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Editor's comment: With this issue, we are introducing a new feature in which one article will be highlighted and for which free access, along with brief comments regarding the article by one of the editors, will be provided. The article selected for this issue, by van der Eijk and colleagues, reminds us that patient care does not consist merely of taking care of our patients' direct medical requirements, but also involves addressing their emotional and psychosocial needs. The authors provide us with a means to assess the degree to which we are providing patient-centered care in our clinics and their findings present a clarion call to all of us caring for individuals with Parkinson's disease to improve the patient-centered focus of our practice.

Ronald F. Pfeiffer, MD Editor; Professor and Vice Chair Department of Neurology University of Tennessee Health Science Center

Patient-centeredness in PD care: Development and validation of a patient experience questionnaire
[Universally Available]

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ABSTRACT

Introduction: Patient-centeredness is increasingly recognized as a crucial element of quality of care. A suitable instrument to assess the level of patient-centeredness for Parkinson's disease (PD) care is lacking. Here we describe the development and validation of the Patient-Centered Questionnaire for PD (PCQ-PD), and its initial application in a large patient sample.
Methods: Based on the outcomes of eight focus groups we composed a questionnaire that measures patient-centeredness by assessing patients' care experiences. The questionnaire was sent to 1112 Dutch PD patients, and face-, content- and construct-validity and reliability were assessed. The level of patient-centeredness was determined by calculating scores for overall patient-centeredness [0–3], subscale experiences [0–3], item experience, item priority and quality improvement.
Results: 895 PD patients (net response 82.0%) completed the questionnaire. After the validation procedure, the PCQ-PD addressed 46 care aspects in six different subscales of patient-centeredness. The internal consistency of the instrument, expressed in Cronbach's α per subscale, ranged from 0.62 to 0.84. The overall patient-centeredness score was 1.69 (SD 0.45). 'Emotional support' (1.05, SD 0.90) and 'provision of tailored information' (1.18, SD 0.57) subscales received the lowest experience ratings. 'Access to medical records' obtained the highest item quality improvement score (5.44).
Conclusions: This study produced a valid instrument to measure patient-centeredness in PD care. Psychometric properties of the instrument were good. Application of the PCQ-PD revealed the level of patient-centeredness in the care for PD patients in The Netherlands. The main outcome was a compelling call for the provision of tailored information and emotional support.

1. Introduction

Since the Institute of Medicine (IOM) introduced their aims for improving the quality of healthcare systems in 2001, quality of care has received widespread attention of professionals and leading health organizations in Western countries [1–3]. Patient-centeredness is one of the six IOM quality dimensions and represents a crucial element of quality of care. It has been defined as '*providing care that is respectful towards and responsive to individual patient preferences*' [3].

Recent studies on patient-centered care for people with neurodegenerative diseases have given clear insight in patients' experiences and unmet needs [4,5]. Some authors concluded that

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what patients need, is not what doctors focus on to date. The primary focus of physicians is on disease severity and drug effectiveness, but this does not adequately address experienced changes in patients' quality of life [6]. Grosset found that patients with Parkinson's disease (PD) who perceived greater involvement in their care were more satisfied with the consultation and tended to be more compliant [7]. The variation in patients' expectations of treatment success and the perception of their most troublesome symptoms highlighted the importance of providing care tailored to each patient's individual preferences [8].

Surveys of patients' experiences are increasingly recognized as an essential part of quality of care assessment [9]. Measuring patient *experiences* is believed to discriminate effectively between practices, in contrast to patient *satisfaction* measures [10]. In the US, the Consumer Assessment of Healthcare Providers and Systems (CAPHS) survey is used to measure patient experiences [11]. In The Netherlands, several Consumer Quality Indexes are developed [12]. These questionnaires provide insight in the current state of patient-centered care, thereby providing professionals with tailored feedback that can be used for internal quality improvement. Other applications include benchmarking across care institutions, and their use as outcome measure for future clinical trials on patient-centered care [13].

So far, a suitable instrument to assess the level of patient-centeredness for people with PD is lacking. Therefore, the aim of this study was to build a valid questionnaire to measure patient experiences in PD care. Here we describe the development and validation of the Patient-Centered Questionnaire for PD (PCQ-PD) and its initial application in a large sample of Dutch PD patients.

2. Methods

2.1. Questionnaire development

A patient-centeredness questionnaire was composed using the results of eight focus groups that focused on care experiences, preferences and needs of PD patients and caregivers [5]. The questionnaire covers in- and out-patient care aspects and addresses professionals that are commonly involved in PD treatment, like neurologists, physical therapists and speech-language pathologists. Two researchers independently phrased items on patient experiences. Differences in formulation were discussed and consensus was promptly achieved. Subsequently, items on patients' background characteristics (e.g. level of education) and items on patient priorities were added. The following response categories were used for the experience items: *No, not at all; somewhat; for the most part; yes, absolutely,* and*: No; yes.* In some cases a response option was added, like; '*Not applicable*' or '*I do not know/I haven't tried*'. For priority items, all starting with "*How important did you find…?*", the following answer categories were applied: *Not important; fairly important; important; and extremely important*. After the validation process, the questionnaire was reciprocally converted from Dutch into English by two researchers (MF, ME) and a bilingual translator (esupp file).

2.2. Data collection

The PCQ-PD was sent to 1112 PD patients to determine the psychometric properties of the instrument and the level of patient-centeredness of PD care in The Netherlands. Patients who received PD treatment during the past 12 months were included from five Dutch neurology clinics. Patients with severe cognitive impairment (Lewy Body Disease, Corticobasal Degenerative Disease, Parkinson's disease Dementia, MMSE $<$ 24) and Parkinson syndromes (Multiple System Atrophy, Progressive Supranuclear Palsy) were excluded. Questionnaires were sent accompanied by a cover letter, a refusal form and a postage-paid return envelope. In order to optimize the response rate, participants received a reminder card and a second questionnaire in the weeks after the initial mailing. Participation in this study was voluntary, anonymity was guaranteed. The research protocol was approved by the local ethical committee and Institutional ethical approval for separate clinics was thereby not required.

2.3. Data analysis

All completed questionnaires were processed electronically and data were entered into SPSS. Patients completing $<$50% of the background characteristics were excluded. Item Q18, 19 and 80 were negatively phrased. Thus, a positive answer indicated that the respondent had a negative experience for this care aspect. Data of these items were therefore mirrored, allowing for comparison with other items where higher scores indicated a better care experience. Psychometric properties of the questionnaire were assessed by analysis of the content-, face- and construct-validity (Section 2.3.1), item quality and internal consistency (Section 2.3.2). The level of patient-centeredness was determined by calculating the overall patient-centeredness score, subscale experience scores, item experience-, item priority- and quality-improvement scores (Section 2.3.3).

2.3.1. Instrument validity

'Content validity' is warranted since the questionnaire items were based on the key elements of patient-centeredness as defined by the Picker Institute and the WHO and a disease specific model of patient-centeredness derived in our focus group study [5]. 'Face validity' was determined by pre-testing the questionnaire within 14 cognitive interviews with PD patients, caregivers and professionals. Cognitive interviewing is used to evaluate sources of response error in questionnaires, developed during the 1980's by survey methodologists and psychologists [14]. Consequently, some items were rephrased. In the absence of an external gold standard, univariate linear regression analysis was used to be able to comment on the 'construct validity' of the questionnaire. The following associations between patient characteristics (independent variable) and the overall patient-centeredness score (dependent variable) were tested: PD patients who experience a higher level of patient-centeredness,

1. Are more satisfied with healthcare [15];
2. Are more often supported by a caregiver;
3. More often have access to ParkinsonNet professionals with specific PD expertise [16];
4. Have a higher level of education [17] compared to patients with lower experience scores.

2.3.2. Item quality and instrument reliability

Items that qualified for removal of the questionnaire were: (a) extremely skewed items, i.e. $>$90% in one extreme answer category, (b) relatively unimportant items, i.e. item priority score (IPS) $<$ 1.50 (c) items with a high non-response, i.e. $>$5% missing values [18], (d) redundant items, i.e. Spearman's rho between two items $>$0.80. When patients made many written comments regarding a certain item, restatement or exclusion of the item was considered. An exploratory factor analysis using Principal Component Analysis with oblique rotation was used to determine the underlying structure of the instrument [18–20]. Items should have a factor loading $>$0.30 and all inter-factor correlations should be $<$0.70 [18,19]. The internal consistency was analysed using Cronbach's α. A subscale Cronbach's $\alpha > 0.70$ is considered appropriate. Subscales with Cronbach's $\alpha < 0.60$ are not reliable. Arguments for omission of single items were low contribution to the subscale (Item–Total Correlation, ITC $>$ 0.20) or an increased subscale Cronbach's α when an item was deleted [20].

2.3.3. Outcomes

We first calculated item experience scores [IES, 0 = most negative, 3 = most positive], item priority scores [IPS, 0 = not important, 3 = extremely important] and quality improvement scores [QIS = (3 − IES)*IPS, 0 = low priority, 9 = high priority]. The proportion of negative experiences (PNE) per item represents the percentage of respondents with an IES of 0 or 1. As expected, most participants were unable to answer all survey items. In order to do so, PD patients should have consulted all professionals on the questionnaire and experienced all care aspects in the past year. Therefore, a mean IES was calculated for equal care aspects on different professionals. i.e. scores on"Q22 *Did the neurologist listen carefully to you?*" and "Q36 *Did the PD nurse specialist listen carefully to you?*" were combined into one IES '*listen carefully*'.

Next, subscale experience scores [SES, range 0–3] and an overall patient-centeredness score [OPS, range 0–3] were calculated. Participants who answered $<$50% of the subscale items were excluded from further analysis of the subscale. A mean SES was calculated by adding up the subscale items and divide it by the total number of completed subscale items. i.e. the subscale 'emotional support' consists of six items and two of the items are about the patients' caregiver. When the participant did not have a caregiver, the SES was calculated from the other four items. No data-imputation over the missing values was performed.

Table 1
Background characteristics of responders and non-responders.

	Percentage	Age in years	Gender	Overall satisfaction with care
	% (*n*)	Mean (SD)	% men	Mean (SD) [1–10 scale]
Non-responders (no refusal form)	11.7 (128)	68 (12)	52.0	Unknown
Non-responders (refusal form)	6.3 (69)	74 (9)	34.8	6.8 (1.5)
Responders	82.0 (895)	69 (10)	60.9	7.3 (1.3)

3. Results

3.1. Participants

From the 1112 questionnaires that were distributed, four packages returned unopened and 16 patients had deceased. Of the 1092 patients who received a package, 895 completed the questionnaire (net response 82.0%, Table 1). 875 participants could be included for further analysis; 14 respondents did not receive PD treatment during the past 12 months and six respondents completed <50% of the background characteristics. Self-reported Hoehn & Yahr disease state was between 1 and 3. 197 patients (18.0%) did not return the questionnaire. On average, non-responders who returned the refusal form ($n = 69$) were five years older than responders ($p < 0.001$) and less satisfied with healthcare; 6.8 (1.5) vs. 7.3 (1.3) on a 1–10 scale ($p < 0.05$).

3.2. Psychometric properties of the instrument

3.2.1. Instrument validity

Regression analysis showed significant correlations patient-centeredness and higher patients' satisfaction with healthcare ($r = 0.49$, $p < 0.001$), patients' familiarity with the ParkinsonNet concept ($r = 0.26$, $p < 0.001$), presence of a regional ParkinsonNet network nearby the clinic ($r = 0.12$, $p = 0.001$), support by a caregiver ($r = 0.18$, $p < 0.001$) and higher level of education ($r = 0.11$, $p = 0.002$). These associations support the construct validity of the questionnaire.

3.2.2. Item quality and instrument reliability

Eight omitted experience items that did not meet the psychometric criteria are presented in Table 2 together with the reason for exclusion. For example, the item "*Did your neurologist treat you in a polite manner?*" was deleted since the response pattern was positively skewed. Exploratory factor analysis showed 46 care aspects in six different subscales of patient-centeredness; involvement in decision making; provision of tailored information; accessibility of healthcare; empathy and PD expertise; continuity and collaboration of *professionals and emotional support* (Table 3). All items had a factor loading >0.30 on at least one of the factors and all inter-factor correlations were <0.70. The internal consistency of all subscales was appropriate, with Cronbach's α ranging from 0.62 to 0.84. ITC's reached the threshold of 0.20, except for two items (Q80 and Q82). Replacement of these items caused a small increase of the subscale's internal consistency. However, the items were maintained within the questionnaire based on high priority scores (IPS 2.17 and 2.35 respectively).

Table 2
Omitted items with reason for omission.

Nr of items	Item	Reason for omission
3	Collaboration with professionals not involved in PD treatment (i.e. cardiologist, pulmonologist)	Many missing values
2	Have you been informed about the possibilities of peer contact?	Relatively unimportant
1	Did you feel free to ask questions about alternative medicine as an additional treatment for your illness?	Redundant, overlap with Q10
1	Did your neurologist treat you in a polite manner?	Positively skewed
1	Do you consider the Internet to be a reliable source for PD information?	Many negative comments

3.3. Outcomes

The overall patient-centeredness score (OPS) was moderate; 1.69 (SD 0.45). Generally, patients experienced low levels of emotional support; SES 1.05 (SD 0.90) and they lacked the provision of tailored information; SES 1.18 (SD 0.57). Overall, patients experienced accessibility of healthcare SES 2.63 (SD 0.53) and empathy and PD expertise to be good; SES 2.55 (SD 0.48) (Table 3). Items with the highest QIS and PNE scores were mostly within the 'provision of tailored information', 'emotional support' and 'involvement in decision making' subscales. Table 4 shows that patients desired to have direct access to their medical records, wanted information about medication and treatment options and needed support with acceptance of the disease.

4. Discussion

4.1. Main results

This study yielded a valid instrument to measure patient-centeredness in PD care. Application of the PCQ-PD in a very large cohort of PD patients unveiled the level of patient-centeredness of PD care in The Netherlands: a compelling call to professionals to provide tailored information, emotional support in coping with the disease and access to medical records. In the following paragraph, we will elaborate on opportunities to improve the provision of information and emotional support to PD patients.

PD is a complex and debilitating disease. Psychosocial problems such as feelings of stigmatization, depression and anxiety make coping with the disease difficult [21]. Our results show that current healthcare does not adequately provide patient support, especially when it comes to disease acceptance and changes in personal relationships. Promising initiatives that address these needs have been implemented in recent years. First, the Patient Education Program Parkinson, a standardized psychosocial intervention aiming at improving the health-related quality of life of patients and caregivers, showed significant improvements in patients' mood and caregivers' psychosocial problems [22]. Second, within regional allied health networks of PD professionals, psychosocial caregivers are now trained to provide emotional support [16]. Third, increasing evidence is found that care delivered by a PD nurse specialist has positive effects on patients' well-being and the level of depression and anxiety [23].

Our results clarify that PD patients were in need of information, particularly about anti-Parkinson medication and the various treatment options offered by all professionals involved. This specific information demand was confirmed by our earlier focus group findings and other studies on PD patient's needs [4,5,24]. A British study showed that patients wanted to know when to seek medical advice, and they wanted information about their medication and about treatments available for PD [24]. The study of Buetow showed that patients wanted their GPs to offer information about their condition and involve them in decision making [4]. Patients within a focus group study on self-perceived physical limitations and compensatory strategies voiced a lack of personalized care, individualized attention and information regarding their specific symptoms and limitations [25].

Similar results were found in patient-centeredness studies involving other patient groups [13,26], indicating that the need for emotional support and information is rather universal, and that generic solutions should be developed. A study with patients facing fertility problems showed that participants lacked the information on possible side effects of prescribed medication, and they urged their professionals to pay attention to the enormous impact of fertility problems on their emotional well-being [13]. Increasingly,

Table 3
Factor analysis and internal consistency of subscales.

Subscales and care aspects	SES mean (SD)	Items on the questionnaire	ITC	Cronbach's α if item deleted	Cronbach's α of the subscale
(A) Involvement in decision making	*1.78 (0.61)*	*23 items*			*0.62*
1. Access to your own medical record		Q1	0.28	0.60	
2. Opportunity to decide who has access to your medical record		Q2	0.30	0.59	
3. Opportunity to choose your own professional caregiver		Mean Q16, 45, 52, 59, 66	0.33	0.58	
4. Opportunity to schedule appointments at a time you preferred		Mean Q17, 33	0.28	0.60	
5. Take your personal situation into account		Mean Q25, 38, 46, 53, 60, 67, 71	0.49	0.53	
6. Shared decision making		Mean Q26, 39, 47, 54, 61, 68, 72	0.48	0.52	
(B) Provision of tailored information	*1.18 (0.57)*	*23 items*			*0.80*
7. About Parkinson Disease Patient Association		Q3	0.49	0.78	
8. About tools, home care, and facilities		Q4	0.56	0.77	
9. About where to find reliable information on PD		Q5	0.63	0.77	
10. About medication use and possible side effects		Q6	0.57	0.77	
11. About using medication for the first time		Q7	0.44	0.79	
12. Contact after a new medication policy		Q8	0.31	0.80	
13. About reimbursement of Anti-Parkinson medication		Q9	0.38	0.79	
14. About alternative medicine as an additional treatment		Q10	0.40	0.79	
15. About complex treatment options		Q11	0.30	0.80	
16. About the ability to drive a car		Q12	0.39	0.79	
17. About possible treatment options of a specific professionals		Mean Q13, 30, 42, 49, 56, 63	0.58	0.78	
18. About where to find a specific professionals with PD expertise		Mean Q14, 43, 50, 57, 64	0.47	0.78	
19. Receiving of contra dictionary information		$Q80^{M}$	0.07[a]	0.81[a]	
20. About discussions between professionals regarding your treatment		Q83	0.38	0.79	
(C) Accessibility of healthcare	*2.63 (0.53)*	*6 items*			*0.75*
21. Waiting period before your visit to a neurologist		$Q18^{M}$	0.50	0.72	
22. Waiting period in the waiting room		$Q19^{M}$	0.40	0.74	
23. Opportunity to contact the neurologist by e-mail		Q20	0.64	0.67	
24. Opportunity to contact neurologist by telephone		Q21	0.50	0.72	
25. Opportunity to contact the Parkinson nurse by e-mail		Q34	0.64	0.67	
26. Opportunity to contact Parkinson nurse by telephone		Q35	0.40	0.75	
(D) Empathy and PD expertise	*2.55 (0.48)*	*14 items*			*0.83*
27. Take enough time		Mean Q23, 37	0.68	0.77	
28. Listen carefully		Mean Q22, 36	0.71	0.76	
29. Explain things in a comprehensible manner		Mean Q24, 40, 73	0.63	0.80	
30. Competence of the professional caregiver		Mean Q29, 41, 48, 55, 62, 69, 74	0.60	0.81	
(E) Continuity and collaboration of professionals	*2.24 (0.68)*	*10 items*			*0.82*
31. Collaboration between neurologists		Q27	0.77	0.77	
32. Cooperation with a second opinion		Q28	0.82	0.76	
33. Collaboration between Parkinson nurse and neurologist		Q32	0.66	0.80	
34. Family doctor referral to the neurologist		Q75	0.37	0.81	
35. Collaboration between family doctor and neurologist		Q76	0.54	0.80	
36. Fixed contact assigned for questions, problems and complaints		Q77	0.59	0.79	
37. One professional caregiver in the lead		Q78	0.67	0.78	
38. Someone responsible for the coordination of your disease		Q79	0.22	0.84	
39. Professionals aware of each others 'involvement		Q81	0.62	0.79	
40. Professionals made mutual agreements about your treatment		Q82	0.01[a]	0.85[a]	
(F) Emotional support	*1.05 (0.90)*	*6 items*			*0.84*
41. Emotional support directly after the diagnosis was communicated		Q84	0.64	0.81	
42. Emotional support with coping with the disease		Q85	0.64	0.81	
43. Emotional support with relationship changes		Q86	0.69	0.80	
44. Emotional support problems related to employment		Q87	0.63	0.81	
45. Emotional support of the informal caregiver		Q89	0.67	0.80	
46. Active involvement the informal caregiver		Q90	0.50	0.84	
Total scale	*1.69 (0.45)*	*82 items*			
Screener items		Q15, 31, 44, 51, 58, 65, 70, 88			
Global satisfaction with healthcare		Q91			
Assistance with completing the questionnaire		Q92			

The questionnaire consists of 82 items, representing six different subscales and 46 care aspects. SES = subscale experience score, ITC = Item Total Correlation, $Q18^{M}$ = Item Q18, 19 and 80 are negatively posed items, data must be mirrored.
[a] Items with an ITC lower than threshold value 0.20.

the Internet can provide generic solutions for different patient groups to acquire reliable information and emotional support. Promising examples include online peer support, access to Personal Health Records with integrated social networking tools and Internet-based medical education to instruct PD patients about complicated medication regimens [27,28].

4.2. Strengths

First, the PCQ-PD has been developed according to state-of-the-art procedures [29], including a combination of qualitative methods (focus groups, cognitive interviews) and quantitative methods (questionnaire completed by 895 patients). The representative patient sample, together with the satisfactory response rate (82.0%), ascertained that the results were not affected by sampling bias and contributed to the general applicability of the instrument [10]. Second, the questionnaire covers a wide variety of in- and out-patient care aspects, addressing emotional support, collaborative care, accessibility of care, PD expertise, provision of information and patient involvement. Taken together, all items provide a disease specific model of patient-centeredness. Moreover, the questionnaire's multidisciplinary focus underscores that the provision of

Table 4
Items with the highest quality improvement scores (QIS).

Item		Subscale	PNE (%)	*n*	IES (mean, sd)	IPS (mean, sd)	QIS
Q1	Access to your own medical record	Involvement in decision making	88.0	668	0.36 (0.97)	2.06 (0.88)	5.44
Q9	Information About reimbursement of Anti-Parkinson medication	Provision of tailored information	78.0	846	0,67 (1.03)	2.25 (0.76)	5.23
Q83	Feedback on discussions on your treatment between your professional caregivers	Provision of tailored information	75.1	309	0.72 (1.03)	2.25 (0.78)	5.14
Q49	Information about possible treatment options occupational therapist	Provision of tailored information	76.4	842	0.79 (1.04)	2.31 (0.81)	5.11
Q63	Information about possible treatment options psychosocial caregiver	Provision of tailored information	75.4	846	0.79 (0.87)	2.31 (0.81)	5.10
Q2	Opportunity to decide who has access to your own medical record	Involvement in decision making	85.3	580	0.44 (1.06)	1.98 (0.98)	5.07
Q64	Information about where to find psychosocial caregivers with PD expertise	Provision of tailored information	78.3	843	0.63 (0.93)	2.12 (0.84)	5.04
Q86	Emotional support with relationship changes	Emotional support	81.6	591	0.63 (0.97)	2.03 (0.87)	4.80
Q85	Emotional support with coping with the disease	Emotional support	74.9	813	0.82 (1.05)	2.13 (0.79)	4.65
Q50	Information about where to find an occupational therapist with PD expertise	Provision of tailored information	72.2	837	0.84 (1.18)	2.12 (0.84)	4.58
Q10	Information about alternative medicine as an additional treatment	Provision of tailored information	95.7	855	0.19 (0.57)	1.57 (1.02)	4.42
Q11	Information about complex treatment options	Provision of tailored information	81.2	853	0.65 (1.02)	1.88 (1.00)	4.40
Q56	Information about possible treatment options speech & language pathologist	Provision of tailored information	66.5	835	1.11 (1.12)	2.31 (0.81)	4.35
Q57	Information about where to find a speech & language pathologist with PD expertise	Provision of tailored information	66.6	829	1.00 (1.22)	2.12 (0.84)	4.25
Q8	Contact after a new medication policy	Provision of tailored information	52.7	837	1.38 (1.30)	2.47 (0.69)	3.99

PNE (%) = Proportion of negative experiences. % answer category 0 and 1, QIS = (3 − IES)*IPS, QIS = quality improvement score [range 0–9], IES = item experience score [range 0–3], IPS = item priority score [range 0–3].

patient-centered care is the responsibility of all professionals involved in the treatment of PD patients. Third, the questionnaire can provide PD clinics with feedback about the quality of care through the eyes of their own patients', by asking them about genuine care experiences. Feedback drawn from experience surveys can be easily translated into service improvement initiatives [10].

4.3. Shortcomings

Some weaknesses should be mentioned. First, we do not know whether the observed differences in patient-centeredness between the participating clinics represented actual discrepancies in the quality of care, or merely differences caused by casemix variations. For this purpose, future studies should focus on background characteristics associated with care experiences, like disease duration, level of education and ethnicity. Interestingly, recent work has shown that many variations in the quality and costs of care cannot simply be attributed to casemix variations, but reflect true differences in professional behaviour [30]. Additionally, the responsiveness of the PCQ-PD should be evaluated. i.e. by the establishment of the test-retest reliability in repeated measurements within a small patient sample [29]. Second, despite appropriate Cronbach's α of all subscales, the internal consistency of the total scale could not be calculated using this dataset. Adjustments were made to prevent missing values in future measurements, allowing for estimation of the instrument's internal consistency. Third, it would have been better to have separated the validation study from the initial application study. Since the face validity and content validity was established before the psychometric property data were gathered and no items were changed afterwards, we used the dataset to draw some initial conclusions on the PD population at large. Future work should replicate these findings in an independent population. Fourth, since the Dutch PCQ-PD was translated into English after the validation procedures, future research should include validation of the English PCQ-PD. Some items may be specific to the country's practice and may have to be rephrased. For PCQ-PD users outside The Netherlands a small pre-test with PD patients is advised to confirm the content- and face-validity in their country. Fifth, patients who completed the questionnaire were more satisfied with their care compared to non-responders. Regression analysis demonstrated that a higher level of patient-centeredness was associated with higher patient's satisfaction. Therefore, our results may be slightly overestimated, and the actual level of patient-centeredness of Dutch PD care might be lower in real life. Hence, experience scores can be adjusted by subdividing respondents into different satisfaction levels and to calculate experience scores per cohort.

4.4. Future perspective

Patient experiences should be at the core of future assessments of the quality of PD care. The definition of patient-centeredness suggests that care has to be respectful of and responsive to individual patient preferences and values. In this respect, our current application of the PCQ-PD in a group of almost 900 PD patients (yielding a mean experience score) is somewhat contradictory, as this only offers insight in the quality of care as perceived by mainstream PD patients, but it did not clarify patients' individual needs, expectations and priorities. Possible future applications of the PCQ-PD include benchmarking of and feedback to institutions, in order to improve their quality of care tailored to the wishes of their customers. The overall patient-centeredness score can be used as an outcome measure for future clinical trials aiming to improve patient-centered care. The results will create transparency and better opportunities for PD patients to choose for quality themselves. To date, such comparisons across clinics have not been made in the field of PD.

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Appendix A. Supplementary data

Supplementary data related to this article can be found online at doi:10.1016/j.parkreldis.2012.05.017.

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