Development of a patient experience questionnaire for primary care mental health

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ABSTRACT

Introduction: There are no validated measures available for use in assessing patients' views of the quality of primary care mental health care at practice level.

Methods: The Patient Experience Questionnaire was developed through an initial information-gathering phase with focus groups followed by questionnaire development and validation with patients in nine general practices in the West Midlands. Statistical analyses were performed to test the internal consistency, validity and reliability of the questionnaire.

Results: Fifty six patients participated in focus groups, and 241 patients completed the questionnaire. The 20-item questionnaire had good internal consistency (Cronbach $\alpha = 0.94$) and test-retest reliability ($r = 0.859$ $p = 0.01$).

Discussion: The Patient Experience Questionnaire appears to be a valid and reliable instrument, able to assess patients' views of the quality of primary care mental healthcare at practice level.

INTRODUCTION

Primary care is responsible for much of the delivery of mental healthcare in the United Kingdom (UK).[1] The majority of people with serious mental illness and with common mental health problems are now registered with a General Practitioner (GP), and 90 per cent of patients with all mental health problems, including up to 30-50 per cent of people with severe mental illness (SMI), are only seen in primary care.[2] How well primary care delivers such care is therefore of increasing importance. Patients' views of services are also increasingly recognised as central to improving service design and delivery.[3 4] This is particularly important in mental healthcare where patients and providers often have different perspectives on what constitutes good care[5 6] and where patients experience poorer health and healthcare than the general population and are subject to significant stigma, even from within the medical profession.[7] Previous work has suggested that availability and access, health professional 'humanity', patient involvement in decision-making, provision of information and sufficient time are important to patients when assessing the generic quality of primary care.[8 9 10 11] There are, however, few validated tools able to assess the quality of primary mental healthcare provision.[5 12]

Many questionnaires are largely relevant either only to secondary care; for example, the 'How are you? Scale' (FACE – HRU) and the 'Health of the Nation Scale' (HoNoS), or if relevant to primary care, for example, Clinical Outcomes in Routine Evaluation or Psychological Outcomes Profile, follow the clinical course of individual patients through the treatment process. [13 14 15 16 17 18 19 20] None, to our knowledge, address patient experience of primary care mental health at the practice level.

The aim of this study was to develop a single valid and reliable questionnaire relevant to people with SMI or common mental health problems (CMHPs) that could assess patient experience of primary care mental health at the practice level for patients with mental health problems. The concept of primary care mental health encompassed structures such as practice systems, processes such as GP consultation behaviour and outcomes such as referral to services provided by the extended primary care team.

METHODS

Phase 1: Developing the questionnaire items

Phase 1 of the study used focus groups to explore patients' experiences of receiving care for their mental health problems from the primary care team. Focus groups have been widely used to examine people's experiences of illness and healthcare.[21] They provide an enabling setting for potentially vulnerable patients to express their views and dynamic group interaction that lead to greater insight into attitudes and beliefs.[22 23]

Each focus group comprised up to eight patients with mental health problems, with smaller numbers for the groups with patients with CMHPs. Separate groups were run with patients with SMI in 2003 and those with CMHPs in 2004. Patients with SMI (broadly defined to include severe recurrent depression as well as psychosis such as schizophrenia and bipolar disorder) were recruited through voluntary sector organisations, day hospitals and patient groups across the West Midlands.[24] Patients with CMHPs were recruited from 16 practices in Birmingham already participating in a study on primary care mental health workforce redesign. Patients (18-65 years old), diagnosed as having new or ongoing CMHPs such as depression, anxiety, stress and obsessive compulsive disorder during the course of a normal consultation, were told about the study by their GP. Patients who were interested in learning more about the study were then contacted by a letter from the research team. Table 1 details the demographic backgrounds of patients participating in the focus groups.

The topic guide was informed by previous work on generic quality indicators for primary care and included questions on access, continuity, information sharing and involvement in decision-making. In addition, positive and negative critical incidents of primary care mental health were sought.[25]

Table 1: Characteristics of participants in the focus groups

	N= 56	%
Gender		
Male	22	39
Female	34	60
Age range		
15-20	1	2
20-29	8	14
30-39	22	39
40-49	15	27
50-59	7	13
60-70	3	5
Ethnicity		
European	42	75
African Caribbean	6	11
Asian	4	7
Other	4	7
Diagnosis		
CMHP	11	20
SMI	45	80

Nine focus groups were held, six with patients with SMI and three with patients with CMHPs. Each focus group was facilitated by two researchers and lasted between 60-90 minutes. All focus groups were audiotaped and fully transcribed. Themes were identified and developed by both NM and HL from reading and re-reading transcripts and themes were further refined and clarified using the Framework method.[26] Framework is based on a 'grounded theory' inductive approach to data analysis where theories are generated from data. Focus groups and analysis were conducted concurrently and continued until no new themes emerged and data saturation was felt to be complete. The reliability of the data was further increased by respondent validation of summaries of the focus groups.

Thematic analysis of the focus group data identified a number of key issues for patients with mental health problems in primary care. At a practice level, these included accessibility, continuity of care, perceived attitude of receptionists, the waiting room atmosphere and the provision of treatment choice. GP level qualities felt to be important included listening skills, perceived comfort with shared decision-making and perceived attitude towards mental

illness. These themes were incorporated as items in the Patient Experience Questionnaire (PEQ).

Phase 2: Validating the questionnaire

Based on information gathered from the focus groups, a structured five point Likert-scale questionnaire of 33 items was developed to assess patient experience of primary care mental health. The first 30 items of the questionnaire were relevant to all patients. The three final questions were only relevant to those who had been referred to secondary specialist mental health services. To further increase the face validity of the questionnaire, questions were reviewed by members of the National Institute of Mental Health England (NIMHE) primary care service users steering group. The questionnaire was also reviewed by practice staff and GPs at two practices who agreed to help pilot the questionnaire to ensure that none of the questions were distressing to either patients or primary care practice staff. No item was removed, but wording was occasionally modified as a result of the consultation exercise.

Thirty practices across the West Midlands that varied in list size and practice area deprivation were initially selected and contacted with the assistance of the University of Birmingham's Midland Research Practices Consortium (MidRec). Nine (30%) agreed to participate. Practices ranged in size from 2,000-15,600 patients. Townsend Scores ranged from –2.9 to 1.3.

In order to recruit patients to pilot the questionnaire, practices were asked to access their computerised patient records to identify patients seen at the practice during the past three months where a diagnostic read code of depression, bipolar disorder, obsessive-compulsive disorder, schizophrenia, anxiety, or stress had been recorded. GPs were then asked to exclude any patient they felt would not be suitable to receive or complete a questionnaire, for example because of an acute illness or recent bereavement.

Selected patients were then sent a letter from their GP in summer 2005 asking if they would be willing to complete the questionnaire and provide demographic information including

age, gender and diagnosis as part of the study. Patients were also asked to complete an identical questionnaire two to four weeks after completing the first one. Return of the first questionnaire was taken as consent to participation in the study and no reminder letters were sent.

Statistical analysis

Questionnaires were analysed using Statistical Package for Social Sciences (SPSS) version 14.0. Questionnaire items were scored from 1-5 and 'reverse-scored' when negative questions were asked. The maximum possible score for the 30-item scale is 150 and 100 for the 20 item scale. Total scores are obtained by summing scores for all items. Analysis involved generating descriptive statistics for each item on the questionnaire to evaluate the distribution of scores.

Factor analysis

To investigate the pattern underlying the patients' responses to the PEQ, scores on the 30 and 20 item questionnaires, items were subjected to principal components analysis with Varimax rotation. The factor solution for each was based on eigenvalues greater than one and interpretation of the scree plots to determine the number of factors to retain.[27] A pairwise method was used for handling missing data in the exploratory factor analysis.

Reliability

Internal consistency was assessed by item-total correlation and Cronbach alpha coefficient. Test-retest reliability was assessed using the Pearson correlation between the test and test-retest questionnaires.

RESULTS OF PHASE 2

A total of 1105 patients in the nine study practices were identified from practice records. GPs subsequently highlighted 147 (13.3%) patients as unsuitable to participate. 958 patients were therefore sent a questionnaire in Spring 2005, and 241 (25.1%) patients responded to the first questionnaire. All were sent a second questionnaire at 2-4 weeks, and 149 responded (15.5% of the total cohort and 61.8% of the original respondents). Of the 241

responses to the first questionnaire, 24 had to be excluded from final statistical analysis due to missing data. Eleven had to be excluded for the same reason from the repeated questionnaire. The mean age, gender and diagnosis of the responders to the first questionnaire are shown in Table 2. The average number of patients completing questionnaires in each of the nine practices was 24.

Table 2: Characteristics of respondents to both questionnaires

	First Questionnaire	**Second Questionnaire**
No	241	149
Age mean (SD)	46.4 (13.5)	48.2 (14.5)
Age range	18-83	18-83
Sex (female:male)	168:73	107: 42
Diagnosis No (%)		
Mixed Depression and Anxiety	77 (32)	47 (31.5)
Depression	75 (31.1)	40 (26.9)
Anxiety	48 (19.9)	33 (22.7)
Stress	19 (7.9)	13 (8.7)
Serious Mental Illness *	15 (6.2)	10 (6.7)
Obsessive Compulsive Disorder	2 (0.8)	2 (1.3)

*Schizophrenia, affective psychosis and bipolar disorder

All items on the first questionnaire had responses that included the full range of the Likert scale. No two items on the questionnaire had a correlation score of greater than 0.8 with each other, confirming that each item elicited different information.[28] For the internal consistency reliability analysis, items 1-30 were considered together, while items 31 to 33 (completed only by those who had received referral to secondary care specialist mental health services, n=109), were considered in a separate analysis.

The questionnaire scores had acceptable approximations of univariate and multivariate normality. Using data from the first questionnaire, patients were categorised into the following age groups 16-24, 25-39, 40-59 and 6+. Total scores on the 30-item questionnaire did not differ between age groups ($F(3, 213) = 1.25$, $p>0.05$); gender ($t(153) = 1.47$, $p = 0.14$), or diagnostic category divided into six serious mental illness groups (schizophrenia, affective

psychosis, and bipolar disorder), depression (endogenous, reactive depression and post-natal depression), mixed anxiety and depression, anxiety (anxiety, panic, phobia, PTSD), and obsessive compulsive disorder and stress ($F(5,206) = 1.30$, $p>0.05$). Table 3 shows the mean total scores obtained on the questionnaire by sex, age and diagnosis.

Table 3: Mean (SD) total scores obtained on the first questionnaire

	No	**Total Score Mean**	**(SD)**
Female	149	111.73	19.20
Male	68	114.73	16.40
Age (16-24)	7	123.71	20.56
Age (25-39)	63	110.00	17.11
Age (40-59)	118	112.92	19.45
Age (60 +)	29	114.79	15.34
Diagnoses:			
Depression	75	110.53	17.02
Anxiety	48	118.02	16.33
Stress	19	107.31	22.76
Serious Mental Illness	15	108.83	18.37
Obsessive Compulsive Disorder	2	127.50	16.26
Mixed Depression and Anxiety	77	113.42	18.67

Exploratory factor analysis

Thirty items were used in the initial exploratory factor analysis. The Keyser-Meyer-Olkin measure of sampling adequacy was 0.93 for the scale[29] and Bartlett test of non-sphericity was significant for the solution ($\chi^2 \geq 3710$; $P<0.001$), indicating that the variables entered were adequate for factor analysis.

The initial principal components analysis revealed five components with factor eigenvalues >1. The five factor model explained 59.86% of the total variance (factor 1: 39.67%; factor 2: 7.41%; factor 3: 5.56%; factor 4: 3.89%; factor 5: 3.33%), with most items loading on the first three components. Determination of the number of factors to extract for rotation was also based on identifying the break in the screeplot [27]; see Figure 1. Based on this analysis, two components were subjected to Varimax rotation. A two-factor solution appeared to be most

appropriate and accounted for 47.1% of the total variance (factor 1: 25.81%; factor 2: 21.28%).

Scale Reliability

The 30 item questionnaire demonstrated a reliability score of Cronbach α = 0.94. The three remaining items together had an expected low Cronbach α = 0.022, reflecting the small number of items. The correlation of the total scores from the first questionnaire (n=241) and the second questionnaire (n=149) for the 30 items was r=0.87 p=0.01, suggesting good test-retest reliability.

In order to increase the utility of the questionnaire, a shorter-version that took less than four minutes to complete was developed. Based upon alpha reliability scores after deletion of each item using only the 30 questionnaire items answered by all participants, a 20-item score questionnaire was developed with the lowest item-total correlations removed.

Exploratory factor analysis

The 20 items were subjected to exploratory factor analysis. The Keyser-Meyer-Olkin measure of sampling adequacy was 0.95 for the scale[29] and Bartlett test of non-sphericity was significant for the solution ($\chi^2 \geq 2595.77$; $P<0.001$), indicating sample adequacy for factor analysis.

The initial principal components analysis yielded three components with factor eigenvalues >1. The three factor model explained 61.17% of the total variance (factor 1: 47.24%; factor 2: 8.39%; factor 3: 5.54%). Loading patterns for both the 30 item and 20 item scales were similar, with most items loading on the first two components. Determination of the number of factors to extract for rotation was based on identifying the break in the screeplot [27] (see Figure 2). Based on this analysis, two components were subjected to Varimax rotation. A two-factor solution appeared to be most appropriate and accounted for 55.63% of the total variance (factor 1: 32.03%; factor 2: 23.6%). The factor pattern/structure matrix of the final solution is presented in Table 4. The first factor relates to the attributes of the GP (ability to listen, take the patient's concerns seriously and provide information and choices) and the second factor was related to experiences with the practice in general (experiences with the

practice nurse, receptionists and appointment making, waiting room and easy access to counsellors). Many of these themes are similar to those in Campbell *et al*'s theoretical conceptualisation of quality that focused on access and effectiveness of clinical and interpersonal care.[11]

Scale Reliability

The Cronbach α reliability score of the 20-item questionnaire using the first questionnaire responses was 0.94, with test-retest reliability coefficient r=.859 p=0.01.

In order to ensure that the questionnaire was easy to understand, the 20-item version was crystal-marked by the Plain English Campaign Company.

DISCUSSION

Patient feedback is increasingly seen as a key component of healthcare quality monitoring and improvement in all sectors of healthcare.[30] In recent years there has been a move away from generic satisfaction measures towards a more detailed measurement of patients' experience that can help to pinpoint potential problems more easily. The 20-item PEQ represents the first questionnaire able to evaluate patient experience of primary care mental health at practice level (Box 1).

Strengths and limitations

The content and face validity of the PEQ was increased through the use of focus groups, which helped to ensure that it included issues important to patients. Review by practice staff ensured that the questionnaire was also acceptable to healthcare professionals. The questionnaire also has good internal consistency and test-retest reliability.

The study however has a number of methodological limitations. We held more focus groups with patients with SMI than CMHPs largely because of differing recruitment methods. Patients with CMHPs were only able to join a focus group through an

invitation from their GP, whereas patients with SMI were approached through the voluntary sector. However we found virtually no difference between groups' views of primary care mental health. The questionnaire had a low response rate, and it is possible that the patients who responded may have been different from those who did not respond. However ethical committee approval restrictions meant it was not possible to send out a reminder letter to increase the response rate or learn demographic characteristics of non-responders. However, the response rate is comparable to other postal studies with similar patient populations.[31] The cultural validity of the questionnaire was also not specifically addressed during its development. The total mean questionnaire scores were relatively high (mode of 80/100 for the 20 item version). This suggests that patients were generally satisfied with the primary mental healthcare they received. However, it is possible that by agreeing to be involved, participating practices in this study may have had a particular interest in mental health issues.

Measurement plays an important part in improving healthcare. Formal measurement of patients' experiences is an important way for practitioners to evaluate their work, challenge traditional assumptions and highlight key priorities patients would like to see addressed. It is also a major determinant in altering service provision.[32 33] The overall performance on the PEQ can give practices an indication of the views of their patients, and closer examination of individual question items will enable practices to tailor their improvements. To be of greater value, however, the PEQ also needs to be able to differentiate between optimal and less optimal care.[5 34] A next step in the development will be to benchmark it across practices and use it to assess change in quality of services over time. In summary, the PEQ now enables practices to better understand their patients' views and may help them reflect on and modify their services to improve patients' experience of primary care mental health.

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Competing interests

None.

Ethics approval: Ethics approval was obtained from the West Birmingham Local Research Ethics Committee and South East Multi-regional Ethics Committee (MREC).

Patient consent: Obtained.

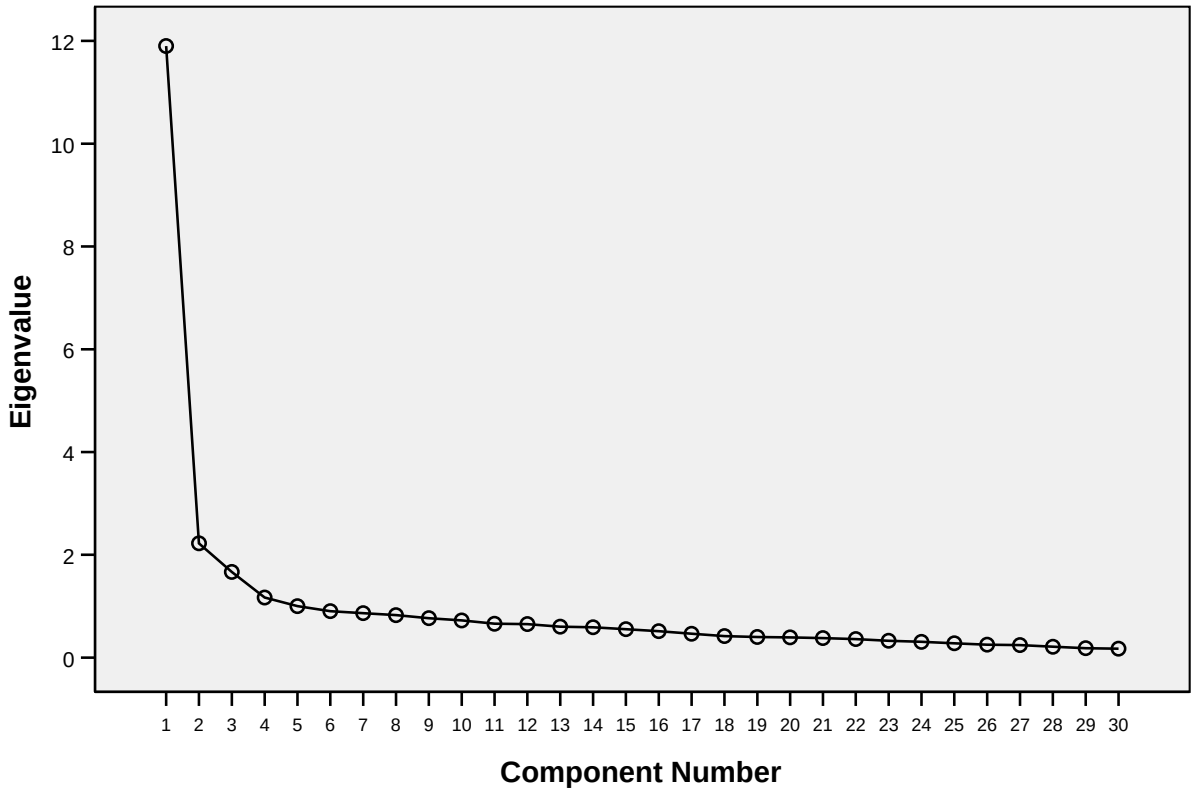

Figure 1. Scree plot for 30 item PEQ data

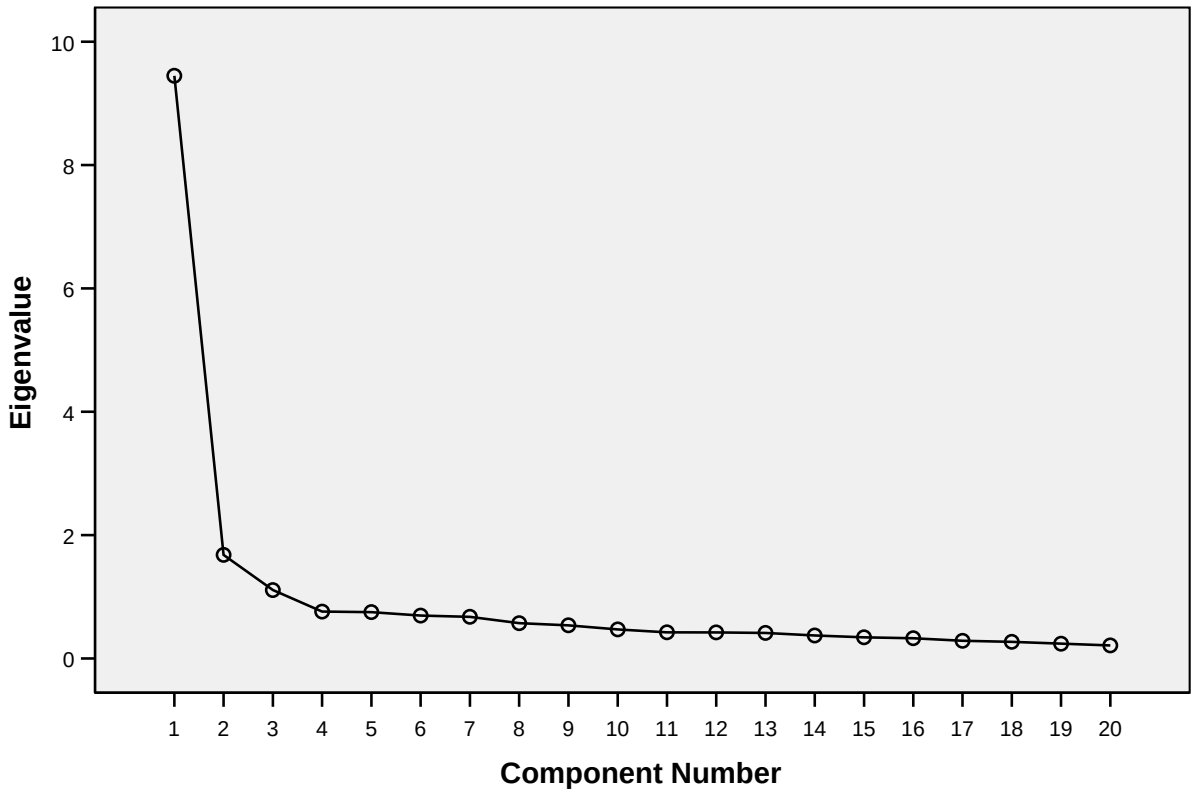

Figure 2. Scree plot for 20 item PEQ data

Table 4 Pattern/structure matrix with factor loadings in the final exploratory factor analysis model

Item	Factor 1	Factor 2
3 GP makes me feel I'm wasting time	0.83	
1 GP does not take anything I tell seriously	0.77	
17 GP treats me as an individual	0.75	
2 GP has time to listen	0.74	0.31
4 GP never encourages talking about worries	0.74	
5 GP is too quick to blame my physical problems on stress	0.71	
7 GP always gives clear information	0.64	0.46
19 Practice does not respect people with mental health problems	0.63	
8 GP never explains things to me	0.63	0.34
15 GP does not deal with my concerns about tablets and side effects	0.58	0.41
6 If I need extra time with my GP, it is never available	0.54	0.76
13 GP works closely with other mental health workers		0.71
10 GP always gives me up-to-date information	0.32	0.71
14 GP never offers me treatments other than tablets		0.70
11 GP offers me treatment choices besides taking medication		0.62
18 I can always get help		0.58
12 I always have to insist that my GP refers me for counselling	0.34	0.57
20 I am satisfied with the mental health care I receive	0.53	0.56
9 My GP is always willing to discuss different options	0.48	0.51
16 My GP regularly reviews my mental health problems	0.43	

The extraction method was principal components analysis and rotation method Varimax.

Factor loadings of > 0.3 are presented.

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