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Assessing the experience of person-centred coordinated care of people with chronic conditions in the Netherlands: Validation of the Dutch P3CEQ

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Abstract

Background: Countries are adapting their health and social care systems to better meet the needs of growing populations with (multiple) chronic conditions. To guide this process, assessment of the 'patient experience' is becoming increasingly important. For this purpose, the Person-Centred Coordinated Care Experience Questionnaire (P3CEQ) was developed in the United Kingdom, and translated into several languages.

Aim: This study aimed to assess the internal and construct validity of the Dutch P3CEQ to capture the experience of person-centred coordinated care of people with chronic conditions in the Netherlands.

Participants and Methods: Adults with chronic conditions ($N = 1098$) completed the Dutch P3CEQ, measures of health literacy and patient activation, and reported the use and perceived quality of care services. Data analysis included Principal Component and reliability analysis (internal validity), analysis of variance and Student's *T*-tests (construct validity).

Results: The two-component structure found was pretty much the same as in the UK validation study. Sociodemographic correlates also resembled those found in the United Kingdom. Women, persons who were less educated, less health-literate or less activated experienced less person-centred coordinated care. P3CEQ scores correlated positively with general practitioner performance scores and quality ratings of the total care received.

Conclusion: The Dutch P3CEQ is a valid instrument to assess the experience of person-centred coordinated care among people with chronic conditions in the Netherlands. Awareness of inequity and more attention to communication skills in professional training are needed to ensure that care professionals better recognize the needs of women, lower educated or less health-literate persons, and improve their experiences of care.

Patient Contribution: The P3CEQ has been developed in collaboration with a range of stakeholders. Eighteen persons with (multiple) chronic conditions participated as patient representatives and codesign experts in (four) codesign workshops. Other patient representatives participated in cognitive testing of the English-language instrument. The usability of the P3CEQ to capture the experience of person-centred coordinated care of older persons has been examined by interviewing 228 older European service users, including 13 living in the Netherlands, as part of the SUSTAIN project. More than a thousand persons with chronic conditions participated in the validation study of the Dutch P3CEQ.

KEYWORDS

care coordination, chronic conditions, patient experience, patient-reported experience measure, person-centred care, validation study

1 | INTRODUCTION

In many countries, a growing number of people are living longer with (multiple) chronic conditions.^{1,2} To maintain quality of life and better meet the needs of these people, countries are adapting their health and social care systems. Improving care continuity, coordination and integration and prioritizing a person-centred relational approach are core tenants of system redesign across the European Union and the United States.^{3,4} To guide the transformation towards more person-centred and integrated care, assessment of the 'patient experience'—which is conceptually related to person-centred care⁵—is becoming increasingly important.⁶

To assess the care experiences of service users, many so-called 'patient-reported experience measures' (PREMs) are available,⁷ and their application in quality improvement initiatives and health system performance assessment is growing.⁸ However, many of these PREMs fail to capture key elements of quality of care from the perspective of people with multimorbidity, who make up an increasing proportion of the population with chronic conditions in countries, such as care coordination and multidisciplinary collaboration.^{6,7,9,10} Moreover, PREMs to assess high-quality chronic care should cover key elements of person-centredness: a comprehensive approach to a

person's needs and working in partnership with the patient and, if applicable, family/carers.^{3,11,12}

The Person-Centred Coordinated Care Experience Questionnaire (P3CEQ)⁵ is a brief questionnaire that meets the requirements for a PREM that could assess the quality of care and guide quality improvement for people with (multiple) chronic conditions. It has been specifically designed to assess the experience of person-centred coordinated care, informed by a theoretical model that was developed to consider the relationship between care coordination, continuity and person-centred care.^{5,9} Person-centred coordinated care has been defined as 'care and support that is guided by and organized effectively around the needs and preferences of individuals', and is a comprehensive approach to care incorporating changes into organizational structures and behaviours of care professionals and service users.⁵

The P3CEQ was originally developed in the United Kingdom for persons with chronic conditions using primary care services. It has been shown to be a reliable and valid instrument, with strong face, construct and ecological validity, and sensitivity to change.¹³ To expand its usability for quality assessment of innovative models of integrated care across Europe, the questionnaire was translated into several languages, including Dutch, as part of the EU-funded

SUSTAIN project.¹⁴ In this paper, we report on the internal validity and construct validity of the Dutch P3CEQ to capture the experience of person-centred coordinated care of people with chronic conditions registered in general practices in the Netherlands.

1.1 | Research questions

1. Internal validity: Does the Dutch P3CEQ administered among people with chronic conditions registered in general practices in the Netherlands reflect the dimensionality and internal consistency of the English P3CEQ as confirmed in the UK validation study?
2. Construct validity: To what extent do the care experiences as assessed with the Dutch P3CEQ of persons with chronic conditions relate to their:
 - a) sociodemographic characteristics;
 - b) illness characteristics;
 - c) health literacy and patient activation level;
 - d) health service use in the previous 12 months; and
 - e) ratings of the quality of their general practitioner (GP) and of the total care that they received over the previous 12 months?

In answering our research questions 1 and 2a, we repeated the analyses of the UK validation study. As for research questions 2b–2e, we formulated a number of hypotheses based on the theoretical construct of person-centred coordinated care to determine the construct validity of the Dutch P3CEQ.

1.2 | Hypotheses

1. Persons with more chronic conditions experience less care coordination, as these people are likely to receive care from more care disciplines and sectors. Although GPs and district nurses in the Netherlands are tasked with care coordination, coordinating care across disciplines and sectors is complicated considering that the Dutch health and social care systems are not integrated.¹⁵ This may also impede person-centredness.
2. Persons with lower levels of health literacy or patient activation experience less person-centred care. This hypothesis arises from the concept of health candidacy,¹⁶ which suggests that people with low perceived candidacy for certain care interventions are offered fewer opportunities to engage in active person-centred care. These people may also lack the confidence and awareness of what this requires, for instance, articulation of what matters to them in the form of a narrative,¹⁷ which is key routine for person-centred care.
3. Persons who had been in contact with a GP over the last 12 months experience more person-centred coordinated care than persons who did not have contact with their GP because a 'whole-person' approach, continuity and coordination of care are considered key features of general practice and family medicine.¹⁸

4. Persons who had been in contact with more care disciplines experience less person-centred coordinated care because of a higher risk of care fragmentation for reasons already mentioned.
5. Persons who experience more person-centred coordinated care evaluate the performance of their GP and the overall quality of the care that they receive more positively, because person-centredness and care coordination are core elements of high-quality primary care and high-quality chronic care from the perspective of people with (multiple) chronic conditions.^{19–22}

2 | METHODS

2.1 | Study sample

The study sample was selected from the National Panel of people with Chronic illness or Disability (NPCD), a nationwide panel study in the Netherlands.^{23,24} People with chronic conditions are recruited each year from (random samples of) general practices in the Netherlands according to the following criteria: diagnosis of at least one somatic chronic disease, aged ≥ 15 years, not permanently institutionalized, life expectancy > 6 months (according to the GP), mentally capable of participating and having an adequate command of the Dutch language. Panel members participate in surveys twice a year, for a maximum of 4 years. They can choose to complete online or paper-and-pencil questionnaires. GPs provide data about their chronic disease(s) with the permission of the panel members. NPCD is registered with the Dutch Data Protection Authority (registration no. 1283171); all data are collected and handled in accordance with the privacy protection guidelines of the Authority. According to Dutch legislation, approval by a medical ethics committee is not mandatory for this study.

The Dutch P3CEQ was included in the NPCD survey of October 2017. A total of 1452 persons (≥ 18 years) with chronic conditions were invited to complete the questionnaire; and 1160 persons (80%) completed the questionnaire. We excluded the data of 17 respondents who appeared not to have a diagnosed somatic chronic disease according to their GP. Furthermore, we excluded the data of 45 persons who reported not to have been in contact with a care provider during the previous twelve months, resulting in a final sample of 1098 individuals.

2.2 | Measures

2.2.1 | Dutch P3CEQ

The included Dutch P3CEQ was developed as part of the EU-funded SUSTAIN project.¹⁴ The translation process was guided by principles of good practice for the translation and cultural adaptation of patient-reported outcomes measures developed by ISPOR²⁵ (see Box 1).

The English P3CEQ originally contained 11 items, but Q4 was excluded from the final version because of too many missing

BOX 1 Translation process followed for the Dutch P3CEQ

The translation process followed a stepwise approach:

1. Preparation: Dutch SUSTAIN researchers (M. L., A. S., N. Z., S. B.) reviewed the English P3CEQ instrument to ensure their understanding of the instrument's goal. They clarified any questions with the developers of the instrument (J. C., H. L.).
2. Forward translation: The instrument was independently translated into Dutch by three Dutch researchers (M. L., A. S., N. Z.).
3. Reconciliation: The three translations were discussed by M. L., A. S. and N. Z. and merged into a single translation. This forward translation was then reviewed for language use (S. B.) and relevance to practice (by an elderly care specialist).
4. Backward translation: The final forward translation was translated back into English by an independent translator who had not been involved in the forward translation.
5. Backward translation review: The developers of the English P3CEQ collected the backward translation results and compared these with the original. Any discrepancies were discussed with the Dutch researchers to resolve issues and revise the translation accordingly.
6. Harmonization: As the P3CEQ was translated into other languages parallel to the Dutch translation (as part of the SUSTAIN project), the developers of the English P3CEQ compared the backward translations from the multiple language translations to identify any discrepancies and achieve consistency across the translations.
7. Cognitive debriefing: The Dutch P3CEQ was then tested with five patient-experts to check for comprehensibility and interpretation, to try out translation alternatives and highlight any items that may have performed insufficiently at a conceptual level.
8. Review of cognitive debriefing results and finalization: The Dutch researchers compared the patient-experts' interpretations with the English P3CEQ to highlight and amend discrepancies.
9. Proofreading: A final review for typographic and grammatical errors was carried out by the Dutch researchers.

responses in the UK validation study. The last item (Q11a, b) is optional but was included in the Dutch P3CEQ. In the UK validation study, Principle Component Analysis supported the two-component structure (Person-centredness, Care coordination), with scalability demonstrated by a Partial Credit Rasch Analysis indicating good fit for both components. Person-centredness is assessed by eight items

(Q1, Q2, Q3, Q5, Q6, Q9, Q10, Q11); care coordination is assessed by five items (Q6, Q7, Q8, Q9, Q10).

The Dutch P3CEQ included in the NPCD survey had slightly different response options compared to the original. The response codes of most items in the English P3CEQ were 'not at all' (0), 'to some extent' (1), 'more often than not' (2) and 'always' (3), whereas the options of these items in the NPCD survey were 'never' (0), 'sometimes' (1), 'often' (2) and 'always' (3). Furthermore, we did not offer the 'not applicable' option, whereas this option is offered in the English version, but is then treated as a missing value in constructing the scale scores.

2.2.2 | Other measures

Sociodemographic characteristics included participants' self-reported gender, age, migration background, education and living situation. Migration background was based on the country of birth of participants' parents and of the participant, in accordance with Statistics Netherlands,²⁶ resulting in three categories: Dutch, western (not Dutch) and non-western. Level of education was determined by the highest level of completed education.

Illness characteristics included were participants' registered chronic diseases and illness duration (since diagnosis of first chronic disease), which were derived from their general practice health records. Participants themselves reported on motor, visual and hearing impairments by completing a Dutch validated questionnaire.²⁷ For each type of impairment, scores could range from 0 (no impairment) to 3 (severely impaired).

Health literacy was assessed using the 16-item Health Literacy Survey-Europe (HLS-EU-16).²⁸ Items are formulated as questions ('How easy would you say it is to ..., e.g., find information on treatments of illnesses' or [...] 'understand your doctor's or pharmacist's instructions on how to take a medicine') and rated on a four-point scale, from 'very easy' to 'very difficult'. In this study, we used a slightly modified version with a fifth answering option 'not applicable', treated as a missing value. Health literacy scores were calculated by coding a response of 'very easy' or 'easy' as 1 and of 'difficult' or 'very difficult' as 0, and summing the answers. Participants had to provide a valid answer on at least 13 questions to obtain a total score. Total scores were subsequently categorized: a score of 0–8 indicating insufficient health literacy, a score between 9 and 12 indicating limited health literacy and a score of 13 or higher indicating sufficient health literacy.²⁸

Participants' *activation level* was assessed using the short Patient Activation Measure (PAM-13).^{29,30} Having checked the internal consistency of the scale (Cronbach's α : .87), we calculated participants' scale scores following the guidelines of Insignia Health.³¹ Based on these scores, participants were assigned to one of four activation stages: (1) overwhelmed and does not consider an active role in managing his/her own health, (2) an active role in managing his/her health, but lacks knowledge and confidence for self-management, (3) beginning to take action but may lack confidence

and skills to adopt new behaviours and (4) confident and active, but may have difficulty maintaining adequate behaviour under stressful circumstances.

Health service use was assessed by participants reporting their contacts with a number of care providers over the previous 12 months: GP, practice nurse, medical specialist(s), occupational physician, specialized nurse working in a hospital, community nurse, home care, physiotherapist, pharmacist and other care provider(s). We calculated the number of different care disciplines that the participant had been in contact with during the 12 months before completion of the P3CEQ.

Quality of care as perceived by the participants was assessed by a performance score for the GP with whom they had been in contact over the last 12 months (ratings from 0 to 10) and a similar rating of the quality of the total care that they had received over the last 12 months, from 0 (very poor) to 10 (excellent).

2.3 | Statistical analysis

Statistical analysis was performed using PASW Statistics 18.³² Univariate analyses were performed to describe the sample. To answer our first research question, we analysed the distribution of the P3CEQ item scores. For Q8 (Care planning), an overall score was calculated by averaging the scores from questions 8a, 8b, 8c and 8d, as per the UK validation study. Next, we explored the dimensionality of the Dutch P3CEQ by means of Principal Component Analysis determining principal components based on an eigenvalue of >1, Varimax rotation and min imputation (missing values set at 0), as was done in the validation study of the English P3CEQ. Also similar to the UK validation study, we calculated Cronbach's α as a measure of internal consistency and constructed scale scores. To answer our second research question, we calculated the mean scale scores and standard deviations for various subgroups of participants, and conducted *T*-tests and analysis of variance to test for differences across subgroups.

3 | RESULTS

3.1 | Sample characteristics

The sample of 1098 persons included a slightly higher proportion of women (54%) than men (46%). The mean age of the participants was 67.9 years, with 73 persons younger than 50 years and 163 aged 80 years or older. Only 10 participants were of non-western origin. A quarter (24%) lived alone and almost three quarters (73%) lived with a spouse or partner. About a third (34%) had been diagnosed with one chronic disease, another third with two chronic diseases, 17% with three and 15% with four or more chronic diseases. The average illness duration was 14.2 years. Motor impairments were present in the majority of the participants, with 28% experiencing mild and 30% experiencing severe impairments. Fourteen percent experienced visual impairments and 31% reported hearing problems. Almost 90% of the participants had been in contact with their GP over the last 12 months. On average, participants had been in contact with four different care disciplines over the same period (range: 1–10).

3.2 | Internal validity

Table 1 presents a summary of the P3CEQ item scores. The proportion of missing values per question ranged from 3.9% (Q11: Confidence to self-manage) to 11.7% (Q7: Single named contact). Scores provided for all items ranged between 0 and 3 (not in table). The mean scores ranged between 0.09 (Q8), indicating that most participants did not experience that their care was guided by an individual care plan, and 2.31 (Q5), indicating that most participants did not need to repeat information that should have been in their medical records. Considering values for skewness and kurtosis between -2 and 2 as acceptable,²⁵ all questions were sufficiently normally distributed, except Q8 (Care planning overall). The nonnormal

TABLE 1 P3CEQ-Dutch item scores of primary care patients with chronic conditions

		Missing %	Mean	SD	Skewness	SE	Kurtosis	SE
Q1	Discuss what is important	5.2	1.26	0.96	0.39	0.08	-0.76	0.15
Q2	Involved in decisions	7.0	2.05	0.95	-0.74	0.08	-0.40	0.15
Q3	Considered 'whole person'	6.1	1.69	0.98	-0.17	0.08	-0.99	0.15
Q5	Repeating information	7.7	2.31	0.70	-0.71	0.08	-0.02	0.15
Q6	Care joined up	10.7	1.15	0.94	0.54	0.08	-0.52	0.16
Q7	Single named contact	11.7	0.59	1.19	1.53	0.08	0.33	0.16
Q8	Care planning (overall)	6.3	0.09	0.43	4.87	0.08	23.52	0.15
Q9	Support to self-manage	8.7	1.40	0.97	-0.54	0.08	-1.21	0.15
Q10	Information to self-manage	7.7	1.87	1.29	-0.40	0.08	-1.63	0.15
Q11	Confidence to self-manage	3.9	2.11	0.69	-0.59	0.08	0.71	0.15

Abbreviation: P3CEQ, Person-Centred Coordinated Care Experience Questionnaire.

		Component 1: Person-centredness	Component 2: Care coordination
Q1	Discuss what is important	0.618	0.283
Q2	Involved in decisions	0.814	0.117
Q3	Considered 'whole person'	0.805	0.150
Q5	Repeating information	0.495	-0.202
Q6	Care joined up	0.530	0.465
Q7	Single named contact	0.231	0.688
Q8	Care planning (overall)	-0.112	0.692
Q9	Support to self-manage	0.594	0.415
Q10	Information to self-manage	0.725	0.200
Q11	Confidence to self-manage	0.524	-0.295

TABLE 2 Principle component analysis with Varimax rotation of Dutch P3CEQ items

Abbreviation: P3CEQ, Person-Centred Coordinated Care Experience Questionnaire.

distribution of the scores of this question can be explained by a large majority of participants reporting not having an individual care plan.

The Principal Component Analysis resulted in a two-component solution (Table 2). The first component explained 38% of the variance of the item scores; the second explained an additional 13%. Based on these results, we followed the UK validation study and constructed two scales by calculating the sum of the scores of the questions assigned to these scales (marked in bold in Table 2): Person-centredness and Care coordination. Cronbach's α was .82 for the Person-centredness scale (eight items) and .68 for the Care coordination scale (five items).

3.3 | Correlates with sociodemographic characteristics

Men experienced higher levels of person-centred coordinated care than women (Table 3). Age groups differed in their reporting of person-centredness, with people aged 70–79 years experiencing lower levels of person-centred care than people aged 50–69 years. There were no significant differences between age groups in experienced care coordination. Education was related significantly to experienced person-centredness, with people who had no formal education, who attended primary school only or with low or preparatory vocational training reporting less person-centred care than those who had completed high vocational education. No effect of education was found on experienced care coordination. Living situation was not related to the experience of person-centred coordinated care.

3.4 | Correlates with illness characteristics

The number of chronic diseases did not relate to the experience of person-centred coordinated care (Table 3). However, people with

mild motor impairments, for example, those who experience difficulties walking outdoors or climbing stairs, reported lower levels of experienced person-centred coordinated care than people without such impairments. Visual and hearing impairments did not have an effect on experienced person-centredness or care coordination.

3.5 | Correlates with health literacy, patient activation and health service use

Table 4 shows that higher levels of health literacy and patient activation were associated with experiencing more person-centred coordinated care. Regarding health service use, we found no difference in the experienced person-centred coordinated care between persons who had been in contact with their GP over the last 12 months and those who had not (Table 4). However, the number of different care disciplines that one had been in contact with was related to the experience of both person-centredness and care coordination. Persons who had been in contact with seven or more disciplines reported the highest levels of person-centredness and differed in that respect from people who had had contact with one or two disciplines. Those who had been in contact with only one discipline also reported lower levels of experienced person-centredness than people who had been in contact with four or five disciplines. Regarding care coordination, the pattern was rather similar. This means that those who had been in contact with seven or more disciplines experienced a higher level of care coordination than people who had had contact with maximally four disciplines. Persons who had been in contact with only one discipline reported the lowest level of coordinated care and differed in that respect from persons who had had contact with four or more disciplines. People who had been in contact with two disciplines also experienced a low level of care coordination and differed from persons who had been in contact with five or seven disciplines.

TABLE 3 Mean and standard deviation of P3CEQ scales for subgroups with different sociodemographic and illness characteristics

	N	Person-centredness		Care coordination	
		M	SD	M	SD
Total sample	1098	12.88	5.40	4.64	3.36
Gender					
Male	510	13.41	5.26	5.06	3.48
Female	588	12.41	5.47	4.27	3.21
T-test		T(1096) = 3098, $p = .002$		T(1096) = 3.905, $p < .001$	
Age (in years)					
18–49	73	13.47	4.45	4.64	2.95
50–59	167	13.50	5.24	4.98	3.20
60–69	312	13.67	5.13	4.63	3.14
70–79	383	12.05	5.52	4.32	3.45
80 And older	163	12.39	5.85	5.05	3.86
ANOVA		F(4, 1093) = 5.116, $p < .001$		F(4, 1093) = 1.891, $p = .110$	
Education					
None/primary school	77	11.57	5.95	4.19	3.71
Low/preparatory vocational education	252	12.19	5.89	4.59	3.67
Intermediate general education	231	12.63	5.66	4.45	3.43
Intermediate vocational education	158	13.17	5.18	4.78	3.50
Advanced general education	84	13.31	4.65	4.57	3.11
High vocational education	208	13.88	4.56	4.94	2.93
University	58	13.95	4.52	5.07	2.74
ANOVA		F(6, 1061) = 3.329, $p = .003$		F(6, 1061) = 0.844, $p = .536$	
Living situation					
Alone	256	12.33	5.07	4.47	3.42
With spouse/partner	785	13.06	5.44	4.70	3.35
With family (not spouse)	37	13.84	5.29	5.04	3.22
With roommates ^a	3	-	-	-	-
ANOVA		F(2, 1075) = 2.378, $p = .093$		F(2, 1075) = 0.692, $p = .501$	
Number of diagnosed somatic chronic diseases					
One	376	12.83	5.37	4.64	3.35
Two	368	12.89	5.51	4.46	3.38
Three	195	13.04	5.36	4.80	3.29
Four or more	159	12.77	5.31	4.86	3.46
ANOVA		F(3, 1094) = 0.092, $p = .965$		F(3, 1094) = 0.710, $p = .546$	
Motor impairment(s)					
None	447	13.27	5.67	4.64	3.43
Mild	291	12.21	5.14	4.30	3.24
Moderate/severe	313	13.09	5.00	5.06	3.41
ANOVA		F(2, 1048) = 3.655, $p = .026$		F(2, 1048) = 3.826, $p = .022$	

(Continues)

TABLE 3 (Continued)

	N	Person-centredness		Care coordination	
		M	SD	M	SD
Visual impairment(s)					
None	924	13.02	5.33	4.63	3.33
Mild	74	12.53	5.07	4.92	3.39
Moderate/severe	79	11.66	6.08	4.50	3.73
ANOVA		F(2, 1074) = 2.493, <i>p</i> = .083		F(2, 1074) = 0.330, <i>p</i> = .719	
Hearing impairment(s)					
None	733	13.16	5.46	4.68	3.30
Mild	218	12.51	4.90	4.44	3.32
Moderate/severe	112	12.66	5.47	5.04	3.77
ANOVA		F(2, 1060) = 1.446, <i>p</i> = .236		F(2, 1060) = 1.179, <i>p</i> = .308	

Abbreviations: ANOVA, analysis of variance; P3CEQ, Person-Centred Coordinated Care Experience Questionnaire.

^aAs this category contained only three persons, it was not included in the analysis.

3.6 | Correlates with quality-of-care ratings

Table 5 shows a rather linear association between participants' person-centredness scores and their GP performance scores, although the small group of persons rating the performance of their GP lower than 6 (*N* = 42) did not have the lowest mean score for person-centredness. The association of experienced person-centredness with the ratings for the overall quality of care is stronger. The associations for care coordination show a similar pattern.

4 | DISCUSSION

Our results support the internal validity of the Dutch P3CEQ to assess the experience of person-centred coordinated care among people with chronic conditions registered with general practices in the Netherlands. The two-component structure of the Dutch P3CEQ resembled the structure found in the UK validation study, though some differences emerged. Q6 ('Care joined up') loaded on both components in our study, whereas in the UK validation study, this question strongly related to the Person-centredness component (0.71) and less to the Care coordination component (0.24).¹³ In contrast, Q10 ('Information to self-manage') did not load sufficiently on the Care coordination component in our study, whereas it loaded on both components in the UK validation study. The low factor loading of Q10 on this component in our study also explains the relatively low Cronbach's α of the Care coordination scale (.68), though this may still be considered acceptable,³³ given that the scale consists of only five items. It is important to understand that person-centredness and care coordination are related concepts, with coordination of care being a key element of person-centred care.^{34,35} This is reflected in the Person-Centred Coordinated Care (P3C)

construct^{5,9} underlying the P3CEQ, which is the main reason for allowing questions to load on both components.

The scale scores of both scales of the Dutch P3CEQ were substantially lower than those in the UK validation study. This might be explained by the use of slightly different response options in the two studies. In addition, differences in response style between Dutch and English respondents may be considered. Differences in acquiescence and extreme responding have been found across European countries,³⁶ though such differences seem less likely between western European countries, as the previously mentioned study did not find differences between French, German and UK respondents (Dutch citizens were not involved). A third and perhaps more plausible explanation is that primary care users with chronic conditions in the Netherlands genuinely experience less person-centred coordinated care compared to their counterparts in the UK validation study. For instance, developing an individualized care plan is not common practice for all chronic patients within primary care in the Netherlands.³⁷ This is also clear from our results regarding Q8 (Care planning overall): a large majority of participants reported not to have an individual care plan. In contrast, the participants in the UK validation study were recruited from a primary care system (Somerset) where substantial and ongoing initiatives are in operation to develop countywide person-centred coordinated care.^{38,39}

Similar to the UK validation study, men scored higher than women on both scales, which is in line with other studies reporting women to be less positive about the care that they receive.^{40,41} It has been argued that current health services are predominantly built on a 'male model', with women being less involved in their design and, consequently, less attention being paid to women's needs and a gender-sensitive management of health conditions.⁴² Differences between women and men in communication styles may also play a role.^{43,44}

TABLE 4 Mean scores and standard deviation of P3CEQ scales for subgroups with different levels of health literacy and patient activation and different health service use

	N	Person-centredness		Care coordination	
		M	SD	M	SD
Health literacy					
Inadequate	76	10.88	4.63	3.93	2.99
Limited	179	13.30	4.55	5.07	3.19
Sufficient	551	14.22	5.02	5.09	3.27
ANOVA		F(2, 803) = 16.343, $p < .001$		F(2, 803) = 4.398, $p = .013$	
Patient activation					
Stage 1	156	11.44	4.54	4.09	3.06
Stage 2	235	12.18	4.91	4.34	3.06
Stage 3	336	13.14	5.05	5.03	3.44
Stage 4	296	14.51	5.44	5.03	3.41
ANOVA		F(3, 1019) = 15.782, $p < .001$		F(3, 1019) = 4.764, $p = .003$	
Contact with GP in the previous year					
No	124	12.77	6.03	4.33	3.39
Yes	956	12.94	5.29	4.69	3.35
T-test		T(148.618) = -0.303, $p = .762$		T(1078) = -1.140, $p = .254$	
Number of different care disciplines contacted in the previous year					
1	51	9.86	6.77	2.92	3.22
2	138	11.80	6.23	3.90	3.48
3	249	12.53	5.68	4.21	3.42
4	283	13.49	4.80	4.83	3.08
5	201	13.50	4.85	5.08	3.18
6	102	12.82	5.11	4.92	3.24
7 Or more	74	14.16	4.59	6.37	3.75
ANOVA		F(6, 1091) = 5.644, $p < .001$		F(6, 1091) = 8.468, $p < .001$	

Abbreviations: ANOVA, analysis of variance; GP, general practitioner; P3CEQ, Person-Centred Coordinated Care Experience Questionnaire.

In contrast to the results found in the UK, participants' age appeared to be associated with the level of experienced person-centredness. However, a closer look at the distributions across age categories shows that in both studies, persons aged 60–69 years had slightly higher person-centredness scores than persons aged 50–59 years and persons aged 70 years and older. This contrasts with the frequent observation of older people reporting more positive care experiences.⁴⁵ A detailed analysis across age groups including more than 145,000 patients from various studies showed, however, that a general tendency of older people responding more positively about their care may not exist.⁴⁶ In the UK validation study, the mean

TABLE 5 Mean scores and standard deviation of P3CEQ scales for subgroups with different ratings of the quality of care

	N	Person-centredness		Care coordination	
		M	SD	M	SD
GP performance score over the last 12 months					
5 Or lower	42	11.55	6.49	4.02	3.58
6	50	10.90	4.57	3.61	3.18
7	152	10.93	4.48	3.51	2.84
8	414	13.12	4.87	4.84	3.19
9	203	14.04	5.20	5.13	3.38
10	81	15.62	5.92	6.28	3.68
ANOVA		F(5, 936) = 13.682, $p < .001$		F(5, 936) = 10.311, $p < .001$	
Rating of quality of the total care received over the last 12 months					
5 or lower	13	6.85	3.29	2.00	2.55
6	58	9.53	3.66	3.12	3.29
7	223	11.60	4.30	4.03	3.00
8	498	13.86	4.44	5.01	3.02
9	160	15.77	4.63	5.87	3.46
10	54	17.48	5.50	7.38	3.55
		F(5, 1000) = 40.839, $p < .001$		F(5, 1000) = 19.430, $p < .001$	

Abbreviations: ANOVA, analysis of variance; GP, general practitioner; P3CEQ, Person-Centred Coordinated Care Experience Questionnaire.

scores were also calculated for four age groups younger than 50 years, although some of these groups were very small. This may have caused a less stable pattern across age categories younger than 50 years of age, resulting in a nonsignificant age effect in that study.

Importantly, our study shows that lower educated persons experience less person-centred care, which was also found in the UK validation study. This may relate to their lower socioeconomic position (SEP), as other studies have shown that people with a lower SEP receive less guidance, less collaborative care and less positive feedback and receive more clinically directed care than people with a higher SEP.^{16,47} This may be explained by the concept of health candidacy,¹⁶ already mentioned in the introduction. People with a low perceived candidacy for certain care interventions may be offered fewer opportunities to engage in active person-centred care or find it more difficult to engage. Lower educated people are also at risk of experiencing epistemic injustice,⁴⁸ both due to a lack of understanding about their health and how to improve it, and by not being taken seriously and 'heard' in clinical encounters. People who lack health knowledge may find self-representation and communication with care professionals less effective. Since person-centred care builds on a person's narrative and the pursuit of a partnership between the patient and the care professional, notions of epistemic injustice and candidacy may therefore explain why less educated people report poorer experiences of person-centred care. A previous

study provided some evidence that implementation of person-centred care benefits less educated persons in terms of increased self-efficacy.⁴⁹

We found partial support for our hypotheses specifying the relationships of participants' P3CEQ scores with their illness characteristics, levels of health literacy and patient activation, health service use and ratings of the quality of care that they received. Participants with more chronic conditions did not experience less person-centred coordinated care than participants with less chronic conditions (hypothesis 1 rejected). We had expected people with more chronic conditions to experience a lack of care coordination more often, as in general, less positive care experiences have been found among people with more chronic conditions,⁴⁵ and because these people will usually be in contact with more care disciplines, which do not share patient records in the Netherlands. However, this lack of care coordination may be less felt by people with chronic conditions that are managed by chronic disease management programmes (DMPs) within primary care. People included in these programmes may experience more care coordination, as far as it concerns care covered by the DMP, though not necessarily more person-centredness, as the single-disease focus of these programmes might even blur a view on the 'whole person'.^{50,51}

Our findings confirm our second hypothesis that persons with lower levels of health literacy and/or patient activation experience less person-centred care. Participants with limited health literacy or less-activated participants also appeared to experience less care coordination. We already pointed to the concepts of health candidacy and epistemic injustice as possible explanatory phenomena. Given that inequitable treatment of people within healthcare is unacceptable, care providers and policy-makers should give the highest priority to improving care for disadvantaged people who are precisely the ones who may need more support and possibly also other types of support from care professionals to manage their health and care.

Our third hypothesis, that contact with the GP would increase the experience of person-centred coordinated care, was not confirmed. This may be because of the specific nature of our sample: all participants had one or more chronic conditions known by their GP and almost 90% reported having been in contact with the GP over the last year. Although the persons who reported contact with the GP had slightly higher mean scores on both P3CEQ scales, the *T*-test may have lacked power because of the small number of participants not having seen their GP.

Surprisingly, and in contrast to our fourth hypothesis, persons who had been in contact with more different care disciplines did not experience less person-centred coordinated care. People who had been in contact with only one care discipline experienced the lowest levels of person-centred coordinated care. This may be explained by these people experiencing or expressing less need for person-centred coordinated care. However, care professionals should be aware that person-centred care is equally important for people with less complex care needs, to support their self-management and prevent deterioration of their health problems as much as possible and to signal any new health problems or related problems in other domains of life

at an early stage. For people who receive care from many disciplines, the necessity for person-centred coordinated care may be more visible and recognized by care professionals, eliciting more care coordination and possibly also more attention to the quality of life and well-being from a broader perspective. We do not know whether our participants with a more complex care need were receiving care from an integrated care programme. Integrated care programmes for frail older people are increasingly being implemented in Dutch primary healthcare.⁵²

Finally, our fifth hypothesis about the correlates of the P3CEQ scale scores with other PREMs was confirmed. People experiencing more person-centred coordinated care were also more positive about their GP's performance and the quality of the total care that they received, which can be considered support for the convergent validity of the Dutch P3CEQ.

5 | METHODOLOGICAL CONSIDERATIONS

A strength of our study is the large sample of people with chronic conditions randomly selected in general practices throughout the Netherlands. The NPCD panel has been shown to be representative for the Dutch population of people with chronic conditions registered with general practices regarding age and gender distribution, but people with limited health literacy and people from non-Western origin are underrepresented.⁵³ The translation process that resulted in the Dutch P3CEQ followed the principles of good practice for the translation and cultural adaptation of patient-reported outcome measures as developed by ISPOR in great detail. Nevertheless, further testing of the Dutch P3CEQ on the comprehensibility of the items by means of cognitive interviews, in particular among the oldest age group, is recommended based on what we have learned from applying the P3CEQ in the SUSTAIN project.⁵⁴ This cognitive testing will be done as part of the development of the International Survey of People Living with Chronic Conditions (PaRIS)⁵⁵ initiated by the Organization for Economic Cooperation and Development. The PaRIS survey aims to support countries in making their health systems more people-centred by collecting patient-reported data, in particular, from primary care service users aged 45 years and older who are likely to have—or develop—chronic conditions. The PaRIS survey questionnaires, including the P3CEQ, have recently been adopted by all participating countries, including the Netherlands.

6 | IMPLICATIONS FOR POLICY AND PRACTICE

The results of our study provide guidance for the training of care professionals and quality improvement initiatives within primary care. In particular, a targeted focus on improving candidacy, health literacy and on person-centred care for women and people with less formal education may enhance the care experiences of many people with

chronic conditions as well as their health and well-being. Furthermore, given the persisting and even growing inequalities in health and access to health services within and across countries, person-centred coordinated care should be prioritized for all marginalized groups.

7 | CONCLUSION

The Dutch P3CEQ has been proven to be a valid instrument to assess the experience of person-centred coordinated care among people with chronic conditions registered with general practices in the Netherlands. Its internal validity was confirmed by the high resemblance in dimensionality with the English P3CEQ validated in the United Kingdom. Correlates with other PREMs support its convergent validity. Findings of the Dutch P3CEQ point to the experience of less person-centred coordinated care by women and/or lower educated, less health-literate or less-activated persons. This calls for increased attention to inequity in developing primary care and health services in general, and to the attitude and communication skills of care professionals in professional training to ensure that care professionals are able to recognize and discuss the needs for care and support of patients and clients from marginalized groups.

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CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

AUTHOR CONTRIBUTIONS

Mieke Rijken designed the study; analysed the data; and wrote the manuscript. James Close codesigned the data analysis plan, contributed to the interpretation of the data and reviewed the manuscript. Juliane Menting contributed to the data collection and analysis and reviewed the manuscript. Manon Lette, Annerieke Stoop, Nick Zonneveld and Simone de Bruin developed the Dutch P3CEQ within the SUSTAIN project in collaboration with Helen Lloyd, James Close and other SUSTAIN partners; they contributed to the interpretation of the data and reviewed the manuscript. Helen Lloyd contributed to the interpretation of the data and writing of the manuscript. Monique Heijmans codesigned the study, was responsible for the data collection and reviewed the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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