fewer were diagnosed with PAH (49% vs. 62%), which can affect generalisability (personal communication SPAHR, 2017). The sample size in the study meets a general rule of having at least five times as many observations as items [23]. Thus, the PAHC-PREM scale can be considered a useful instrument to evaluate health care experiences from all patients who visit the PAH outpatient clinics.

Quality improvement advocates repeated measurement over time to capture changes in health care processes and behaviours. The PAHC-PREM is planned to be used at least once a year at scheduled follow-up visits at the PAH outpatient clinics.

Limitations

This study has limitations. The PAHC-PREM scale was tested in a Swedish population of patients visiting PAH outpatient clinics, which might limit transferability. For this study we used a single test administration, and therefore, further testing of reliability of the PAHC-PREM is needed, such as test-retest reliability and responsiveness. Although this instrument was specifically developed with and for patients visiting a PAH outpatient clinic, there are general PREMs for patients visiting an outpatient clinic with items addressing similar aspects of health care as the items in the PAHC-PREM [24,25]. The fact that the items developed in the PAHC-PREM are not disease specific was not known a priori of the study. The study design might have been stronger if convergent validity assessment with comparison to existing general PREM instruments for patients visiting an outpatient clinic was performed. The strength of the PAHC-PREM is, though, that the patient population who will use it have been involved in the design of the instrument. The instrument also needs to be tested to identify scores to differentiate between good and poor patient experience of PAH outpatient clinic health care quality. The ability of the PAHC-PREM scale to drive improvement at the PAH outpatient clinics is also a matter for future work.

Conclusion

The PAHC-PREM scale is a brief, valid and reliable instrument for evaluating patient experience of health care after visiting a PAH outpatient clinic. Measuring the health care quality from the patient's perspective and with an instrument based on items derived from the patient's own experiences of the health care, makes the PAHC-PREM scale a strong and useful tool.

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Author Contributions

Study design of the work: BI, TJ, BK, AS, NW; Data collection: BK, NW; Data analysis: NW, KÅ: Drafting the work or revising it critically for important intellectual content: BI, TJ, BK, AS, NW, KÅ; Final approval of the version: BI, TJ, BK, AS, NW, KÅ.

Conflict of Interest

There are no conflicts of interest for any of the authors.

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References

[1] Galie N, Humbert M, Vachiery JL, Gibbs S, Lang I, Torbicki A, et al. 2015 ESC/ERS Guidelines for the Diagnosis and Treatment of Pulmonary Hypertension: The Joint Task Force for the Diagnosis and Treatment of Pulmonary Hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS): Endorsed by: Association for European Paediatric and Congenital Cardiology (AEPC), International Society for Heart and Lung Transplantation (ISHLT). Eur Respir J 2015;46:903–75.

[2] Rådegran G, Kjellström B, Ekmehag B, Larsen F, Rundqvist B, Blomquist SB, et al. Characteristics and survival of adult Swedish PAH and CTEPH patients 2000-2014. Scand Cardiovasc J 2016;50:243–50.

[3] Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. BMJ Open 2013;3.

[4] Anhang Price R, Elliott MN, Zaslavsky AM, Hays RD, Lehrman WG, Rybowski L, et al. Examining the role of patient experience surveys in measuring health care quality. Med Care Res Rev 2014;71:522–54.

[5] Beattie M, Shepherd A, Howieson B. Do the Institute of Medicines' (IOM) dimensions of quality capture the current meaning of quality in health care? An integrative review. J Res Nurs 2012;18:288–304.

[6] Beattie M, Shepherd A, Lauder W, Atherton I, Cowie J, Murphy DJ. Development and preliminary psychometric properties of the care experience feedback improvement instrument (CEFIT). BMJ Open 2016;6: e010101. http://dx.doi.org/10.1136/bmjopen-2015-010101.

[7] Mohammed K, Nolan MB, Rajjo T, Shah ND, Prokop LJ, Varkey P, et al. Creating a patient-centered health care delivery system: a systematic review of health care quality from the patient perspective. Am J Med Qual 2016;31:12–21.

[8] Bertakis KD, Azari R. Patient centered care is associated with decreased health care utilization. J Am Board Fam Med 2011;24:229–39.

[9] Boulding W, Glickman SW, Manary MP, Schulman KA, Staelin R. Relationship between patient satisfaction with inpatient care and hospital readmission within 30 days. Am J Manag Care 2011;17:41–8.

[10] Epstein RM, Franks P, Shields CG, Meldrum SC, Miller KN, Campbell TL, et al. Patient centered communication and diagnostic testing. Ann Fam Med 2005;3:415–21.

[11] Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. J Fam Pract 2000;49:796–804.

[12] Beattie M, Lauder W, Atherton I, Murphy DJ. Instruments to measure patient experience of health care quality in hospitals: a systematic review protocol. Syst Rev 2014;3:4.

[13] Darby C, Crofton C, Clancy CM. Consumer assessment of health providers and systems (CAHPS): evolving to meet stakeholder needs. Am J Med Qual 2006;21:144–7.

[14] Teale EA, Young JB. A patient reported experience measurement (PREM) for use by older people in community services. Age Ageing 2015;44:667–72.

[15] Ivankova NV, Creswell JW, Stick SL. Using mixed-methods sequential exploratory design: from theory to practice. Field Methods 2006;18:3–20.

[16] SPAHR annual report (2015). published 2016. Downloaded 17-03-12 on: http://www.ucr.uu.se/spahr/arsrapporter?task=document.viewdoc&id=38.

[17] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005;15:1277–88.

[18] Field AP. Discovering statistics using IBM SPSS statistics, 4th ed. London: Sage publications; 2013.

[19] Timmerman ME, Lorenzo-Seva U. Dimensionality assessment of ordered polytomous items with parallel analysis. Psychol Methods 2011;16:209–20.

[20] Zumbo BD, Gadermann AM, Zeisser C. Ordinal versions of coefficients alpha and theta for Likert rating scales. J Mod Appl Stat Methods 2007;6:21–9.

[21] Nunnally JC, Bernstein IH. Psychometric theory, 3rd ed. New York, NY: McGraw-Hill; 1994.

[22] Institute of Medicine. Crossing the quality chasm: a new health system for 21st century. Washington DC: National Academy Press; 2001.

[23] Hair JF, Anderson RE, Tatham RL, Black WC. Multivariate data analysis, 5th ed. Upper Saddle River, NJ: Prentice-Hall; 1998.

[24] Garratt AM, Bjærtnes ØA, Krogstad U, Gulbrandsen P. The OutPatient Experiences Questionnaire (OPEQ): data quality, reliability, and validity in patients attending 52 Norwegian hospitals. BMJ Qual Saf 2005;14:433–7.

[25] Sjetne IS, Bjertnaes OA, Olsen RV, Iversen HH, Bukholm G. The Generic Short Patient Experiences Questionnaire (GS-PEQ): identification of core items from a survey in Norway. BMC Health Serv Res 2011;11:88.