Person-centred care in nurse-led outpatient rheumatology clinics: Conceptualization and initial development of a measurement instrument

Sidona-Valentina Bala¹,², Kristina Forslind²,³, Bengt Fridlund⁴, Karin Samuelson¹, Björn Svensson³, Peter Hagell⁵

¹ Department of Health Sciences, Lund University, Lund, Sweden
² Section of Rheumatology, Department of Medicine, Helsingborg Central Hospital, Sweden
³ Department of Clinical Science, Section of Rheumatology, Lund University, Helsingborg, Sweden
⁴ School of Health and Welfare, Jönköping University, Jönköping, Sweden
⁵ The PRO-CARE Group, School of Health & Society, Kristianstad University, Kristianstad, Sweden

As accepted for publication in Musculoskeletal Care on December 15, 2017.

Reference to final publication:
(doi: 10.1002/msc.1233)

Corresponding author:
Sidona-Valentina Bala
Section of Rheumatology
Department of Medicine
Helsingborg Central Hospital
SE-251 87 Helsingborg
Sweden
E-mail: sidona-valentina.bala@skane.se
ABSTRACT

Background: Person-centered care (PCC) is considered a key component of effective illness management and high quality care. However, the PCC concept is underdeveloped in outpatient care. In rheumatology, PCC is considered an unmet need and its further development and evaluation is of high priority.

Objective: To conceptualize and operationalize PCC in order to develop an instrument for measuring patient perceived PCC in nurse-led outpatient rheumatology clinics.

Methods: A conceptual outpatient PCC framework was developed based on experiences of persons with rheumatoid arthritis (RA), person-centeredness principles and existing PCC frameworks. The resulting framework was operationalized into the PCC instrument for outpatient care in rheumatology (PCCoc/rheum), which was tested regarding acceptability and content validity among 50 persons with RA attending a nurse-led outpatient clinic.

Results: The conceptual framework focuses on the meeting between the person with RA and the nurse, and comprises five interrelated domains: social environment, personalization, shared decision-making, empowerment, and communication. Operationalization of the domains into a pool of items generated a preliminary PCCoc/rheum version which was completed in a mean (SD) of 5.3 (2.5) minutes. Respondents found items easy to understand (77%) and relevant (93%). The Content Validity Index of the PCCoc/rheum was 0.94 (item level range, 0.87-1.0). About 80% of respondents considered some items redundant. Based on these results, the PCCoc/rheum was revised into a 24-item questionnaire.

Conclusions: A conceptual outpatient PCC framework and a 24-item questionnaire intended to measure PCC in nurse-led outpatient rheumatology clinics were developed. The extent to which the questionnaire represents a measurement instrument remains to be tested.

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

Introduction

In the healthcare system there has been a major focus on person-centered care during the last decades. Person-centered care is emphasized as a key component of effective illness management (Kogan et al., 2016; WHO, 2015; Cloninger, 2013), high quality care and improved outcomes (Harding et al., 2015; Olsson et al., 2013; Coulter and Collins, 2011; Mead and Bower, 2000). The point of departure for person-centered care is the person behind the patient and her/his individual perspectives, needs, values, expectations, abilities and capacities (WHO, 2015; Ekman et al., 2011). Person-centered care implies that healthcare professionals use the perspectives and attributes of person-centeredness for developing and maintaining relationships as well as for care planning and delivery (Slater, 2006). Person-centered care represents a shift away from production of care to co-production of care, from the traditional biomedical model where the patient is a passive target of medical interventions to a more human and value-based model, which involves the patient as an active part in her/his care and in the decision-making process (McCormack et al., 2015; Miles, 2012; Ekman et al., 2011; Leplege et al., 2007). The International College of Person-Centred Medicine has described person-centered care as “a medicine of the person, for the person, by the person and with the person” (Casell, 2010). In contrast to patient-centered care, which is more disease-focused, person-centered care is based on accumulated knowledge of the person for better recognition of health problems and needs over time (Starfield, 2011); “the disease is part of the person and not the person part of the disease” (Miles, 2012).
There has been considerable progress in person-centered care in areas such as care of the elderly, palliative care and primary care (Kogan et al., 2016; Harding et al., 2015). In contrast, there is currently a tremendous gap and a need for means to assess person-centered care practice in outpatient care (Kogan et al., 2016) including outpatient rheumatology care, where person-centered care and co-management of chronic rheumatic diseases have been identified as unmet needs (Winthrop et al., 2016). Despite advances in rheumatology treatment and care, more than a third of persons with rheumatoid arthritis (RA) still have an active persistent disease (Cook et al., 2016; Svensson et al., 2016). Moreover, according to a recent qualitative study, persons living with persistent RA felt that current rheumatology care did not meet their individual needs sufficiently in terms of security, access to and coordination of care as well as team and rehabilitation services (Bala et al., 2017). Consequently, there is a need for a more collaborative person-centered care model in which patients to a larger degree can decide what services they need and how these services should be delivered (Kjeken et al., 2006).

Nurse-led care (NLC) has an increasingly prominent role in the healthcare system for persons with chronic disorders and is considered essential for the development of a more person-centered care (Nolte and McKee, 2008). Arguably, NLC is in an excellent position to promote and deliver person-centered care for people with chronic conditions, such as RA (Larsson et al., 2014; Bala et al., 2012). Although the contribution of nurse-led clinics to improve patient outcomes in rheumatology has been recognized (Garner at al., 2017; van Eijk-Hustings et al., 2012; Ndosi et al., 2011), its connection to person-centered care is less well understood. The availability of an instrument to measure the degree of person-centered care from the patient’s perspective could circumvent this situation and enable monitoring of person-centered outcomes. However, the development of such an instrument requires identification of what aspects of care that really matter to persons with, e.g., RA as well as conceptualization of person-centered care within an outpatient context and in relation to person-centeredness and existing person-centered care frameworks, and to operationalize the resulting framework into a measurement instrument.

**Aspects of outpatient nurse-led care experienced as essential by persons with RA**

NLC in outpatient rheumatology clinics has been defined as a practice in which nurses provide independent patient care and perform nursing interventions such as monitoring of disease course and treatment, support, education, counseling, coordination of care, and collaborate with physicians and other healthcare professionals (Garner et al., 2017; Ndosi et al., 2011). Thus, NLC in outpatient rheumatology clinics allows nurses to undertake extended roles and a holistic person-centered approach to the delivery of care (Garner et al., 2017; Bala et al., 2012; Larsson et al., 2012; van Eijk-Hustings et al., 2012; Ryan et al., 2006; Arvidsson et al., 2006). The holistic person-centered care approach has been identified as a success factor for this model (Garner et al., 2017) by taking into account the individuals’ needs, their unique experiences, perspectives, values and expectations (van Eijk-Hustings et al., 2013; Bala et al., 2012; Ndosi et al., 2011; Ryan et al., 2006).

Patients with RA experience the professional approach of the nurse (i.e., empathy, knowledge, skill and support), the added value of nursing care (i.e., security, accessibility and continuity), as well as the social environment of nurse-led clinics (i.e., warm encounter, familiar atmosphere and pleasant premises) as particularly relevant for person-centered NLC (Bala et al., 2012). This is in accordance with other studies that emphasize the importance of nurses’
competence, skills and professionalism to meet patients’ needs of security, accessibility, continuity, trust, hope, confidence, familiarity and participation (Larsson et al., 2012; Primdahl et al., 2010; Ryan et al., 2006; Arvidsson et al., 2006; Hill, 1986). The nurses’ skills to personalize the care, to identify abilities and to involve the patients in deciding about their health is experienced as pivotal for the quality of the received care (Bala et al., 2017; Bala et al., 2012; Larsson et al., 2012). By using the persons’ illness narratives as a starting point for dialogue and partnership, nurses can involve patients to take an active role in their treatment and care planning, to find solutions and to solve their problems (Bala et al., 2017; Larsson et al., 2014; Arvidsson et al., 2006). Persons with RA expect to be listened to and understood, to get attention and sufficient time for contacts, to receive appropriate, tailored and timely information, advice and supportive communication, and to share their health problems with healthcare professionals in addition to the support received from relatives and friends (Bala et al., 2017; van Eijk-Hustings et al., 2013; Ryan et al., 2013; Bala et al., 2012; Primdahl et al., 2010). Furthermore, a well-organized and coordinated care with good collaboration and communication between nurses and other healthcare professionals is also expected (Bala et al., 2017; van Eijk-Hustings et al., 2013; Bala et al., 2012). A key factor for a good partnership between the patient and the nurse is considered to be a relationship based on empathy, mutual respect, and dignity, where the nurse confirms the person and establishes equality in the meeting (van Eijk-Hustings et al., 2013; Bala et al., 2012; Arthur and Clifford, 2004). Communication, verbal as well as non-verbal appears to be one of the most important aspects of care with major implications for the whole care process and how this is experienced (Bala et al., 2017, 2012; Ryan et al., 2013).

**Person-centered care and person-centeredness from theoretical standpoints**

The World Health Organization has promoted person-centered care by establishing a set of core principles including attributes such as tailored, holistic, collaborative, ethical, empowering, and co-produced (WHO, 2015). The Health Foundation suggested four key principles underpinning person-centered care, stating that the person should be (i) treated with dignity, compassion and respect, and offered a (ii) personalized, (iii) coordinated and (iv) enabling care (Collins, 2014). Similarly, person-centeredness is advocated as an approach to practice which encompasses principles of respect for persons, for their human rights, values and beliefs, and development of therapeutic relationships based on mutual respect and understanding (McCormack et al., 2008). Thus, these similarities reinforce an obvious inherent synergy between person-centered care and person-centeredness. In both, “the person” is central and person-centeredness is a significant focus for person-centered care as it confirms the importance of human and ethical rights of the persons and the importance of relationships and holistic care in maintaining wellbeing (Slater, 2006).

To enable nurses to explore person-centered care systematically and ensure person-centeredness in their practice, McCormack and McCance (2006) developed the person-centered nursing framework, consisting of four components: prerequisites (the attributes of the nurse); the care environment (the context in which care is delivered); person-centered processes (the range of activities used for delivering care); and expected outcomes (the results of person-centered nursing). This framework has been proposed as a tool that enables identifying key dimensions in nursing practice as well as an operationalization of person-centered care (McCance et al., 2011). Furthermore, to facilitate transition to person-centered care and its implementation Ekman et al., (2011) developed the Gothenburg person-centered care model that establishes three routines for co-creation of care: (i) initiating the partnership:
patient narratives; (ii) working the partnership: shared decision-making; (iii) safeguarding the partnership: documenting the narrative.

**Measurement of person-centered care outcomes**
Phenomena that cannot be directly observed (e.g., person-centered care) are considered latent variables and their measurement relies on observable expressions and manifestations that operationalize variations in the latent variable (Hagell, 2014). Person-centered care measurement can therefore be seen as a critical test related to the complexity of the concept, particularly in view of the lack of an agreed definition (Kogan et al., 2016).

Available person-centered care instruments are generally restricted to inpatient and long-term residential contexts and staff perceived person-centered care (de Silva, 2014). However, instruments for evaluating person-centered care from the patients’ perspective have also been proposed. For example, concerning hospital patients, Edvardsson et al. (2009) proposed the Person-Centered Climate Questionnaire–Patient version (PCQ-P); Suhonen et al. (2005) proposed the Individualized Care Scale (ICS); Coyle and Williams (2001) proposed the Patient-Centred Inpatient Scale (P-CIS). Operationalizing person-centered care by starting from its components has been a common approach in existing instruments, and communication, shared decision-making, co-production and self-management are some of the most commonly operationalized person-centered care aspects (Harding et al., 2015).

To measure and evaluate person-centered care is essential for further development of person-centered practice in outpatient care. Development of an instrument to measure the degree of perceived person-centered care from the patients’ perspective in outpatient rheumatology care would not only be useful in monitoring quality of care but, importantly, also for identification of areas in need of improvement. Arguably, the latter can be considered the most important goal from a quality assurance perspective. It is therefore a high priority to devise a measurement instrument for outpatient person-centered care as a means to better understand the benefits of this approach for persons with RA and for further development of outpatient rheumatology NLC. The aim of this study was to conceptualize and operationalize person-centered care in order to develop an instrument for measuring patient perceived person-centered care in nurse-led outpatient rheumatology clinics.

**Methods**
The study was conducted through theoretical reasoning and performed in two stages: 1) conceptual framework and initial instrument development; 2) evaluation of items and response categories.

**Stage 1: Conceptual framework and initial instrument development**
The process of this stage took into account the perspective of patients with different levels of disease burden (from patients in remission to patients with severe, persistent RA). This was done based on a secondary analysis of available interview data (Bala et al., 2017; Bala et al., 2012) and a review of experiences described in other rheumatology nursing research (Larsson et al., 2014, 2012; van Eijk-Hustings et al., 2013, 2012; Ryan et al., 2013, 2006; Primdahl et al., 2010; Arvidsson et al., 2006; Arthur and Clifford, 2003; Hill, 1986), and was substantiated by the principles of person-centered care (WHO, 2015) and person-centeredness (McCormack et al., 2008), the person-centered nursing framework (McCormack
The co-creation of care according to the Gothenburg person-centered care model (Ekman et al., 2011), and existing person-centered care instruments from other contexts (Edvardsson et al., 2009; Suhonen et al., 2005; Coyle and Williams 2001).

The conceptual work was undertaken to develop a person-centered care framework for the outpatient context focusing on the meeting between the person with RA and the nurse, and on the patient as an active partner in the care process. The development of the framework was conducted through a process of deductive logical reasoning aiming at identifying aspects (domains) of person-centered care and to generate a pool of items to operationalize the framework into a measurement instrument. According to Wolfe and Smith (2007) it is recommended to create a fairly large list of items to sample from. In doing so, a “bottom-up approach” (Enos, 2008; Wolfe and Smith, 2007; Wilson, 2005) was used to describe the latent person-centered care variable, its variations and expressions from low to high levels of outpatient person-centered care, and to develop items that operationalize these variations. Based on conceptual considerations, it was decided that items were to be expressed as statements, to which respondents should indicate their level of agreement based on their experiences from interactions with their outpatient NLC. Two persons with RA, two rheumatology nurses and two rheumatologists reviewed the item pool regarding wording. Items were then conceptually mapped along a theoretical continuum from lower to higher levels of person-centered care. That is, a lower-level item represents something that does not require a very large degree of person-centered care to be achieved, whereas a higher-level item represents something that requires a relatively well-developed level of person-centered care. Two response formats were developed: one using four response categories and one using two response categories. The resulting preliminary person-centered care instrument for outpatient care in rheumatology (PCCoc/rheum) was then subjected to further testing.

Stage 2: Evaluation of items and response categories

Participants, recruitment and data collection
Fifty persons with RA (Table 1) attending a nurse-led RA clinic were asked to complete the preliminary PCCoc/rheum instrument along with demographic questions. Participants were recruited consecutively by four nurses in connection with visits at the clinic. Participants were then interviewed by the first author (SVB), who was not involved in their care.

Procedures and analyses
All participants answered the PCCoc/rheum independently, with the interviewer being present in the first 30 cases to note any obvious difficulties and to record the time taken to complete the questionnaire. The first 20 participants answered both PCCoc/rheum versions in random order; those who started with four response categories were then asked to complete the version with two response categories, and vice versa. After that, participants were asked to comment on the instructions, items and response categories and to consider the acceptability, clarity, comprehensiveness, and relevance of item contents according to a structured interview guide. Based on the results from these 20 interviews the questionnaire was reviewed for potential revision. The PCCoc/rheum was then completed by the remaining 30 participants. Ten of them performed the same evaluation of items and response categories as described above, as well as an evaluation of content validity (see below). The last 20 participants only responded to the version with four response categories and evaluated content validity (Figure 1).
Content validity was estimated by calculating the Content Validity Index which is an approach to assessing content validity of individual items (I-CVI) and of the overall scale (S-CVI) (Polit and Beck, 2006; Lynn, 1986). Respondents were asked to indicate if they considered the content of each item as “not”, “somewhat”, “quite”, or “highly” relevant with respect to how one’s care may be experienced. I-CVI is expressed as the proportion of respondents considering each item as “quite” or “highly” relevant, and S-CVI is calculated as the average I-CVI across items (Polit and Beck, 2006). I-CVI values of 0.78 or higher and a minimum S-CVI value of 0.90 were considered acceptable (Polit and Beck, 2006). Interview and demographic data were analyzed descriptively. All statistical analyses were performed using IBM SPSS version 22.

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

**Results**

**Stage 1: Conceptual framework and initial instrument development**

**Conceptual domain representation and theoretical underpinnings**

Following the deductive theoretical reasoning approach, the current state of knowledge regarding experienced person-centered care in outpatient rheumatology clinics confirmed the need for a tailored meeting and care enabled by an active partnership between the two key players, the person with RA and the nurse. This was recognized and underpinned by existing theoretical frameworks and principles of person-centered care and person-centeredness. Taken together, these considerations resulted in a preliminary person-centered care framework for outpatient rheumatology nurse-led clinics comprising five main aspects (domains): social environment, personalization, shared decision-making, empowerment, and communication, further described below.

**Social environment** represents the way persons with RA are confirmed, received, approached and communicated to, as well as the conditions for good relationships and for establishing a warm, calm and friendly atmosphere. Furthermore, it refers to the physical environment of the clinic in terms of ensuring integrity and pleasant premises (Bala et al., 2012; Larsson et al., 2012). A welcoming and familiar care environment with opportunities for undisturbed conversations during the meeting is perceived as engaging, safe and strengthening.

**Personalization** represents the identification and recognition of the unique person’s needs and concerns, preferences and values as well as abilities and capabilities. In this respect, the person is the most important source of information (Coulter et al., 2015). Personalization is therefore dependent on the communication between the person with RA and the nurse, which enables the beginning of a partnership and creates conditions for planning of person tailored care. Personalization is facilitated when persons with RA feel confirmed, get opportunities to tell their stories, when their problems are taken seriously, when their experiences are respected, their self-knowledge is used, and their personal information is documented.

**Shared decision-making** represents a collaborative, interpersonal and interdependent process in which healthcare professionals communicate with patients about potential care options and support them in their decision-making (Légaré and Witteman, 2013). This requires interaction and engagement, mutual respect and trust, as well as an effective exchange of knowledge and expertise (Coulter et al., 2015). In the context of the meeting, shared decision-making refers to good collaboration between the person with RA and the nurse, understanding of the person’s situation, agreement over care needs and planning, coordination of care and follow-
up, shared care information with other healthcare professionals, family participation, and clarity over the person’s responsibilities and opportunities to influence her/his care. **Empowerment** represents the enabling of persons’ resources and abilities, by actively engaging them to participate in their care and support them to take actions and control of their needs and life situation. Empowerment is a mutual process of interaction and learning in which nurses contribute with information, encouragement and support, and the person accepts shared or transferred power, autonomy and responsibility (McCarthy and Freeman, 2008). In the meeting context, empowerment refers to involving the person with RA to take an active role and influence their care planning and treatment as well as support them to find own solutions to their problems. In addition, they need to be provided with opportunities to develop new knowledge and skills, and to strengthen their self-confidence and ability to cope. **Communication** represents the exchange of information, the management of emotions and feelings, and creating a relationship between the person and the nurse (Bala et al., 2012; Street et al., 2009). It is through listening, encouraging and involving persons with RA in dialogue that the person’s narrative emerges and a common understanding is achieved. Communication is considered a prerequisite for the processes of personalization, shared decision-making, care planning and empowerment, and has received considerable attention in the person-centered care context (Ekman et al., 2011; Street et al., 2009). Therefore, communication is embedded across all aspects of outpatient person-centered care.

In summary, the outpatient person-centered care framework focusing on the meeting can be conceptualized as holistic nursing in a partnership between the person with RA and the nurse comprising social environment, personalization, shared decision-making, empowerment, and communication.

**Item generation**

The domains of the conceptual outpatient person-centered care framework were operationalized into a pool of 36 items (five to nine items per domain). The items were thought to have the potential to be person-centered so they were formulated from the perspective of the person and in the light of the principles and values of person-centered care and person-centeredness (i.e. respectful, tailored, holistic, collaborative, ethical, empowering, and co-produced). Individual review of the item pool by six experts (2 persons with RA, 2 rheumatology nurses and 2 rheumatologists) resulted in suggestions to simplify and ensure that item wording was consistent with the patients’ perspective, and to emphasize (in the instructions) that items relate to outpatient nursing care. Conceptual mapping of items along the theoretical continuum from lower to higher levels of **person-centered care** revealed that items related to social environment and personalization represented a low to medium level of **person-centered care**, shared decision-making items represented a medium to high level and items related to empowerment represented a high level of **person-centered care**. Communication was considered an integrated aspect of most items and therefore cuts across all levels. In this process four of the 36 items were discarded due to conceptual ambiguity, and the remaining 32 items were selected for further testing.

**Stage 2: Evaluation of items and response categories**

Participants completed the preliminary 32-item PCCoc/rheum version with four response categories in a mean (SD) of 5.3 (2.5) minutes and the two-category version in 4.3 (2.2)
minutes. Items were found easy to understand (77%) and relevant (93%), and the instructions were considered simple and clear (93%). The response categories were considered easy to use by 87% and 93% of participants for the two- and four-category versions, respectively, and both response formats were found easy to distinguish (97% for both). However, most participants (73%) preferred the four-category version.

A majority (77%) found some items to be redundant, and 20% of respondents missed items regarding facilitation of accessibility to care and care-related information and documentation. Following the addition of three items in accordance with participants’ suggestions, no further suggestions were made among the remaining 30 participants. I-CVI values ranged from 0.87 to 1.00, and the S-CVI was 0.94.

Based on the results described above and conceptual considerations, the preliminary PCCoc/rheum was revised by item reduction. The participants were clear about which items they recommended for deletion or felt doubtful about. As expected, redundancy was the main reason for item deletion. Other reasons were that some item wordings were considered ambiguous, too broad, or out of context. This resulted in a 24-item PCCoc/rheum with four response categories that yield a raw total score between 0-72 (higher scores = greater degree of perceived person-centered care). The 24-item PCCoc/rheum is presented in Table 2 together with its related domains.

**Discussion**

In recent decades, RA care has undergone positive changes related to significant drug development and new treatment strategies (Smolen et al., 2016; Winthrop et al., 2016). However, there are also challenges related to increased accessibility requirements (Combe et al., 2016; Smolen et al., 2016, 2014), lack of rheumatologists (Primdahl et al., 2014; Bala et al., 2012; Qian et al., 2010), and a shift from inpatient to outpatient care with an increased workload in outpatient care (Klareskog et al., 2000). Therefore, new care models have been required. NLC is one such model that is considered effective, acceptable, and safe (Garner et al., 2017). However, it is also in need of development and quality assurance to ensure high quality of care (Garner et al., 2017). An instrument that provides the means to monitor care from the patients’ perspective is therefore a high priority to better understand the benefits of and further develop outpatient rheumatology NLC. Accordingly this is the first study filling the gap by conceptualizing and operationalizing outpatient person-centered care in order to develop an instrument for measuring patient perceived person-centered care in nurse-led outpatient rheumatology clinics.

Person-centeredness and person-centered care are considered “a global movement” (McCormack et al., 2015) towards models of care that adopts the perspective of individuals and prioritize co-production of health by organizing care around persons’ needs and expectations rather than diseases (WHO, 2015). But the challenges to define the concept have represented barriers for measurement and implementation of person-centered care into routine clinical practice, particularly in outpatient care (Kogan et al., 2016; Harding et al., 2015; de Silva, 2014).

The proposed PCCoc/rheum and its underpinning framework emerged from the patients’ perspective through their experiences. This approach is considered pivotal in determining the required content and organization of care, and also in decisions about quality of care (Miles,
Furthermore, we chose to focus the PCCoc/rheum framework on the context of the care meeting because persons with RA attach major importance to the meeting with the nurse. The meeting is also a natural part of the necessary care environment for initiation, planning, delivery and follow-up of person-centered care. Therefore, the PCCoc/rheum does not aspire to cover the full person-centered care spectrum, but focuses on the meeting in view of the persons’ life situation as a whole. This is in line with the collaborative nature of person-centered care and with the view of the person as the most important source of information in the care process (Coulter et al., 2015).

The PCCoc/rheum operationalizes five interrelated and intermingled person-centered care domains (social environment, personalization, shared decision-making, empowerment, and communication) represented by items that are both specific and overlapping across domains. This is an advantage since person-centered care is considered a continuum where some domains predominantly represent higher levels of person-centered care, while others predominantly represent lower levels. The domains are aligned with holistic nursing by considering all four constructs of the person-centered nursing framework (McCormack and McCance, 2006), and with partnership and co-creation of care by considering the Gothenburg person-centered care model (Ekman et al., 2011).

The domains of the framework were further operationalized by developing items for an instrument intended to represent the framework and to be used for measuring outpatient person-centered care from a patient perspective. Conceptual mapping of items from lower to higher levels of person-centered care revealed a structure among the domains of the outpatient person-centered care framework; they are interrelated and their ordering is hypothesized to represent a clinically relevant and logical continuum of outpatient person-centered care. Furthermore, the generated items were found to have good content validity and were perceived as relevant and easy to use by persons with RA. Moving beyond the suggested outpatient person-centered care framework, the items can be linked to the principles of person-centered care (WHO 2015) and person-centeredness (McCormack et al., 2008). Taken together, this suggests that the items align with the intentions of the underpinning theoretical framework.

However, in addition to the importance of conceptualization for developing the PCCoc/rheum measurement instrument, the conceptual outpatient person-centered framework has additional implications for clinical practice which has to be considered from a patient, healthcare organization as well as a societal perspective.

Patients with chronic diseases need care that meets their needs and expectations throughout their life with the disease. The framework contributes to clarifying and explaining what outpatient person-centered care means. This has great value for forming and rethinking the patients’ role in nurse-led clinics and adapting the services accordingly. It has for example been shown that nurse specialists using interactional styles as partnership-building and socio-emotional, supportive communication improved patients’ participation in their care (Vinall-Collier et al., 2016).

Likewise, the conceptual framework argues for and supports a more active involvement of patients with RA in clinical practice, as well as in the design, planning, implementation and evaluation of healthcare services. It also highlights an empowering, shared-decision making and integrating care climate based on healthful relationships between patients, nurses and other healthcare professionals, as well as between different healthcare providers. Such
integrated collaborations have been challenging so far in outpatient care due to an increased fragmentation of care delivery that is often based on organizational divisions instead of the patients’ needs. Vinall-Collier et al. (2016) also described that clinic structure often is outside the practitioner’s control and can undermine care continuity. Accordingly, reorientation of care towards more outpatient care during the last few decades necessitates a more holistic management approach to overcome such fragmentation. The outpatient person-centered framework promotes a holistic approach to care, and the PCCoc/rheum may contribute to identify and monitor existing critical integration and coordination issues. However, attention must be focused on adopting and enabling a person-centered culture which is a key prerequisite for organizations to promote person-centeredness.

The conceptual outpatient person-centered framework may also influence education and policy development by conveying a more engaging, humanistic and ethical view that promotes more active and healthy living, with reduced dependency on specialist care.

Conclusion

A conceptual framework of person-centered care focusing on the care meeting in the context of outpatient setting and rheumatology nurse-led clinics has been proposed. The framework generated a preliminary person-centered care model comprising five interrelated main domains (social environment, personalization, shared decision-making, empowerment, and communication) that were further operationalized into a proposed instrument for measuring person-centered care, the PCCoc/rheum. The proposed PCCoc/rheum was found to have good content validity and was considered as relevant and easy to use by persons with RA. This can be taken as initial support for the underpinning PCCoc/rheum conceptualization and operationalization. Although the framework is likely to be challenged and subject to further development, it appears to be the first of its kind. As such, the resulting clarity over the concept of outpatient person-centered care has potential to contribute to progress in person-centered care practice, evaluation, measurement and education. However, the extent to which the PCCoc/rheum represents the hypothesized person-centered care continuum and whether it may be useful as an instrument for measurement remains to be tested.
References


<table>
<thead>
<tr>
<th>Characteristics</th>
<th>PCCoc/rheum evaluation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Initial version (32 items)</td>
<td>Second version (35 items)</td>
</tr>
<tr>
<td>N</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>64.2 (13.3)</td>
<td>55.4 (16.7)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>12 (60)</td>
<td>24 (80)</td>
</tr>
<tr>
<td>Disease duration (years), mean (SD)</td>
<td>15.5 (10.3)</td>
<td>9.9 (8.4)</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohabiting</td>
<td>11 (55)</td>
<td>19 (63)</td>
</tr>
<tr>
<td>Living alone</td>
<td>9 (45)</td>
<td>11 (37)</td>
</tr>
<tr>
<td>Educational level, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehensive school</td>
<td>4 (20)</td>
<td>12 (40)</td>
</tr>
<tr>
<td>Upper secondary school</td>
<td>11 (55)</td>
<td>11 (37)</td>
</tr>
<tr>
<td>University</td>
<td>5 (25)</td>
<td>7 (23)</td>
</tr>
<tr>
<td>Contact with nurse-led clinic (years), mean (SD)</td>
<td>6.4 (4.9)</td>
<td>6.3 (4.5)</td>
</tr>
</tbody>
</table>

PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology
RA, rheumatoid arthritis
Table 2. Conceptual domain representation and associated PCCoc/rheum items

<table>
<thead>
<tr>
<th>Domains a</th>
<th>PCCoc/rheum items (abridged) b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Environment</td>
<td>Welcoming care environment</td>
</tr>
<tr>
<td></td>
<td>Undisturbed conversations</td>
</tr>
<tr>
<td></td>
<td>Confirmed as a person</td>
</tr>
<tr>
<td>C</td>
<td>Understanding my situation</td>
</tr>
<tr>
<td>O</td>
<td>Problems are taken seriously</td>
</tr>
<tr>
<td>M</td>
<td>Sufficient time allocated</td>
</tr>
<tr>
<td></td>
<td>Equality in meeting</td>
</tr>
<tr>
<td></td>
<td>Self-knowledge is considered</td>
</tr>
<tr>
<td></td>
<td>Confident nurse contacts</td>
</tr>
<tr>
<td>N</td>
<td>Opportunity to tell my story</td>
</tr>
<tr>
<td>I</td>
<td>Personal information documented</td>
</tr>
<tr>
<td></td>
<td>Family participation</td>
</tr>
<tr>
<td></td>
<td>Good nurse collaboration</td>
</tr>
<tr>
<td></td>
<td>Care follow-up and documentation</td>
</tr>
<tr>
<td>A</td>
<td>Needs determine care planning</td>
</tr>
<tr>
<td></td>
<td>Care information shared as needed</td>
</tr>
<tr>
<td></td>
<td>Coordinated care</td>
</tr>
<tr>
<td></td>
<td>Agree with nurse on what to do</td>
</tr>
<tr>
<td></td>
<td>Care responsibility is clear</td>
</tr>
<tr>
<td></td>
<td>Information facilitating decisions</td>
</tr>
<tr>
<td></td>
<td>Can influence care</td>
</tr>
<tr>
<td>N</td>
<td>Gain new knowledge</td>
</tr>
<tr>
<td></td>
<td>Strengthened ability to cope</td>
</tr>
</tbody>
</table>

a The communication domain is considered to be represented across all other domains.
b Items are conceptually but not individually ordered; grey areas represent items considered to overlap conceptually across adjacent domains.
PCCoc/rheum, the Person-Centered Care instrument for outpatient care in rheumatology
Figure 1. Procedure map: evaluation of the preliminary Person-Centered Care instrument for outpatient care in rheumatology (PCCoc/rheum)