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Patient-reported outcome measures in value-based healthcare: A multiple methods study to assess patient-centredness

Martha Kidanemariam[a,*], Olaf M. Neve[b], Isabelle van den Heuvel[c], Sana Douz[a], Erik F. Hensen[b], Anne M. Stiggelbout[a,c], Arwen H. Pieterse[a]

[a] *Medical Decision Making, Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, the Netherlands*
[b] *Department of Otorhinolaryngology and Head & Neck Surgery, Leiden University Medical Center, Leiden, the Netherlands*
[c] *Erasmus School of Health Policy and Management, Erasmus University Rotterdam, Rotterdam, the Netherlands*

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ABSTRACT

Objectives: Value-based healthcare (VBHC) involves the use of standardised outcome measures, including patient-reported outcome measures (PROMs). This study aimed to assess to what extent discussion of PROMs is associated with patient- and person-centredness.

Methods: This study used a separate sample pre-/post-test design and multiple methods (observations, questionnaires, and interviews) in a VBHC care pathway for patients with a vestibular schwannoma, to assess to what extent the implementation of PROMs is associated with a difference in patient- and person-centredness.

Results: A total of 139 patients with a vestibular schwannoma and their four treating physicians were included in the study. No significant differences were found in observed patient-centredness (M_{pre}=6.71 ± 2.42 vs. M_{post}=6.93 ± 2.01; P = 0.60) or patient-reported patient-centredness (M_{pre}=1.73 vs. M_{post}=1.68; P = 0.63) and person-centredness after PROM implementation (M_{pre}=11.81 vs. M_{post}=13.42; P = 0.34). We observed more discussion of patient-reported outcomes**.** However, a majority of patients did not expect PRO discussion in consultations.

Conclusions: The implementation of standardised PROMs in a VBHC care pathway was associated with more discussion on patient-reported outcomes in clinical consultations. Overall, the implementation of PROMs was not observed or perceived as leading to more patient-centred consultations.

Practice implications: Physicians should assess whether the discussion of PROMs add value collaboratively with patients.

1. Introduction

Value-Based Healthcare (VBHC) has been introduced as a management strategy to improve value in patient care [1]. *Value* is defined as outcomes that matter to patients relative to the costs needed to achieve them [2]. Outcome measures (and costs) may be used at the aggregate level for benchmarking to improve value. To that end, standardisation of outcome measures is integral [2,3]. In VBHC, PROMs are used both at the aggregate level for value improvement, and at the individual patient level, where the patients' filled-out PROMs are used as input during clinical consultations, to support shared decision making and discuss the patients' needs [4–6].

Before the introduction of VBHC, PROMs were already in use in individual patient care to screen for patients' needs, monitor symptoms, and support decision making [7]. Research on the benefits of using PROMs in individual patient care has shown mixed results [8–10]. PROMs were observed to increase discussion of symptoms and aspects of health-related quality of life (HRQOL), and subsequently counselling [11,12]. Using PROMs for symptom monitoring was shown to lead to better clinical outcomes [13]. However, only a small number of studies are considered robust enough to provide adequate evidence [8,9]. A realist synthesis on the use of PROMS showed that their structure partially determined whether they were perceived as supportive or not in consultations [7]. Standardised PROMs might constrain patient-clinician relationship-building [14–20]. For example, in mental health PROMs were perceived to trivialise patients' emotions and to retrieve information in a mechanistic way [14]. It also seemed difficult to capture complex or dynamic symptoms [15]. Discussing PROMs with

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* Correspondence to: Leiden University Medical Center, P.O. Box 9600, 2300 RC Leiden, the Netherlands.
E-mail address: m.kidanemariam@lumc.nl (M. Kidanemariam).

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patients may disrupt the flow of the conversation and increase experienced time pressure [14,16]. Outcome sets that do not include those outcomes that matter most to the individual patient may be less appropriate to support patient-centred care, and possibly lead to less *person*-centred care [21]. Patient-centredness and person-centredness are similar concepts and are underpinned by the same dimensions (Fig. 1), yet the goals differ: in patient-centred care the goal is to achieve a functional life, in person-centred care to achieve a meaningful life [22]. In a qualitative study healthcare professionals indicated that they experience PROMS to support person-centred care [23], yet more evidence is lacking.

To assess whether the use of PROMs at the individual level promotes or jeopardises patient- and person-centredness in clinical consultations we studied:

1) to what extent individual patients' PROMs are used in consultations, and to what extent the use of PROMs determines what symptoms are discussed and in what depth;
2) to what extent the implementation of PROMs is associated with patient- and person-centredness in consultations;
3) how patients and their physicians experience the use of PROMs in the consultation.

2. Methods

2.1. Study setting and population

We evaluated the use of PROMs in a VBHC care pathway for patients with a vestibular schwannoma (VS), at the Leiden University Medical Center (LUMC), The Netherlands. A VS is a benign tumour originating from the vestibulocochlear nerve between the inner ear and the brain. The local collaboration between the departments of otorhinolaryngology/head and neck surgery, neurosurgery, radiotherapy, and radiology in VS care was started in 1995, and the care pathway was restructured according to VBHC principles from 2017–2021. An outcome set was defined, including clinical outcomes and PROMs. These included the generic (RAND-36) and disease-specific (PANQOL) quality of life questionnaires; patients who scored at least four points on one or more of the PANQOL dizziness subdomain questions, were asked to complete the Dizziness Handicap Inventory (DHI).

At the individual patient level, clinical outcomes and PROMs are visualised in a dashboard within the electronic health record, to facilitate patient counselling and shared decision making.

As of April 2021, the clinical team sent patients a secured email two weeks prior to the consultation, with a link to the electronic patient portal to complete the PROMs (Box 1). The implementation was incremental, gradually increasing to an invitation to all patients visiting the out-patient clinic.

Before the first PROMs were sent out, physicians participated in an educational session to understand: i) how to access the PROMs dashboard in the electronic patient record, ii) the visualisations of PROM results, and iii) how PROMs can be used in clinical consultations. After the start of the implementation in April 2021, the VBHC advisors monitored physician experiences with the use of PROMs and updated the dashboard according to their preferences, including incorporating reference values for scores.

2.2. Study design

A separate-sample pre-/post-test (with different patients included in the pre-test than in the post-test), and multiple-methods design was used to investigate the association between the implementation of PROMs and observed and patient-reported patient- and person-centredness. To this aim, we collected observer ratings of audio-taped consultations and patient questionnaires on patient- and person-centredness. After the implementation, we performed qualitative interviews to obtain information on the experiences of patients and physicians with the use of the PROMs. Moreover, in a post-consultation checklist, we explored if physicians experienced time pressure, and if PROMs affected this.

2.3. Ethical approval

The medical ethics committee exempted our study from a full ethics review, according to the Medical Research Involving Human Subjects Act (Wet Medisch-Wetenschappelijk Onderzoek met Mensen; N19.116).

2.4. Recruitment and study procedures

We invited patients over 18 years who had recently been diagnosed with a unilateral VS and who were scheduled for their first visit at the outpatient clinic of the LUMC, a tertiary referral centre, between July 2020 and March 2021 (pre-test) or between April 2021 and March 2022

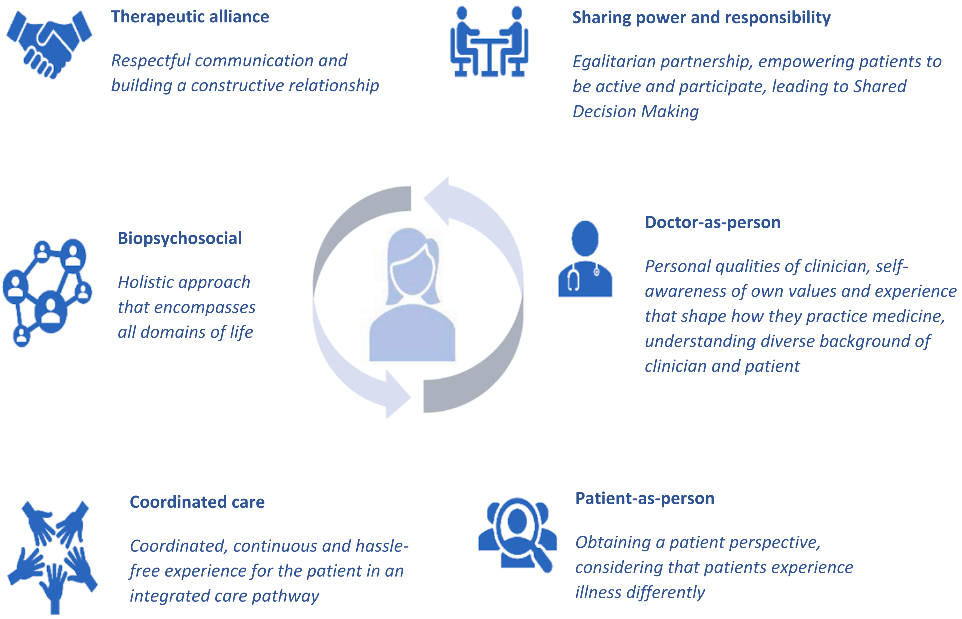

Fig. 1. Six recurrent dimensions defining patient-centredness over time, as identified in the review of Langberg et al. [24].

Box 1
PROMs as implemented in the VBHC vestibular schwannoma care pathway.

1. Research and Development-36 (RAND-36).
2. Penn Acoustic Neuroma Quality-of-Life Scale (PANQOL)
3. Dizziness Handicap Inventory (DHI), on indication

(post-test). Eligible patients received an invitation letter by mail, together with an information leaflet about the study and an informed consent form. Patients agreeing to participate were asked to complete the informed consent form and to bring it to the consultation. The physician audio-recorded the consultations with consenting patients. Audio-recorded consultations were transcribed verbatim. In the week following the consultation, the researchers sent the patients two questionnaires on patient- and person-centredness, electronically or on paper, depending on the patient's preference. Data on patients' sex and age were collected from the electronic health record after informed consent. A selection of the patients included in the post-test phase who gave permission to be contacted for follow-up research, and all physicians, were interviewed about their experiences with PROMs and its relation to patient-centredness. Purposive sampling was applied to include patients varying in age, sex, and who had or had not completed the PROMs. The interviews were scheduled face-to-face at the LUMC or by (video)phone, depending on the patient's preference. We stopped recruiting when no new themes emerged in two sequential interviews.

2.5. *Quantitative measures: questionnaires*

2.5.1. *Patient-reported patient- and person-centredness*

We translated the Patient Perception on Patient-Centredness-revised (PPPC-R) [25] into Dutch using a forward-backward procedure [26]. The PPPC-R is an 18 item-scale, containing three subscales (Healthcare processes, Roles, and Context & Relationship), with response categories ranging from 1 to 4, lower scores indicating more patient-centredness.

We used the Dutch version of the eight-item 'Person-centredness' subscale of the Person-Centred Coordinated Care Experience Questionnaire (P3CEQ) [27] response categories ranging from 0 to 3, higher scores indicating more person-centredness.

2.5.2. *Physician-reported time pressure*

During the post-test phase, we asked physicians to complete three self-developed items on experienced time pressure after each out-patient clinic during which they had seen at least one patient who had been invited to complete PROMs (Appendix A). One item asked about time pressure on a scale from 0 (none) to 10 (very high); in the next physicians were asked to report the number of minutes by which the scheduled time for an out-patient clinic day had overrun; and the last asked how much the use of PROMs had affected experienced time pressure (from 1–2 (small or large decrease), to 4–5 (small or large increase) or 3, had no impact on experienced time pressure).

2.6. *Quantitative measures: observer ratings of the consultations*

The research team developed a rating scheme and manual to score the use of PROMs, the symptoms discussed during the consultation, and patient-centred behaviour. Three coders (MK, ON, SD) were trained in consistently applying the scheme. Two coders (MK, ON) then rated 21 consultations independently; inter-rater reliably was high (intraclass coefficient, ICC=0.94). One coder (MK) then single-rated the remaining consultations collected in the pre-test phase. In the post-test phase, MK and SD double-rated all consultations independently and then discussed rating until consensus was reached.

2.6.1. *PRO discussion with explicit reference to PROMs*

We scored: i) mention of the PROMs (yes/no), ii) discussion of PROM results in more detail (yes/no). We scored specifically if physicians checked how the patients evaluated the PROM results and/or whether these results were affected by other illnesses or life events.

2.6.2. *Symptoms discussed*

We scored: i) mention (yes/no) and exploration (yes/no) of symptoms concerning domains corresponding to the implemented PROMs (Box 1) and symptoms not concerning PRO domains, ii) who initiated or explored the symptom (physician, patient, or patient companion), and iii) if physicians counselled the patient, or made a referral to another clinician (yes/no). We scored exploration of symptoms as present if physicians asked at least one follow-up question or if patients or their companions elaborated on symptoms unprompted.

2.6.3. *Patient-centredness*

We developed a rating scheme consisting of 22 items to score patient-centredness, using both a deductive and an inductive approach. First, we used the dimensions of patient-centredness identified by Langberg (Fig. 1) as the primary coding categories [24]. Then, we inductively developed coding items per category based on four consultations. No items were developed for the categories 'Coordinated care' and 'Doctor-as-person' as we did not consider it possible to assess these dimensions based on a single encounter and/or from an observer perspective. For the dimension 'Therapeutic alliance', we used behaviours from the Patient-centred Behaviour Coding Instrument (PBCI) [28]. Items were scored as $0 =$ not observed, $1 =$ observed, and $-1 =$ inhibiting patient-centredness.

2.7. *Qualitative interviews*

We aimed to explore the experiences of patients and physicians with the use PROMs and its relation to patient-centredness. Two trained interviewers (IH and MK) conducted the interviews based on a topic guide, informed by the dimensions of patient-centredness (Appendix B1 and B2). IH conducted the patient interviews and MK conducted the physician interviews. The interviewers made field notes after each interview. All interviews were audio-recorded and transcribed verbatim.

2.8. *Data analysis*

Quantitative data were analysed using SPSS 25. We used Chi-square tests for categorical data and t-tests or Mann–Whitney U tests for continuous data, as appropriate, to compare scores in the pre- versus post-test phase. We used multiple imputation with 100 imputed datasets to account for missing data on the PPPC-R and P3CEQ subscales, using age, sex, and phase (pre-test/post-test) as additional predictors when at least one item was completed on the questionnaire [29]. As recommended by the authors, we calculated the mean of all 18 PPPC-R items (possible range, 0–1) and total score of the eight-item P3CEQ sub-scale 'Person-centredness' (possible range, 0–24), respectively. For the PPPC-R, we calculated the internal consistency of the total scale and three subscales using Cronbach's alpha and compared sub-scale scores when Cronbach's alpha was > 0.8.

A qualitative thematic analysis was performed of the interviews with patients and physicians, supported by Atlas.t.i. version 9, MK an IH coded the first two interviews independently and reached consensus by discussion. IH coded the remaining interviews and MK checked the coding. In regular meetings, codes were discussed until consensus was reached. MK and IH collaboratively grouped codes in code groups, identified (sub)themes, and renamed and refined code groups and themes iteratively if necessary. We started with the dimensions of patient-centred care as deductive themes and inductively added new themes if applicable.

3. Results

We approached 183 patients, 34 declined participation. Ten patients were excluded because they did not complete at least one item of one of the questionnaires and/or because the physician did not audio-record the consultation. In total, we included 139 individual patients, 76 in the pre-test and 63 in the post-test phase.

3.1. Questionnaires

We obtained complete or partial questionnaire data for 98 patients, 62 in the pre-test and 36 in the post-test; 61 patients fully completed both questionnaires, and 37 patients had 13% to 75% missing data per questionnaire (Fig. 2). In the pre-test phase, 32/62 patients were men and mean age was 58 years. In the post-test phase, 21/36 patients were men and mean age was 62 years. For the PPPC-R, we calculated internal consistency for three subscales. Cronbach Alpha was 0.848 for subscale Healthcare processes, 0.837 for subscale Roles and 0.871 for subscale Context & Relationship.

The physicians completed the three items during 24 out-patient clinic days in total in the post-test phase.

3.2. Observer ratings of the consultations

The four physicians, all male between 36 and 65 years old, audio-taped 126 consultations. From these, we randomly selected similar numbers of audiotaped consultations from the pre- and post-test phase, taking care to include an equal proportion of tapes per physician per phase. We thus coded 110 consultation, 52 from the pre-test and 58 from the post-test. In the pre-test phase 24/52 patients were men and mean age was 54 ± 12 years (range, 27–78). In the post-test phase 32/58 patients were men and mean age was 62 ± 11 years (range, 32–84).

3.3. Qualitative interviews

We conducted 11 patient interviews and 4 physician interviews between December 2021 and July 2022. We had randomly sampled 27 patients to participate in the qualitative interview; 16/27 did not reply to our invitation and one patient explicitly declined due to lack of time. We reached data saturation after 11 patient interviews. One patient interview was conducted face-to-face at the hospital, the others by (video)phone. Half of the patients were male (6/11) and ages ranged from 35–73. All interviews took approximately 30 min.

3.4. Quantitative results: questionnaires

3.4.1. Patient-reported patient- and person-centredness

Most PPPC-R items (12/18) showed slightly increased patient-centredness, but there were no significant differences in mean PPPC-R total score between pre-test and post-test (M_{pre}=1.73 vs. M_{post}=1.68; $P = 0.63$). Mean scores on the sub-scales of the PPPC-R also did not show significant differences (Table 1).

All individual items on the P3CEQ person-centred subscale showed a trend towards increased person-centredness (Table 1). The P3CEQ person-centred subscale scores were not significantly different between pre- and post-test either (M_{pre}=11.81 vs. M_{post}=13.42; $P = 0.34$).

3.4.2. Physician-reported time pressure

Mean (SD) experienced time pressure was 5.59 (3.11) on a 10-point scale. The median time the out-patient clinic had overrun was 30 min (range 0–60). Physicians indicated that the PROMs did not contribute to time pressure (11/24), or added little to the time pressure (8/24). On 5/24 days, patients had not completed PROMs or physicians did not use them.

3.5. Quantitative results: observer ratings of the consultations

3.5.1. Explicit use of PROMs

The PROMs were mentioned in 31/58 consultations in the post-test phase and were explored in 24/58 consultations. In 10/58 consultations the physician checked how the patients evaluated the PROM results and whether the scores were affected by other illnesses or life

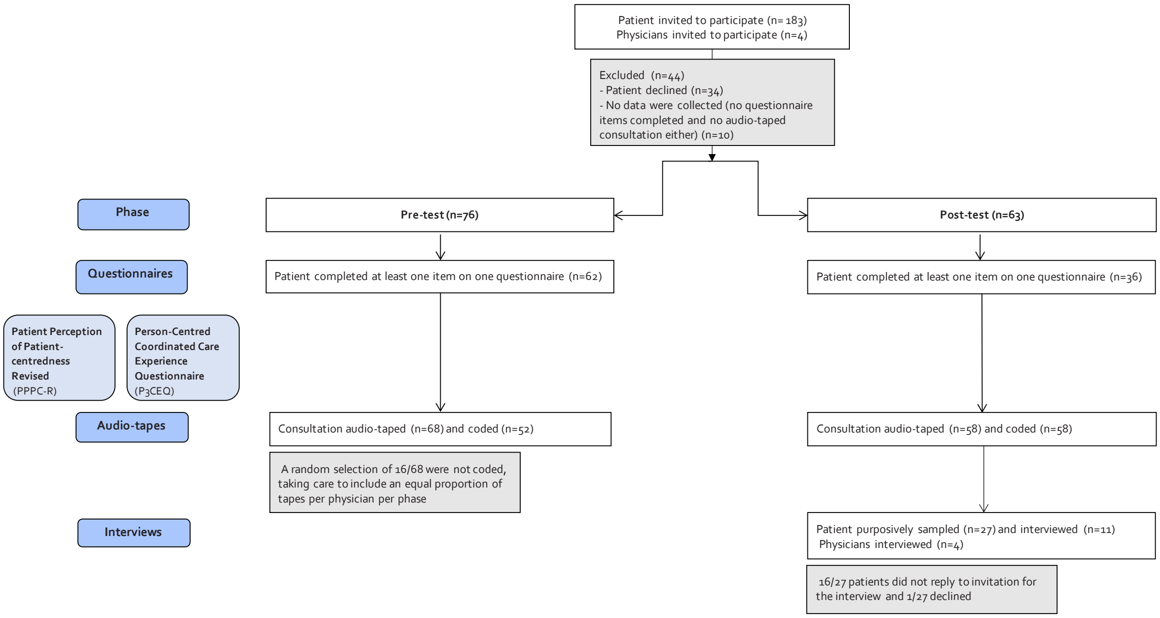

Fig. 2. Participant inclusion in study phases.

events.

Table 1

Comparison of patient-reported patient- and person-centredness during pre-test (N = 62) versus post-test (N=36) consultations.

Patient-reported patient-centredness Item or scale	**Pre-test** *Mean*	**Post-test** *Mean*	**P-value**
1. To what extent was your main problem(s) discussed today?	*1.40*	*1.25*	*N.A.*
2. How well do you think your provider understood you today?	*1.42*	*1.25*	
3. How satisfied were you with the discussion of your problem today?	*1.43*	*1.54*	
4. To what extent did your provider explain this problem to you?	*1.31*	*1.22*	
5. To what extent did you agree with your provider's opinion about the problem?	*1.31*	*1.31*	
6. To what extent did your provider ask about your goals for treatment?	*1.97*	*2.08*	
7. To what extent did your provider explain treatment?	*1.57*	*1.41*	
8. To what extent did your provider explore how manageable this treatment would be for you?	*1.95*	*1.77*	
PPPC-R Subscale: Healthcare processes *	*1.55*	*1.48*	*0.59*
9. To what extent did you and your provider discuss your respective roles?	*2.0*	*2.0*	*N.A.*
10. To what extent did your provider encourage you to take the role you wanted in your own care?	*2.21*	*1.98*	
PPPC-R Subscale: Roles *	*2.10*	*1.99*	*0.66*
11. How much would you say that this provider cares about you as a person?	*1.72*	*1.76*	*N.A.*
12. To what extent does your provider know about your family life?	*2.86*	*3.0*	
13. How comfortable are you discussing personal problems related to your health with your provider?	*1.81*	*1.85*	
14. To what extent does your provider respect your beliefs, values and customs?	*1.76*	*1.56*	
15. To what extent does your provider consider your thoughts and feelings?	*1.86*	*1.82*	
16. To what extent does your provider show you compassion?	*1.89*	*1.69*	
17. To what extent does your provider really listen to you?	*1.42*	*1.47*	
18. To what extent do you trust your provider?	*1.26*	*1.18*	
PPPC-R Subscale: Context & Relationship *	*1.82*	*1.79*	*0.80*
Mean total score PPPC-R *	*1.73*	*1.68*	*0.63*
Patient-reported person-centredness			
1. Did you discuss what was most important for you in managing your own health and wellbeing?	*1.31*	*1.57*	*N.A.*
2. Were you involved as much as you wanted to be in decisions about your care?	*1.59*	*1.84*	
3. Were you considered as a 'whole person' rather than just a disease/condition in relation to your care?	*1.68*	*1.91*	
4. Were there times when you had to repeat information that should have been in your care records?	*1.19*	*1.21*	
5. Is your healthcare joined up in a way that works for you?	*1.60*	*1.62*	
6. Have you had enough support from the healthcare staff to help you to manage your own health and wellbeing?	*1.17*	*1.62*	
7. To what extent do you receive useful information at the time you need it to help you manage your health and wellbeing?	*1.43*	*1.80*	
8. How confident are you that you can manage your own health and wellbeing?	*1.84*	*1.86*	
P3CEQ Sum score Person-centredness scale *	*11.81*	*13.42*	*0.34*

PPPC-R, Patient-Perception on Patient-Centredness-revised; lower scores indicate more patient-centredness

P3CEQ, Person-Centred Coordinated Care Experience Questionnaire; higher scores indicate more person-centredness

Note. Mean or sum scores were tested using independent sample t-tests.

3.5.2. *Symptoms discussed*

Four PRO domains were discussed significantly more often in the post-test than in the pre-test phase: anxiety, vitality, general health, and general pain (Table 2). In the post-test phase, physicians and their companions initiated symptom discussions significantly more often, patients and companions elaborated significantly more often on symptoms unprompted, and physicians gave significantly more often advice after a symptom discussion (Table 2).

3.5.3. *Patient-centredness*

Most items (13/22) showed a trend towards more patient-centredness. Overall, observed patient-centredness did not significantly differ between pre- and post-test (M_{pre}=6.71 ± 2.42 vs. M_{post}=6.93 ± 2.01; $P = 0.60$) (Table 3). Four items were observed significantly more often at post-test: 'encouragement to ask questions', 'impact on daily life', 'summary of what patient said', and 'patient experience with illness or treatment'. One item was observed significantly less often at post-test: 'patient perspective on treatment'.

3.6. *Supplemental analysis*

Table 2

Comparison of symptoms addressed during pre-test (N = 52) versus post-test (N = 58) consultations.

Symptoms addressed during the consultations	**Pre-test** *N*	**Post-test** *N*	***P*-value**
Dizziness	*48*	*56*	0.42
Hearing loss	*47*	*54*	0.733
Tinnitus	*42*	*46*	0.849
Facial nerve	*18*	*29*	0.103
Anxiety	*14*	*27*	0.034*
Headache	*11*	*14*	0.709
Cognitive functioning	*1*	*5*	0.210
Mental health	*0*	*3*	0.245
Vitality	*2*	*12*	0.008*
General health	*0*	*8*	0.007*
General pain	*0*	*17*	< 0.001 *
Symptoms not related to PRO domains:			
- Physical	*30*	*27*	0.243
- Psychosocial	*7*	*2*	0.082
Physician action following symptom discussion:			
- Advice	*22*	*38*	0.015*
- Referral	*1*	*4*	0.367
Initiative in symptom mentioning, Mean (SD):			
- Physician	*3.0 (1.59)*	*3.6 (1.53)*	0.034*
- Patient	*1.1 (1.20)*	*1.5 (1.57)*	0.170
- Patient companion	*0.0 (0.19)*	*0.2 (0.53)*	0.023*
Initiative in symptom exploration or unprompted elaboration, Mean (SD):			
- By physician	*1.77 (1.18)*	*2.02 (1.37)*	0.314
- By physician	*0.33 (0.61)*	*0.78 (0.96)*	0.009*
- By patient companion	*0.00 (0.00)*	*0.14 (0.40)*	0.010*

PRO, Patient-reported outcome

Note. The presence of symptom discussion related to PRO domains symptoms not related to PRO domains and whether actions followed symptom discussion were tested using Chi-squared tests. Initiation and exploration of symptoms by physicians were tested using independent samples t-tests. Elaboration on symptoms by patients and partners were tested using Mann-Whitney u tests.

[*] *P*-value ≤ 0.05

To explore the possibility that pre-/post-test differences in outcomes

Table 3
Comparison of observed patient-centredness during pre-test (N = 52) versus post-test (N=58) consultations.

Observed patient-centredness	**Pre-test N**	**Post-test N**	***P*-Value**
Physician			
A	17	17	N.A.
B	15	19	N.A.
C	15	11	N.A.
D	5	11	N.A.
Sharing power			
Encouragement to ask questions	26	42	0.02*
Shared agenda setting	3	3	1
Choice awareness	23	16	0.068
Patient involvement in decision making	18	23	0.585
Patient perspective on treatment	17	7	0.009*
Information sharing	39	47	0.444
Patient-as-person			
Impact on daily life (mentioned)	25	40	0.026*
Impact on daily life (explored)	3	7	0.199
Therapeutic alliance			
Open question	0	4	0.120
Summary of what patient said	0	6	0.028*
Verbal encouragement	6	5	0.611
Cut-off	1	3	0.620
Premature recommendation	2	1	0.602
Premature referral	0	0	N.A.
Biopsychosocial			
Social network	28	22	0.094
Work	26	29	1
Hobbies	10	8	0.442
Physical symptoms (mentioned)	51	58	0.473
Physical symptoms (explored)	44	50	0.813
Psychosocial symptoms (mentioned)	4	1	0.102
Psychosocial symptoms (explored)	3	0	0.085
Patient experience with illness or treatment	22	36	0.038*
Total score, observed patient-centredness *Mean (SD)*	6.71 (2.42)	6.93 (2.01)	0.604

N.A., Not applicable
Note. All items were scored positively (+1) except for cut-offs, premature recommendations or referrals that were scored negatively (−1).
Total score was tested using independent samples t-tests. Individual items were tested using a Chi-squared test.
[*] *P*-value ≤ 0.05

were associated with variability across physicians, we conducted post-hoc analyses on variables that showed statistically significant differences. This was true for one outcome (data not shown). The increase in score on 'Patient experience with illness or treatment' was significantly associated with one physician (12/34 pre-test vs 22/34 post-test, B= 2.59, p = 0.037), and no significant changes were seen in the others.

3.7. Qualitative results: interviews

We have structured the experiences of the patients and the physicians around four themes: i) patient motivation, ii) facilitators and barriers, iii) misalignment with expectations of care, and iv) relation to patient-centred care. We report the themes from the patients' and physicians' perspectives separately, together with illustrative quotes (Table 4).

3.7.1. Patient motivation

The patients were motivated to complete PROMs, considering that PROMs could be helpful for their own care trajectory or could benefit other patients. Regarding their own trajectory, PROMs were perceived as a part of the preparation for the consultation, to learn more about the illness, and/or as a standard intake element. At the population level, PROMs were perceived as contributing to scientific knowledge.

Table 4
Exemplary quotes from qualitative interviews with patients and physicians.

Theme	Patient perspective	Physician perspective
Motivator	Consultation preparation *"Maybe it was a bit out of curiosity. [...] This is something new [to me] and it keeps me busy. [...] I was in the phase that I was thinking well okay, I am going to read about it: what is there to be done about it?"*	*N.A.*
Facilitator	Support *" I filled it out together with my husband, because sometimes I did not understand it. Then, my husband would say, you do have this symptom, that happens all the time. And I realise: he is right "*	Technology *" For example, I am inclined to look at the PANQOL* because that is well presented in the dashboard.", " [...] that is relatively easy to understand for someone that does not has inside knowledge about this [...] you can see the domains well".*
Barrier	Perceived confounder: comorbidity *"I did not complete the questionnaire [...] I had a very rough six months [...] I am also being treated by a pulmonologist [...] I just can't answer those questions right."*	Technology and time *"The dashboard of these things is crucial. Actually, you need to be able to see it at a single glance, it needs to be seconds work and not minutes work, because minutes work takes too long [...] and now it is not ideal, how we built it."*
Alignment with expectations of care	Biomedical focus *"This is about how people experience things and I don't expect a clinician [...], who is going to explain what is wrong and what can be done about it, to go over those questions [...] I also don't think that is the right place."*	Limitations of a consultation *"You might know better who the patient is [...] but the question is if that is medically worthwhile. You have to deliver a certain level of quality of care within the time that is set for it."*
Positive relation to PCC*	Patient-as-person *" [...]You provide information [with PROMs], that allows someone else to better empathise with your situation."*	Biopsychosocial view *"She had a psychological illness and I think she did not want to bring it up, but that she did see that it was important to discuss. And we discussed it because of the PROMs* "*
Negative relation to PCC*	Disregard of patient preferences *"The intake had not even taken place yet and there were various statements [about symptoms in the PROMs*] that I apparently was going to encounter [...] It is not a pleasant way to learn that these things might happen. [...] Emotionally seen it is not pleasant, because it raises questions that you cannot ask, because you don't have a conversation [with a clinician] yet. "*	Risk of losing the human connection *"[...] you need to reflect on the problems people have, even if they write it all down. [...], if you don't say it, then what? You build zero relation."*

PANQOL, Penn Acoustic Neuroma Quality-of-Life Scale; PCC, patient-centred care; PROMs, patient-reported outcome measures

3.7.2. Facilitators and barriers

For the patients, having better digital skills and prior experience with PROMs facilitated in completing PROMs. The presence of the following factors hampered completing PROMs: having comorbidity, experiencing PROMs as difficult or lengthy, and the content as irrelevant.

For the physicians, a clear visualisation of the PROM results facilitated the use of PROMs and lacking prior experience with PROMS or perceiving time pressure hampered the use of PROMs.

3.7.3. *Misalignment with expectation of care*

Multiple patients indicated that they had not expected that the PROM results would be discussed during the consultation. Patients explained that they had expected that the focus would be on what could be done about the symptoms, rather than on how they experienced them, that they prioritised getting information above discussing PROMs, and/or that if physicians could not treat the symptoms, this consultation was not the right place to discuss how they are experienced.

The physicians indicated that the goal of the first consultation was to inform patients about the disease, to understand what symptoms patients experience and how they impact patients' lives, and to help patients cope with possible worries. Given these objectives, one physician questioned whether PROMs provide added value. Some physicians noted that PROM results could also be caused by life events, comorbidity, or symptoms unrelated to VS and were distracting in the conversation. None of the physicians asked the patients what PROM results they would like to discuss.

3.7.4. *Relation to patient-centred care*

3.7.4.1. Sharing power and responsibility. The patients indicated that filling out PROMs helped them to reflect and prepare questions for the consultation. Patients and physicians also indicated that PROMs might empower patients to ask questions or talk about sensitive topics. A minority of patients had experienced the PROMs as confrontational, and as a harsh way of learning information about their illness.

3.7.4.2. Biopsychosocial. The physicians reported that the use of PROMs shows patients that multiple domains of their health are considered in decision making about their healthcare.

3.7.4.3. Patient-as-person. Multiple patients indicated that PROMs could improve patient-centredness by giving physicians a better insight in the patients' perspectives, thereby supporting physicians' empathic capability. Some physicians indicated that PROMs helped to initiate discussions of symptoms that physicians or patients normally would not bring up, and that it helped physicians understand what patients are going through.

3.7.4.4. Therapeutic alliance. The patients did not experience that PROMs contributed to building a good therapeutic relationship. Some physicians indicated that they thought that it could support relationship-building, because patients might feel better listened to. Both the patients and physicians hypothesised that a possible risk of PROMs would be losing a chance for relationship-building, because it provides physicians with information in advance and physicians may then be inclined to stop asking questions during consultations.

3.7.4.5. Coordinated care. Two physicians hypothesised how in the future PROMs might help coordinate care, by making decisions concerning follow-up based on the PROMs score. For example, scheduling an appointment when PROM scores worsen.

4. Discussion and conclusion

4.1. *Discussion*

We found that the implementation of PROMs was followed by more discussion about symptoms relating to PRO domains, especially anxiety, vitality, general health, and pain. These symptom discussions were also followed more often by advice from the physicians. We observed a positive trend but did not find a significant difference in observed or patient-reported patient-centredness. In interviews, patients and physicians reported possible ways in which PROMs could improve patient-centredness in consultations. Patients also reported to have experienced a misalignment between their expectations of the consultations and the role of PROMs, and patients and physicians questioned the feasibility of using PROMs in individual care. Physicians did not indicate a strong impact on time pressure.

Our findings align with prior studies showing that the implementation of PROMs led to more symptom discussion, more discussion about, and more counselling [11,12]. Our study further shows that patients do not necessarily perceive more discussion as increased patient-centredness. These results confirm survey and interview results from a prior explorative study on PROM use and patient-centredness which showed no significant impact on patient-centredness [30]. To our knowledge, this is the first study to observe PROM use and patient-centredness in addition to using self-report measures.

It is noteworthy that our results do not confirm the general assumption that an increase in PRO discussion leads to a significant increase in perceived patient-centredness. We hypothesise that PROMs tap into specific aspects of patient-centredness but might not impact all patient-centred communication practices. This might explain why we did not find significant differences when comparing pre-implementation versus post-implementation scores. For example, we found significant evidence of PROMs leading to more discussion about symptoms related to quality of life and to discussion on patient experience with illness or treatment but did not find evidence for a more frequent display of other behaviours in the Biopsychosocial dimension. This fits the hypothesis that PROMs empower patients and clinicians to raise issues and discuss quality of life but overall do not change communication practices, and that medical consultations remain predominantly focused on biomedical aspects [7]. Future research could be aimed at elucidating patients' expectations during the different phases of the care trajectory, to better align and adapt interventions to clinical practice, and develop multi-faceted interventions, combining the introduction of patient-reported outcome data with reflection and training, in order to achieve a patient-centred care model.

Contrary to Greenhalgh et al.' hypothesis, we did not find evidence that PROMs constrain relationship-building. Strikingly, results from the interviews showed that patients and physicians deemed some behaviours that are typically defined as patient-centred, to not fit their expectations of how a consultation is conducted; a finding that has been reported before [31]. To illustrate, most patients did not expect the first consultation to focus on the impact of the disease on their lives or social wellbeing. Instead, they were primarily focused on receiving information about illness and treatment.

In the context of our study, the use of PROMs seemed to not fully meet the patients' and physicians' expectations. The patients expressed various motives for filling out PROMs, often concerning providing information for the physician in preparation for the consultation, yet a majority did not expect that the PROMs would be discussed in their first visit to the outpatient clinic. We hypothesise that patients' expectations of the consultation might change over the course of their care trajectory, and we expect this to shift from gathering information about the disease or treatment options to symptom monitoring and evaluation of the impact of disease or treatment. This may consequently improve how patients evaluate the usefulness of PROMs. Thus, it is important to limit the use of PROMs to those consultations for which they are relevant, rather than applying a one-size-fits-all approach.

In the interviews, the physicians expressed time pressure as a barrier to use PROMs. In contrast, in daily practice the physicians did not report significantly increased time pressure. Interestingly, none of the physicians asked patients what PRO topic they would like to discuss. Asking the patient could help navigate time constraints, elucidate to what extent PROs are related to the disease, explore what PRO topic to discuss together and limit discussion during the consultation to what matters most to the patient. In that way, PRO discussion might support physicians to better uncover patients' needs, to which the physicians then could respond in an adaptive way, e.g., by listening, counselling, treating symptoms, or making referrals.

A strength of this study is that multiple methods, both quantitative and qualitative, and both observation and self-report, were used to evaluate the implementation of PROMs, allowing for a comprehensive understanding of how care is perceived and takes shape with and without PROMs. The study was performed in the context of a single care pathway, and thus outcomes of the study were not affected by differences in disease burden or care delivery. A possible disadvantage of the study is that data collection started during the first COVID-19 lockdown in The Netherlands and ended one month after all measures had been lifted. Yet, care for patients with a VS was not postponed and all observed consultations were face-to-face. A limitation was that the coders were not blinded for the phase of data collection (pre- or post-implementation), which may have introduced selective perception bias. However, the post-test phase was coded with a second, new coder, limiting this risk. Furthermore, we observed average to high questionnaire scores, especially on the PPPC-R, reducing the potential for improvement. Finally, physicians reported little experience with PROMs, suggesting that our results reflect a learning effect, possibly underestimating the association between PROMs and patient-centredness. The latter might increase if physicians gain more experience and feel comfortable to explore PROM results in a collaborative manner with patients.

4.2. Conclusion

This study demonstrates that the implementation of PROMs in a VBHC care pathway led to more frequent symptom discussion of generic PRO domains and showed a positive trend towards, but no significant differences in, observed or patient-reported patient-centredness. Further, our study indicates that PRO discussion might not always align with patients' prior expectations of the consultation, may lead to discussion of symptoms and topics unrelated to the illness of interest, and should be implemented in situations in which they are the most relevant.

4.3. Practice implications

In the widespread transition to VBHC throughout healthcare systems, PRO data are collected and used both for individual care and for population improvements in quality of care. It is often assumed that PRO discussions in clinical consultations automatically lead to more patient-centredness. This does not necessarily seem the case. Importantly, healthcare professionals and patients should explore together, whether the timing of PRO discussion fits the moment in the care trajectory and which topics are relevant. Given the investment required to implement PROMs, it remains open for debate if the cost-benefit trade-off is always in favour of implementation. A patient-centred focus in a value-based healthcare pathway further requires healthcare professionals to remain attentive to individual needs and expectations and recognise when PRO discussion adds value.

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CRediT authorship contribution statement

Martha Kidanemariam: Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Olaf M. Neve**: Writing – review & editing, Investigation, Formal analysis, Conceptualization. **Isabelle van den Heuvel**: Writing – review & editing, Investigation, Formal analysis. **Sana Douz**: Writing – review & editing, Formal analysis. **Erik F. Hensen**: Writing – review & editing, Methodology, Conceptualization. **Anne M. Stiggelbout**: Writing – review & editing, Methodology, Conceptualization. **Arwen H. Pieterse**: Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: A. M. Stiggelbout reports a relationship with Sprink that includes: consulting or advisory. A.H. Pieterse is associate editor at Patient Education and Counseling.

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Confidentiality

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Appendix A. Self-developed survey on experienced time pressure by physicians

1. How much time pressure did you experience during this out-patient clinic?

0 1 2 3 4 5 6 7 8 9 10
No time pressure Very high time pressure.

2. How did the discussion of PROMs with the patient influence how much time pressure you experienced?

Large increase of time pressure
Small increase of time pressure
No impact of time pressure
Small decrease of time pressure
Large decrease of time pressure
PROMs not discussed

3. To what extent did you have to overrun the scheduled time set for the out-patient clinic?

Approximately … minutes.

Appendix B. Topic guides of the semi-structured patient and physician interviews

B1. Topic guide for interviews with patients

- Complaints due to Vestibular Schwannoma
  - How do these complaints impact your daily life?
- Expectations of consultation
  - Did you have topics in mind which you wanted to discuss during the consultation?
  - What did you hope would be discussed during the consultation?
- Filling-in PROMs
  - Did you experience anything which made it easy for you to fill in the PROMs?
  - Did anyone help you with completing the PROMs?
  - Did you experience anything which made it hard for you to fill in the PROMs?
  - Did the PROMs make you reflect on your illness?
- What was your motivation to fill in the questionnaire?
- PROM content
  - Which questions did you consider important?
  - Were there questions you considered not relevant?
  - Did you miss anything within the questionnaire?
- Expectations regarding feedback on PROM outcomes during the consultation
  - Did you expect your responses on the PROMs to be discussed during the consultation?
  - Who do you think should initiate to discuss the PROM outcomes?

- Expectations with consultation (and, if applicable, discussing the PROM outcomes)
  - Can you describe how you experienced the consultation?
  - Did you have the opportunity to ask questions during this consultation?
  - Did you discuss the PROM outcomes with your clinician?
  - If so, who initiated this?
  - Were the PROM outcomes discussed satisfactorily?
  - Did you experience benefit from discussing the PROMs?
  - Do you think that the consultation would have been different if you had not filled out the PROMs?
- Dimensions of patient-centredness
  - Do you think that the PROMs could support you in making decisions with your clinician? (Sharing Power)
  - Do you think that the PROMs could support you in sharing how you experience your illness? (Patient-as-person)
  - Do you think that the PROMs could support you in sharing aspects of your health beyond the physical aspects (e.g. mental health)? (Biopsychosocial)
  - Do you think that the PROMs could support you and your clinician in building a therapeutic relationship? (Therapeutic alliance)
- Undiscussed topics?

B2. Topic guide for interviews with physicians

1. What do you think are the most important goals for the first consultation?

2. Has anything changed in your approach to the care of new patients with a vestibular schwannoma since the introduction of PROMS?

- Is this the case with every new patient?

[If not] Can you tell me more about that?

- How do you experience that?

Perceptions, expectations, facilitators, barriers.

3. How do you think PROMS can contribute to the care of this group of patients?

- What are your expectations of how the PROMS can be used?

- Are there things that make it easier to use the PROMS for this?

- Are there things that make it more difficult to use the PROMS for this?

3. What benefits do you see from using PROMS?

For whom?

4. What disadvantages do you see of using PROMS?

PROMS and patient-centredness.

To consider all aspects of health, such as mental health in addition to the physical aspect, is considered as an important dimension of patient-centredness.

5. Do you think the PROMS play a role in this? (Biopsychosocial).

Patient-centeredness concerns six dimensions in the literature, of which 4 dimensions have been shown or suspected to be associated with PROMS.

6. Do you think the PROMS play a role in understanding how an individual patient experiences the disease? (Patient-as-person).

7. Do you think the PROMS play a role in shared decision-making? (Sharing power).

8. Do you think the PROMS play a role in establishing the doctor-patient relationship? (Therapeutic alliance).

References

[1] Porter ME, Teisberg EO. Redefining health care: creating value-based competition on results. Boston, MA: Harvard Business School Press; 2006.
[2] Porter ME. What Is Value in Health Care? N Engl J Med 2010;363(26):2477–81.
[3] ⟨https://www.ichom.org/⟩, Accessed February 16th 2023.
[4] Steinmann G, Delnoij D, van de Bovenkamp H, Groote R, Ahaus K. Expert consensus on moving towards a value-based healthcare system in the Netherlands: a Delphi study. BMJ Open 2021;11(4):e043367.
[5] van Engen V, Bonfrer I, Ahaus K, Buljac-Samardzic M. Identifying consensus on activities that underpin value-based healthcare in outpatient specialty consultations, among clinicians. Patient Educ Couns 2023;109:107642.
[6] Damman OC, Jani A, de Jong BA, Becker A, Metz MJ, de Bruijne MC, et al. The use of PROMs and shared decision-making in medical encounters with patients: an opportunity to deliver value-based health care to patients. J Eval Clin Pr 2020;26(2):524–40.
[7] Greenhalgh J, Gooding K, Gibbons E, Dalkin S, Wright J, Valderas J, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. J Patient Rep Outcomes 2018;2:42.
[8] Graupner C, Kimman ML, Mul S, Slok AHM, Claessens D, Kleijnen J, et al. Patient outcomes, patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care: a systematic review. Support Care Cancer 2021;29(2):573–93.
[9] Ishaque S, Karnon J, Chen G, Nair R, Salter AB. A systematic review of randomised controlled trials evaluating the use of patient-reported outcome measures (PROMs). Qual Life Res 2019;28(3):567–92.
[10] Campbell R, Ju A, King MT, Rutherford C. Perceived benefits and limitations of using patient-reported outcome measures in clinical practice with individual patients: a systematic review of qualitative studies. Qual Life Res 2022;31(6):1597–620.
[11] Takeuchi EE, Keding A, Awad N, Hofmann U, Campbell LJ, Selby PJ, et al. Impact of patient-reported outcomes in oncology: a longitudinal analysis of patient-physician communication. J Clin Oncol 2011;29(21):2910–7.
[12] Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. JAMA 2002;288(23):3027–34.
[13] Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: a randomized controlled trial. J Clin Oncol 2016;34(6):557–65.
[14] Leydon GM, Dowrick CF, McBride AS, Burgess HJ, Howe AC, Clarke PD, et al. Questionnaire severity measures for depression: a threat to the doctor-patient relationship? Br J Gen Pr 2011;61(583):117–23.
[15] Dowrick C, Leydon GM, McBride A, Howe A, Burgess H, Clarke P, et al. Patients' and doctors' views on depression severity questionnaires incentivised in UK quality and outcomes framework: qualitative study. BMJ 2009;338:b663.
[16] Mitchell C, Dwyer R, Hagan T, Mathers N. Impact of the QOF and the NICE guideline in the diagnosis and management of depression: a qualitative study. Br J Gen Pr 2011;61(586):e279–89.
[17] Hughes R, Aspinal F, Addington-Hall JM, Dunckley M, Faull C, Higginson I. It just didn't work: the realities of quality assessment in the English health care context. Int J Nurs Stud 2004;41(7):705–12.
[18] Hughes R, Aspinal F, Addington-Hall J, Chidgey J, Drescher U, Dunckley M, et al. Professionals' views and experiences of using outcome measures in palliative care. Int J Palliat Nurs 2003;9(6):234–8.
[19] Pettersson A, Bjorkelund C, Petersson EL. To score or not to score: a qualitative study on GPs views on the use of instruments for depression. Fam Pr 2014;31(2):215–21.
[20] Gamlen E, Arber A. First assessments by specialist cancer nurses in the community: an ethnography. Eur J Oncol Nurs 2013;17(6):797–801.
[21] Wolpert M. Uses and abuses of patient reported outcome measures (PROMs): potential iatrogenic impact of PROMs implementation and how it can be mitigated. Adm Policy Ment Health 2014;41(2):141–5.
[22] Hughes JC, Bamford C, May C. Types of centredness in health care: themes and concepts. Med Health Care Philos 2008;11(4):455–63.
[23] Wheat H, Horrell J, Valderas JM, Close J, Fosh B, Lloyd H. Can practitioners use patient reported measures to enhance person centred coordinated care in practice? A qualitative study. Health Qual Life Outcomes 2018;16(1):223.
[24] Langberg EM, Dyhr L, Davidsen AS. Development of the concept of patient-centredness - a systematic review. Patient Educ Couns 2019;102(7):1228–36.
[25] Ryan BL, Brown JB, Tremblay PF, Stewart M. Measuring patients' perceptions of health care encounters: examining the factor structure of the revised patient perception of patient-centeredness (PPPC-R) questionnaire. J Patient Cent Res Rev 2019;6(3):192–202.
[26] Sousa VD, Rojjanasrirat W. Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user-friendly guideline. J Eval Clin Pr 2011;17(2):268–74.
[27] Rijken M, Close J, Menting J, Lette M, Stoop A, Zonneveld N, et al. Assessing the experience of person-centred coordinated care of people with chronic conditions in the Netherlands: validation of the Dutch P3CEQ. Health Expect 2022;25(3):1069–80.
[28] Zandbelt LC, Smets EM, Oort FJ, de Haes HC. Coding patient-centred behaviour in the medical encounter. Soc Sci Med 2005;61(3):661–71.
[29] Van Buuren S. Flexible Imputation of Missing Data. Second Edition, 2nd New edition ed. London: Taylor & Francis Ltd; 2018.
[30] Abma IL, Rovers MM, I.J. M, Hol B, Nagele M, Westert GP, et al. Does the Patient-Reported Apnea Questionnaire (PRAQ) increase patient-centredness in the daily practice of sleep centres? a mixed-methods study. BMJ Open 2019;9(6):e025963.
[31] de Haes H. Dilemmas in patient centeredness and shared decision making: a case for vulnerability. Patient Educ Couns 2006;62(3):291–8.