Measuring person-centred care in nurse-led outpatient rheumatology clinics

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Abstract

Background: Measurement of person-centered care (PCC) outcomes is underdeveloped due to the complexity of the concept and lack of conceptual clarity. A framework conceptualizing outpatient PCC in rheumatology nurse-led clinics has therefore been suggested and operationalized into the PCC instrument for outpatient care in rheumatology (PCCoc/rheum).

Objective: To test the extent to which the PCCoc/rheum represents the underpinning conceptual outpatient PCC framework, and to assess its measurement properties as applied in nurse-led outpatient rheumatology clinics.

Methods: The 24-item PCCoc/rheum was administered to 343 persons with rheumatoid arthritis from six nurse-led outpatient rheumatology clinics. Its measurement properties were tested by Rasch measurement theory.

Results: Ninety-two percent (n=316) answered the PCCoc/rheum. Items successfully operationalized a quantitative continuum from lower to higher degrees of perceived PCC. Model fit was generally good, including lack of differential item functioning (DIF), and the PCCoc/rheum was able to separate persons with a reliability of 0.88. The four response categories worked as intended except for one item. Item ordering provided general empirically support of a priori expectations, except for three items that were omitted due to multidimensionality, dysfunctional response categories, and unexpected ordering. The 21-item PCCoc/rheum showed good accordance with the conceptual framework, improved fit, functioning response categories, no DIF and its reliability was 0.86.

Conclusion: We found general support for the appropriateness of the PCCoc/rheum as an outcome measure of patient perceived PCC in nurse-led outpatient rheumatology clinics. While in need of further testing, the 21-item PCCoc/rheum has potentials as a means to evaluate outpatient PCC from a patient perspective.

Keywords: person-centered care, measurement, nurse-led rheumatology clinics, outpatient
Introduction

Person-centered care is considered a valuable approach for the improvement of quality of care (Coulter et al., 2015; WHO, 2015). Person-centered care is rooted within a holistic paradigm, which puts the individual’s perspective in focus and ensures that healthcare is built on the needs and preferences of the persons using it (Harding et al., 2015; WHO, 2015; Ekman et al., 2011). Person-centered care is therefore widely advocated as a desirable approach intended to personalize care (Olsson et al., 2013). Thus, implementation of person-centered care in clinical practice is prioritized, which also implies a commitment to measure person-centered outcomes (Harding et al., 2015; Collins, 2014; McCormack et al., 2006).

Using measures that can provide insights into practice is important in demonstrating the effectiveness of person-centered care and particularly in identifying areas for improvement, as well as which individuals and contexts that would benefit most from a greater degree of person-centered care (McCance et al., 2009). However, despite efforts to develop valid and reliable measures, progress in person-centered care measurement has been challenged due to the complexity of the concept and lack of consensus about what person-centered care means (Harding et al., 2015; de Silva, 2014). This is particularly evident in the context of outpatient care and in terms of measuring person-centered care from the perspective of people living with long-term conditions (Kogan et al., 2016; de Silva, 2014). A central prerequisite in moving towards such person-centered outcomes is an understanding of what really matters to patients in their care (de Silva, 2014).

To circumvent this situation and enable measurement of person-centered outcomes in nurse-led rheumatology outpatient care, Bala et al. (2017a) conceptualized person-centered care in this context. The resulting conceptual framework was then operationalized into a proposed instrument for measuring person-centered care (the person-centered care instrument for outpatient care in rheumatology, PCCoc/rheum). The PCCoc/rheum and its underpinning conceptual framework focuses on the care meeting between the person and the nurse in view of holistic nursing in a partnership. This is represented by five related and partially overlapping domains: social environment, personalization, shared decision-making, empowerment, and communication. The four first domains are hypothesized to represent increasingly higher levels of person-centered care, whereas the last domain (communication) is considered intermingled across the other four (Bala et al., 2017a).

Based on this conceptual outpatient framework, the PCCoc/rheum was developed in collaboration with patients with rheumatoid arthritis (RA) and healthcare professionals, and from the perspective of patients with different levels of disease burden (from patients in remission to those with severe, persistent RA) by taking into account the aspects of care that patients identify as most crucial from a person-centered perspective (Bala et al., 2017a). Patient participation was central to the operationalization and development (item generation) as well as the evaluation of the PCCoc/rheum. This approach is grounded on partnership and helps ensuring that the resulting measure will be relevant to persons with RA using nurse-led clinics services, useful in monitoring quality of care and, importantly, for identification of needs for improvements.

Initial evaluations supported the user friendliness, relevance and content validity of the PCCoc/rheum from the patient perspective (Bala et al., 2017a). However, the extent to which the PCCoc/rheum represents the hypothesized person-centered care continuum in an expected manner and whether it may be useful as an instrument for measurement remains to be tested. Therefore, the aim of this study was to test the extent to which the PCCoc/rheum represents
the underpinning conceptual outpatient person-centered care framework, and to test its measurement properties as applied in nurse-led outpatient rheumatology clinics.

**Methods**

**Design and setting**
The study was a multicenter cross-sectional survey involving six south Swedish nurse-led outpatient rheumatology clinics participating in the BARFOT study (Svensson et al., 2016).

**Participants**
The survey was administered to 343 patients with RA (of which 58 had clinically known persistent disease). Data were collected between February 2015 and March 2016. Eligible participants were Swedish-speaking adults with RA and at least three documented nurse clinic contacts (of which at least two were clinic visits).

**Data collection**
Rheumatology nurses at the participating clinics informed patients about the study and collected informed consents. The nurses also distributed a questionnaire booklet (including the PCCoc/rheum, demographic and RA/health-related questions, and the Stanford Health Assessment Questionnaire, HAQ) in connection with a clinic visits. Patients were instructed to complete the questionnaires independently and then return the booklet to the first author (SVB) using a pre-stamped and addressed envelope. Reminders were sent to non-responders after 2 and 5 weeks. Participants were also invited to complete the PCCoc/rheum once again to estimate test-retest stability. Those who consented were asked to provide their address when returning the initial questionnaire booklet and were then sent a second copy of the PCCoc/rheum two weeks later (the second questionnaire only comprised the PCCoc/rheum).

The PCCoc/rheum (Bala et al., 2017a) consisted of 24 items (statements) intended to reflect various levels of patient perceived person-centered care according to five related domains (social environment, personalization, shared decision-making, empowerment, and communication). Each item has a 4-category response scale (0=Totally disagree; 1=Disagree; 2=Agree; 3=Completely agree) yielding a raw total score that can range between 0 and 72 (higher scores = greater degree of perceived person-centered care).

The HAQ is a 20-item patient-reported rating scale covering eight areas of daily activities (Ekdahl et al., 1988; Fries et al., 1980). Each item is scored according to a 4-point scale (0-3) and the highest scores from each area are summed and divided by eight to derive a total HAQ score, which can range from 0 to 3 (3=worse). A cut-off score at <1 vs. ≥1.0 has been suggested to define clinically relevant levels of disabilities (Thyberg et al., 2012).

In addition, nurses reported the most recent disease activity assessments according to the composite Disease Activity Score, calculated on 28 joints (DAS28) (Prevoo et al., 1995). DAS28 includes the number of swollen joints, number of tender joints, patient’s global assessment of disease activity rated on a visual analogue scale (0-100 mm, best to worse) and erythrocyte sedimentation rate (ESR, mm/h). DAS28 values >5.1 imply high disease activity, ≤5.1→3.2 moderate disease activity, ≤3.2→2.6 low disease activity, and <2.6 remission (Prevoo et al., 1996). Persistent RA was defined as DAS28 >2.6 at all predefined follow-up visits following the first 6 months after diagnosis (Svensson et al., 2016).
Data analyses

Demographic and RA/health-related data were analyzed descriptively and PCCoc/rheum test-retest stability was assessed by the intra-class correlation (2-way mixed model, single measure, absolute agreement) between total scores from time 1 and time 2 using IBM SPSS version 22.

The measurement properties of the PCCoc/rheum were tested according to Rasch measurement theory (RMT) (Hobart and Cano, 2009; Andrich, 1988; Rasch, 1960). In RMT, the total score is a sufficient statistic, and the probability of a certain item response is a function of the difference between the levels of the measured construct (in this case, person-centered care) represented by the item and the person, respectively. Analyses focused on the following main aspects: targeting, reliability, model fit, differential item functioning (DIF), response category functioning, and hierarchical item ordering. For methodological details, see Andrich et al., 2013; Hobart and Cano, 2009; Andrich, 1988; Wright and Masters, 1982.

Targeting refers to the accord between item and person locations. Preferably, person locations along the measurement continuum should be mirrored by item locations at approximately the same levels in order to maximize precision in estimated person measures. Similarly, person representation at item locations optimizes precision in item estimates and conditions for scale evaluation. RMT allows for detailed targeting analysis since the model separately locates persons and items on a common linear logit (log-odd units) metric, which can take values from minus to plus infinity (with mean item location set at zero).

Reliability is linked to targeting as it relates to the instrument’s ability to separate persons, as well as to measurement precision. Here, reliability was estimated by the person separation index (PSI), which is conceptually analogous to coefficient alpha but based on linear RMT estimates. In addition, we computed the number of strata, which is based on reliability and indicates the number of statistically distinct groups of persons a scale distinguishes (Wright and Masters, 1982).

Model fit concerns the extent to which observed item response data accord with RMT expectations. Three related main indicators were used to examine model fit: (i) standardized residuals that summarize the difference between observed and expected responses. These have an expected value of 0 and a generally acceptable range between −2.5 to +2.5. In general, large positive values signal multidimensionality (i.e., the item represents a different construct than the instrument as a whole) and large negative values represent local response dependence (i.e., item responses are dependent on responses to one or several other items). To the latter end, correlations between standardized item residuals were examined to assess the extent of local dependence in more detail. (ii) Item chi-square statistics that test the statistical significance of differences between observed and expected item responses. (iii) Item characteristic curves (ICC) that graphically display the relationship between observed and expected responses across the PCC continuum. In addition, unidimensionality was tested by comparing person locations based on items from PCCoc/rheum domains hypothesized to represent lower levels of person-centered care (social environment and personalization) with person locations estimated by items intended to reflect higher person-centered care levels (empowerment) using the independent t-test approach (Hagell, 2014; Horton et al., 2013; Andrich, 2010; Smith, 2002). If the proportion (or its 95% binomial Agresti-Coull confidence interval) of persons with significantly different location estimates is less than 5%, unidimensionality is considered supported.
DIF is an additional aspect of model fit and concerns the extent to which item responses are influenced by factors external to the measured construct and therefore, whether they function similarly across different conditions or groups of persons. There are two main types of DIF, uniform (i.e., a systematic difference in item response probabilities between groups despite similar levels of person-centered care) and non-uniform (i.e., an interaction between groups and levels of person-centered care). Uniform and non-uniform DIF were tested by a two-way analysis of variance (ANOVA) of item residuals across levels of person-centered care by seven factors: age (defined by the median, \( \leq 64 \) vs. \( >64 \) years), gender (women vs. men), disease duration (defined by the median, \(<13.5 \) vs. \( \geq 13.5 \) years), HAQ-score (<1 vs. \( \geq 1.0 \)), low vs. at least moderate disease activity (DAS28 \( \leq 3.2 \) vs. \( >3.2 \)), disease course (non-persistent vs. persistent RA) and time (time 1 vs. time 2).

Response category functioning is assumed when using ordered response categories that imply a continuum of increasing levels from less to more (e.g., 0=Totally disagree to 3=Completely agree). The ordering of response category thresholds tests this assumption. Thresholds are the locations on the measurement continuum at which the probability of responding to either of two adjacent categories is equal. Disordered thresholds imply that the response categories do not function as intended across the continuum from less to more.

The hierarchical item ordering was studied to assess the internal construct validity of the PCCoc/rheum. This is possible since RMT locates items along a linear continuum from less to more according to how much they represent of the measured construct. The empirical item ordering was therefore compared to theoretical expectations. Specifically, items representing the dimensions of social environment, personalization, shared decision-making and empowerment were generally expected to be located at increasingly higher but partially overlapping levels of person-centered care; communication is considered an integral part of all dimensions (Bala et al., 2017a). General agreement was taken as support for the underpinning conceptual framework and its operationalization in terms of the PCCoc/rheum.

RMT analyses were conducted using the unrestricted polytomous (“partial credit”) Rasch model, with the sample divided into six class intervals (subgroups reporting similar levels of person-centered care) using the RUMM2030 software (Professional Edition, version 5.4) (Andrich et al., 1997-2015). Due to the large number of tests, Bonferroni adjustments for multiple null hypothesis testing (Bland and Altman, 1995) were applied using an alpha level of significance of 0.05 (Hagell and Westergren, 2016).

Ethical approval
The local ethical review board approved the study (Dnr. 2013/258) and all participants gave written informed consent.

Results
A total of 316 participants (Table 1) returned the initial questionnaire booklets (response rate, 92%). There were no missing responses to 13 PCCoc/rheum items and the remaining 11 items exhibited low levels of missing responses (\( \leq 2.8 \% \)). This indicates that item wording and contents were acceptable and relevant to respondents. Sixty-five per cent of the participants (n=207) answered the PCCoc/rheum once again after two weeks.
Targeting and reliability

The person – item threshold distribution of the 24-item PCCoc/rheum displayed a relatively even distribution of item thresholds with no major gaps, spanning about 8 logits from lower to higher levels of patient perceived person-centered care (Fig. 1A). This means that the scale was successful in representing a quantitative continuum from less to more. Similarly, the PCCoc/rheum was able to separate persons along the same quantitative continuum with a reliability (PSI) of 0.88, implying 3 to 4 detectable person strata. However, targeting was compromised at the lower end (below -1 logits) of the PCCoc/rheum range of measurement in that there were very few persons located at these levels. Similarly, the PCCoc/rheum failed to represent higher levels of person-centered care (>4 logits), where a substantial proportion of the sample was located. This was illustrated by a mean (SD) person location of 3.2 (1.88) logits, i.e., the sample reported perceived person-centered care levels on average about 3.2 logits above that represented by the PCCoc/rheum.

Test-retest stability

Assessment of test-retest stability of the raw total PCCoc/rheum 24-item score yielded an intra-class correlation of 0.82.

Model fit

The fit of PCCoc/rheum item response data to the Rasch measurement model is shown in Table 2 (Initial version). Data were largely consistent with expectations; 20 items exhibited fit residuals within the recommended range, and 22 items had non-significant chi-square values. Inspection of the residual values indicated that item 15 (“family participation”) misfitted, which also is corroborated by inspection of the associated ICC (Fig. 2A). Similar patterns were also seen for items 1 (“welcoming care environment”) and 2 (“undisturbed conversations”). This implies that these items did not work as intended within the overall PCCoc/rheum frame of reference, and the patterns of indices suggested that these items appear to represent something different from the other items (i.e., multidimensionality).

Items 5 (“opportunity to tell my story”), 6 (“understanding my situation”) and 7 (“experiences are respected”) showed unexpectedly large negative residuals. Yet, these deviations were not statistically significant and graphically the ICCs appeared acceptable (Fig. 2B), and similar to those of items with good fit (Fig. 2C). However, the relatively large negative residual values suggest local response dependence. This observation was corroborated by relatively large correlations (0.338-0.457) between residual values of these items as well as item 8 (“self-knowledge is considered”). The impact of the identified local dependency was examined by combining locally dependent items into a subtest, which absorbs dependency by treating dependent items as a single item in the analysis (Andrich et al., 2013; Andrich 1985). The results suggested that local dependence induced negligible bias in reliability, which dropped from 0.88 to 0.86. Similarly, person measures were not appreciably affected as illustrated by an intra-class correlation of 0.99 between the original and subtest corrected scores.

The independent t-test protocol identified 22 individuals (7%; 95% CI, 4.6-10.4%) with significantly different locations when estimated from social environment/personalization items compared to when based on empowerment-related items.
Differential item functioning (DIF)
All items performed similarly across different groups of persons as well as by time. That is, there were no uniform or non-uniform DIF by age, gender, disease duration, HAQ, DAS28, disease course (persistent vs. non-persistent disease) or time. However, results regarding disease course should be interpreted with some caution due to the small number of people with persistent RA (n=58).

Response category functioning
Assessment of the empirical functioning of the four response categories showed that these worked as intended with all items, except for item 15. For this item, response category 1 was never the most likely outcome.

Hierarchical item ordering
The empirical ordering of item locations from lower to higher levels of perceived person-centered care is displayed in Table 2. Inspection of the pattern of the hierarchical item ordering provided general support of a priori expectations, except for items 1, 2 and 15. The polyserial correlation between a priori expectations and empirical item locations was 0.22.

Revision of the 24-item PCCoc/rheum
Based on the analyses summarized above items 1, 2 and 15 were considered candidates for deletion from the PCCoc/rheum due to compromised model fit suggesting multidimensionality (all 3 items), dysfunctional response categories (item 15), and unexpected hierarchical ordering (all 3 items). The three items were eliminated successively and the PCCoc/rheum was assessed iteratively according to results from the quantitative analyses in interaction with conceptual considerations. This process resulted in the elimination of all 3 items, leaving a 21-item PCCoc/rheum that can yield a raw total score between 0-63 (higher scores = greater degree of perceived person-centered care). The resulting item revisions were considered conceptually reasonable given the intention to focus on the meeting between the person with RA and the nurse.

The person – item threshold distribution was similar to that of the 24-item version (Fig. 1B), with a mean (SD) person location of 3.59 (2.05) logits; reliability was 0.86 (still implying 3-4 detectable person strata). Rasch model fit was generally good, with only one item (item 6) displaying an out of range residual value (Table 2, Revised version). This implies local dependency and inspection of the residual correlation matrix suggested that this involved items 6, 7 and 8. Following subtest analysis, reliability was minimally affected (dropping from 0.86 to 0.84) and person measures were not notably affected (intra-class correlation 0.99 between the original and subtest corrected scores). T-tests identified 12 individuals (3.8%; 95% CI, 2.1-6.6%) with significantly different locations. There was no DIF and response categories were now functioning as expected for all items. Test-retest stability (intra-class correlation) of the raw total PCCoc/rheum 21-item score remained at 0.82.

The empirical ordering of item locations from lower to higher levels of perceived person-centered care (Table 2) displayed a generally expected pattern. Conceptually, the PCCoc/rheum continuum primarily represents aspects of personalization at the lower levels, then shared decision-making and finally, at the higher person-centered care levels, empowerment. The polyserial correlation between a priori expectations and empirical item locations had now increased to 0.83.
Discussion
This study describes the empirical testing and further development of the PCCoc/rheum, a new person-centered outcome measure of patient perceived person-centered care in nurse-led outpatient rheumatology clinics. Rigorous testing of its measurement properties using RMT in close interaction with theoretical considerations provided general support for the appropriateness of the new measure. However, the analyses also identified needs for revision, which resulted in a 21-item PCCoc/rheum that maps out the underpinning theoretical person-centered care construct in an overall expected manner and exhibits promising measurement properties.

RMT analyses identified three items (numbers 1, 2, and 15) that were not in accordance with the PCCoc/rheum as a whole, thus indicating multidimensionality. Two of these items (items 1 and 2) were the sole specific representatives of the social environment domain, primarily representing physical environment. However, the social environment domain is not limited to the physical environment (Bala et al., 2017a) and the aspects represented by these items can be argued to go beyond the patient/nurse meeting, which is a core target of the PCCoc/rheum. Furthermore, review of the full item set suggests that other aspects of the social environment domain (e.g., respect, empathy, sensitivity) are embedded across other PCCoc/rheum items. It therefore not only makes quantitative but also qualitative and theoretical sense to omit these items.

Similarly, item 15 (which exhibited the most pronounced misfit) also represents something external to the patient/nurse meeting. While the involvement of family members is considered an important aspect of person-centered care (Ekman et al., 2011), it does not only involve something external to the clinical meeting but it also depends on whether the patient has a relevant family member at all and if so, whether s/he actually wants that person to participate. Furthermore, while family involvement is experienced as positive, persons with RA also value support that can decrease burden on relatives and friends (Bala et al., 2017; van Eijk-Hustings et al., 2013). Outpatient visits are usually planned on a continuous basis and family participation may not always be prioritized. Therefore, while still part of the underpinning conceptual outpatient person-centered care framework, deletion of this item appears reasonable. This does not mean that nurses should disregard whether patients want to involve family member(s), as this may be of great importance for the individual patient. However, the item does not appear productive in measuring person-centered care as represented by the PCCoc/rheum.

Importantly, the deletion of items 1, 2, and 15 did not seriously affect the measurement properties of the PCCoc/rheum. For example, the instrument largely preserved its reliability and ability to separate persons along the latent measurement continuum despite the deletion of these items. Furthermore, the conceptual clarity of the revised measure may actually be viewed as enhanced, as the revised instrument is in better accordance with the underpinning outpatient person-centered care framework and more clearly focuses on the patient/nurse meeting. Therefore, the PCCoc/rheum framework is also somewhat revised in that social environment is reconsidered in a manner similar to the communication domain. This is illustrated in Figure 3, which represents the conceptual framework underpinning the revised PCCoc/rheum.

Another three items (numbers 6, 7 and 8) displayed signs of local response dependency. However, we did not find any evidence that this potential dependency had any practical implications regarding the measurement of person-centered care. That is, the influence of the
observed dependencies on reliability as well as person measures was negligible. Furthermore, these items exhibited good conceptual fit with the underpinning framework and are also considered to represent conceptually important aspects. While acknowledging that the role of these items need to be further assessed in future studies, they were therefore retained at this stage.

Although the analyses provided support for the PCCoc/rheum as an instrument to measure PCC in outpatient rheumatology nurse-led clinics, we also identified areas in need of further attention. Particularly, there was a targeting problem in that the levels of person-centered care were perceived as higher than those operationalized by the PCCoc/rheum. From a measurement perspective, a main implication of this is that persons located at the upper end of the person-centered care continuum are measured with relatively low precision (Hobart and Cano, 2009). However, this is considered a relatively minor concern given the primary purpose of the PCCoc/rheum, i.e., to measure patient perceived levels of person-centered care as a means of quality assurance and identification of needs for improvement. This means that the differentiation of relatively well-developed levels of person-centered care is of less concern. However, there are also implications in terms of the PCCoc/rheum itself. Specifically, the fact that there were very few persons located at the lower end of its measurement range means that the conditions for evaluation of items located at these levels of the person-centered care continuum are compromised (Hobart and Cano, 2009). Additional data collections are therefore needed, including a wider range of clinics that also represents lower levels of person-centered care.

However, and importantly, our results suggest that the PCCoc/rheum successfully represents the underpinning conceptual outpatient person-centered care framework. The generally good correspondence between theoretical expectations (Bala et al., 2017a) and empirical item locations demonstrated a relatively strong correlation in the final PCCoc/rheum. The empirical item ordering displays a description of what happens when patient perceived person-centered care goes from lower to higher levels. By analogy, the item hierarchy may thus be viewed in terms of a theoretically corroborated person-centered care road map. That is, the outpatient person-centered care journey begins with the meeting between the person with RA and the nurse, where the unique person is confirmed regarding her/his experiences, preferences, values and problems (e.g., item 4: "confirmed as a person"). This then develops into a partnership aiming at collaboration to identify and manage the patient’s individual needs. Finally, higher levels of person-centered care strengthen the person and her/his capacity and preparedness (e.g., item 13: “strengthened ability to cope”). This type of information also has implications for quality improvement. For example, a clinic perceived to provide relatively low levels of person-centered care may focus on developing strategies to improve shared decision-making before being able to expect patients to experience empowerment.

Several aspects of the PCCoc/rheum appear to make it a novel type of person-centered care outcome measure. First, it is based on a specific outpatient person-centered care framework developed through theoretical reasoning involving available theoretical standpoints in combination with direct patient narratives (Bala et al., 2017a). Second, patient participation was central in all stages of its conceptualization and development. Third, its operationalization was guided by fundamental measurement principles, as articulated through RMT. Finally, empirical iterative RMT based testing of the measurement properties of the PCCoc/rheum, in interaction with conceptual considerations yielded results in support of its conceptual and metric integrity. Taken together, these features set the PCCoc/rheum apart from available instruments proposed
to target person-centered care from a patient perspective (Edvardsson et al., 2009; Suhonen et al., 2005; Coyle and Williams, 2001). In particular, the PCCoc/rheum enables measurement of aspects of nursing care that traditionally have been difficult to measure. The intention is for the PCCoc/rheum to serve as a tool for clinical as well as research purposes in monitoring person-centered outcomes as an indicator of the quality of care. Although PCCoc/rheum scores can be used at both individual and group levels, its main application may be to monitor quality of care at the levels of clinics, hospitals or organizations, e.g., through implementation into national quality registers and other audit systems. As such, it has potential to contribute towards the facilitation and development of a more person-centered clinical culture.

While the PCCoc/rheum was developed for and tested within the context of nurse-led outpatient rheumatology clinics, it is appropriate to consider the generalizability of the underpinning conceptual framework to outpatient care of persons with other long-term disorders. Given available empirical data from, e.g. neurological settings (Hellqvist and Berterö, 2015) it appears that the suggested theoretical framework for outpatient person-centered care (Bala et al., 2017a) may be applicable beyond rheumatologic care, as well as beyond nurse-led clinics. However, at this point this is to be considered hypothetical since no empirical data are available to support this notion. Therefore, in addition to the need for further testing of the PCCoc/rheum in clinics that provide lower levels of person-centered care, this is an area in need for further research.

Conclusions
The PCCoc/rheum is a patient-reported instrument developed to contribute to the evaluation of nurse-led clinics from a person-centered perspective. It exhibits good measurement properties and its items correspond to the underpinning conceptual framework of outpatient person-centered care with respect to the patient/nurse meeting, as applied in nurse-led rheumatology clinics. As such, it provides the opportunity to combine disease-related and other outcomes with more person-centered care-related outcomes.
References


**Table 1. Sample characteristics of the participants (n=316)**

<table>
<thead>
<tr>
<th>Characteristics</th>
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<tbody>
<tr>
<td>Age (years), mean (SD)</td>
<td>63.1 (12.7)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>244 (77)</td>
</tr>
<tr>
<td>Disease duration (years), mean (SD)</td>
<td>14.8 (9.9)</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
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<tr>
<td>Educational level</td>
<td>n (%)</td>
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<tr>
<td>-----------------------------------------</td>
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<tr>
<td>Cohabiting</td>
<td>234 (74)</td>
</tr>
<tr>
<td>Living alone</td>
<td>80 (25)</td>
</tr>
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</table>

| Contact with nurse-led clinic (years), mean (SD) | 9.1 (6.2) |
| Persistent RA, n (%)                          | 58 (18.3)  |
| DAS28 score, mean (SD) ^a                    | 3.3 (1.4)  |
| HAQ score, mean (SD)                         | 0.78 (0.6) |

^a Within the last six months (n=167)

RA, Rheumatoid arthritis; DAS28, Disease Activity Score 28; HAQ, Health Assessment Questionnaire.
Table 2. RMT item and fit statistics of the PCCoc/rheum<sup>a</sup>

| No. | Content (abridged) b | Location | SE | Residual | Chi-2 | P-value c | Location | SE | Residual | Chi-2 | P-value c |
|-----|----------------------|----------|----|----------|------|----------|----------|----|----------|------|----------|----------|----------|
| 4   | Confirmed as a person (SE/P) | -1.428   | 0.153 | -0.399   | 8.490 | 0.620    | -1.350   | 0.159 | 0.399    | 12.786 | 0.025    |
| 9   | Problems are taken seriously (P) | -1.065   | 0.144 | -1.167   | 2.434 | 0.416    | -0.915   | 0.150 | -0.821   | 2.163  | 0.826    |
| 7   | Experiences are respected (P) | -0.942   | 0.138 | -2.597   | 9.456 | 0.030    | -0.764   | 0.145 | -2.267   | 5.179  | 0.394    |
| 6   | Understanding my situation (P) | -0.666   | 0.135 | -3.390   | 17.726 | 0.013    | -0.501   | 0.142 | -3.149   | 8.444  | 0.133    |
| 3   | Equality in meeting (P/SDM) | -0.656   | 0.137 | 0.493    | 8.186 | 0.202    | -0.494   | 0.143 | 1.900    | 13.321 | 0.021    |
| 20  | Good nurse collaboration (SDM) | -0.623   | 0.139 | -2.146   | 14.756 | 0.051    | -0.478   | 0.144 | -1.145   | 10.641 | 0.059    |
| 16  | Care follow-up and documentation (SDM) | -0.455   | 0.128 | -0.612   | 9.973 | 0.079    | -0.284   | 0.134 | 0.060    | 4.733  | 0.449    |
| 11  | Agree with nurse on what to do (SDM/E) | -0.413   | 0.133 | -2.077   | 8.514 | 0.225    | -0.267   | 0.139 | -1.128   | 4.862  | 0.433    |
| 18  | Confident nurse contacts (P/SDM) | -0.409   | 0.133 | -0.956   | 8.813 | 0.250    | -0.266   | 0.137 | -0.621   | 4.169  | 0.525    |
| 8   | Self-knowledge is considered (P/SDM) | -0.343   | 0.129 | -1.478   | 8.409 | 0.451    | -0.137   | 0.135 | -0.496   | 1.473  | 0.916    |
| 5   | Opportunity to tell my story (P/SDM) | -0.233   | 0.130 | -2.832   | 17.853 | 0.003    | -0.063   | 0.135 | -1.372   | 7.626  | 0.178    |
| 19  | Sufficient time allocated (P) | -0.201   | 0.125 | -0.919   | 15.136 | 0.017    | -0.017   | 0.130 | -0.204   | 2.610  | 0.760    |
| 10  | Needs determine care planning (SDM) | -0.051   | 0.124 | -1.237   | 9.081 | 0.354    | 0.134    | 0.131 | -0.230   | 7.024  | 0.219    |
| 24  | Care information shared as needed (SDM) | -0.029   | 0.123 | -0.883   | 12.318 | 0.158    | 0.151    | 0.129 | -0.053   | 4.657  | 0.459    |
| 14  | Coordinated care (SDM) | 0.119    | 0.118 | -1.530   | 14.453 | 0.156    | 0.326    | 0.124 | -0.152   | 4.979  | 0.418    |
| 17  | Care responsibility is clear (SDM/E) | 0.153    | 0.122 | -0.131   | 6.223 | 0.378    | 0.337    | 0.127 | 1.282    | 9.757  | 0.082    |
| 22  | Can influence care (SDM/E) | 0.341    | 0.117 | -1.462   | 7.197 | 0.391    | 0.591    | 0.125 | -0.501   | 6.336  | 0.275    |
| 23  | Personal information documented (P/SDM) | 0.403    | 0.113 | -1.513   | 9.417 | 0.305    | 0.618    | 0.119 | -0.482   | 7.506  | 0.186    |
| 21  | Information facilitating decisions (SDM/E) | 0.766    | 0.107 | -1.834   | 17.088 | 0.049    | 1.013    | 0.113 | -0.873   | 4.324  | 0.504    |
| 12  | Gain new knowledge (E) | 0.873    | 0.109 | 0.171    | 10.393 | 0.278    | 1.146    | 0.115 | 1.984    | 8.584  | 0.127    |
| 13  | Strengthened ability to cope (E) | 0.954    | 0.108 | -2.099   | 7.333 | 0.413    | 1.221    | 0.114 | -0.559   | 2.072  | 0.839    |
| 1   | Welcoming care environment (SE) | 1.035    | 0.109 | 3.451    | 19.104 | 0.007    | 1.093    | 0.110 | 1.967    | 8.845  | 0.127    |
| 2   | Undisturbed conversations (SE) | 1.174    | 0.095 | 5.449    | 104.091 | <0.001   | 1.221    | 0.114 | -0.559   | 2.072  | 0.839    |
| 15  | Family participation (P/SDM) | 1.699    | 0.091 | 6.785    | 81.011 | <0.001   | 1.221    | 0.114 | -0.559   | 2.072  | 0.839    |
Performed with the sample divided into six class intervals according to person locations on the measured variable.

Domain representation in parenthesis (SE, Social Environment; P, Personalization; SDM, Shared Decision-Making; E, Empowerment) separated by “/” for items considered to represent more than one domain. The originally hypothesized ordering of domains from less to more patient-perceived PCC (Bala et al. 2017a) is SE – P – SDM – E, with Communication considered to be integrated across all four domains.

Values in bold indicate statistical significance at the 0.05 level following Bonferroni adjustment.

RMT, Rasch measurement theory; PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology; SE, standard error.
Figure 1. Distribution of locations of persons (upper panel) and PCCoc/rheum response category thresholds (lower panel) on the common logit metric (x-axis; positive values = higher levels of perceived PCC). All locations are relative to the mean item threshold location, which is set at 0 logits. Thresholds are the scale’s points of measurement and represent locations where there is a 50/50 probability of responding in either of two adjacent item response categories. There is thus one threshold less than the number of response categories for each item. Panel A displays the initial 24-item PCCoc/rheum, and panel B exhibits the revised 21-item PCCoc/rheum.

PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology.
Figure 2. ICCs representing PCCoc/rheum items 15 (panel A), 6 (panel B), and 17 (panel C). Grey curves (ICCs) represent expected item responses (y-axis) for each person location (x-axis) on the PCC continuum (positive values = higher levels of perceived PCC). Black dots represent the observed responses from groups of people at similar locations on the measured continuum (x-axis). Item 15 (panel A) displays a large positive residual and the graphical pattern suggests that this item does not represent the same construct as the PCCoc as a whole. Item 6 (panel B) has a large negative residual, although observed responses exhibit relatively minor deviations from the expected ICC. By comparison, item 17 (panel C) represents an item with good fit to the model.

ICC, Item Characteristic Curves; PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology; PCC, Person-Centered Care.
Figure 3. Graphical illustration of the conceptual framework of outpatient person-centered care in nurse-led rheumatology clinics, focusing on the person/nurse meeting, that underpins the Person-Centered Care instrument for outpatient care in rheumatology (PCCoc/rheum).