The patient perspective of nurse-led care in early rheumatoid arthritis: a systematic review of qualitative studies with thematic analysis

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Nurse-led care in early rheumatoid arthritis

Abstract

Introduction: Management of rheumatoid arthritis has changed dramatically over the last decade and is characterised by early start of intensive treatment and tight monitoring of disease activity until remission. The role of nurse-led care at early stage of disease is not well understood.

Aims: To develop an understanding of rheumatology nurse-led care from the perspective of patients with early rheumatoid arthritis.

Methods: A systematic review of qualitative studies, reported in line with PRISMA checklist.

In March 2019, the following databases were searched: MEDLINE, EMBASE, CINAHL, PsycINFO and OpenGrey.

Studies were included if they: included adults with rheumatoid arthritis; were qualitative studies with data on patients' perspectives of nurse-led care; published in peer-reviewed journals, in English, between 2010 and 2019. Due to few studies in early rheumatoid arthritis, inclusion was extended to adults with established rheumatoid arthritis. Two reviewers screened abstracts and full texts. Joanna Briggs Institute Critical Appraisal Tool was used for quality assessment. Thematic synthesis was conducted according to the framework of Thomas and Harden (2008).

Results: The search identified 1034 records. After screening and assessing for eligibility, eight qualitative studies were included in the review (133 patients). Three themes were identified from the synthesis. Nurse-led care was seen to provide professional expertise in planning and delivery of care. A person-centred approach was used combined with good communication skills thus creating a positive therapeutic environment. Nurse-led care was described as providing a sense of empowerment and psychological support.

Conclusion: Patients with rheumatoid arthritis are supportive of nurse-led care. They value its professionalism and person-centred approach which provide a sense of security and confidence.

Relevance to Clinical Practice: The findings outline ingredients of nurse-led care that are important to patients. These can inform nurses' professional development plans, service improvement and the competence framework for rheumatology nursing.

Protocol registration: PROSPERO CRD42019130572.

Keywords: Rheumatology, Systematic Review, Adult Nursing, Musculoskeletal, Nurse-Patient Relationship, Patients' Experience, Qualitative Study.

Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease which causes pain, swollen joints and risk of bone erosion (Aletaha & Smolen, 2018). The disease has a major impact on quality of life (Aletaha & Smolen, 2018) and people often need lifelong medical treatment and care. Guidelines for RA management changed dramatically ten years ago. This started with the 'treat-to-target' recommendations by the European League Against Rheumatism (EULAR) (Smolen et al., 2010) followed by the American College of Rheumatology recommendations (Singh et al., 2012). The recommendations were updated in 2015 (Singh et al., 2016), in 2016 (Bernard Combe et al., 2017; Smolen et al., 2017) and in 2019 (Smolen et al., 2020). They recommend early detection of RA, 'very early' start of intensive treatment with combination of disease modifying anti-rheumatic drugs (DMARDs) and tight monitoring of disease activity until the state remission or low disease activity is achieved. This 'treat-to-target' approach, the target being remission has been shown to have better clinical outcomes and better quality of life, and helps prevent further structural damage, functional disability and job loss (B. Combe et al., 2015; Smolen et al., 2017 Bernard Combe et al., 2017; Smolen et al., 2010, 2020).

For this review, patients were defined as being early RA if they were in their first two years of disease duration (Burgers et al., 2019; Luqmani et al., 2006). These patients with early RA are monitored at rheumatology nurse-led clinics which run alongside rheumatologists' clinics (BSR & NRAS, 2019). The nurse-led clinics started over three decades ago (Bird, 1983) and have been established as normal care in the UK (BSR & NRAS, 2019). Their clinical effectiveness has been established in randomised controlled trials (Bech et al., 2019; de Thurah et al., 2017; Garner et al., 2017; Ndosi et al., 2011; Sousa et al., 2017), and has been shown to be cost-effective (Larsson et al., 2015; Ndosi et al., 2014; Sørensen et al., 2015). However, much of the evidence supporting the effectiveness of nurse-led care is based on patients with long standing or established RA (Bech et al., 2019).

The early stages of RA can be challenging for the patients, as they might be in severe pain, struggle to work and maintain responsibilities as family members and members of their community as they worry for their future life (Ødegård et al., 2007; Rupp et al., 2004; West & Jonsson, 2005). The implementation of treat-to-target regimes in early RA requires close monitoring and support (NICE, 2018; Smolen et al., 2020). Patients' care needs include support in treatment in order to control disease activity and its impact as well as social, emotional and psychological support (NICE, 2018). However, there is limited evidence on how rheumatology nurse-led care meets these needs which are critical in early RA.

Current UK treatment guidelines (NICE, 2018) recommend that patients with RA should have access to a clinical nurse specialist for RA management and support. However, the way nurse-led clinics work in the UK varies from centre to centre (BSR & NRAS, 2019). Also, nurse-led care models vary across countries based on different healthcare systems, legal frameworks and training (Bech et al., 2019). The most recent European recommendations for the role of the nurse in inflammatory arthritis updated the evidence for nurse-led care and innovative ways of working such as tele-health, but they stopped short of defining the role of the nurse in early RA (Bech et al., 2019). Consequently, the role of the nurse in early RA and the related processes of care in nurse-led clinics are not well defined. This is important particularly in this new era of early diagnosis and 'very early' start of treatment with intensive therapy.

Aims

The aim of this review was to develop an understanding of rheumatology nurse-led care from the perspective of patients with early RA. The research question for this review was: What experiences and expectations do patients with early RA have of rheumatology nurse-led care?

Methods

Design

This paper reports a systematic review of qualitative literature, with a thematic synthesis. This design was selected to ensure that rigorous and explicit methods were used to provide reliable answers to the research question (Thomas and Harden, 2008), which is of qualitative nature, focusing on patients' experiences and expectations. This review brings together the findings of primary studies with qualitative data. The protocol was developed and registered in the International Prospective Register of Systematic Reviews, (PROSPERO) ID CRD42019130572.

The reporting of this systematic review of qualitative studies follows appropriate elements of Preferred Reporting Items for Systematic Reviews and Meta-Analyses, PRISMA. (Supplementary material).

Eligibility criteria

A scoping search conducted during the protocol development indicated that qualitative studies in early RA were not many therefore disease duration restriction was not applied in the eligibility criteria. Studies were included if they met the following inclusion criteria: study participants were adults of eighteen years and above with a diagnosis of RA (both early and established RA); utilised a qualitative design with data on patients' perspectives of rheumatology nurse-led care; published in peer-reviewed journal from 2010 to 2019 and published in English language. Articles published from 2010 were included as this was when the treat-to-target recommendations were first published (Smolen et al., 2010).

Records with qualitative research containing individual and aggregated patient data were included. Records were excluded if they were: quantitative studies without qualitative data, reviews (references checked), published before year 2010, studies including other diagnoses than RA (for the paper with mixed diagnoses, if the data for patients with RA were specified, the studies were included), studies including children and adolescents with no adult participants' data, published in other languages than English, commentary and discursive articles, letters to the editor with no patient data, study protocols, conference abstracts and dissertations or theses.

Information sources

In March 2019 searches were carried out on MEDLINE, EMBASE, CINAHL and PsycINFO databases. Contact was made with primary research authors to request full text of articles if these were not available through databases. The databases were chosen, as they are major international databases of scientific literature within medicine, nursing and psychology, and they were expected to give reliable and relevant search outputs. Additionally, Open Grey database was searched for relevant grey literature. A table of searched databases is provided in Supplementary Table S1 (available online).

Search

A search strategy was developed with the help of healthcare librarians, based on three term concepts: 'rheumatoid arthritis', 'experience' and 'nurse-led care'. To maximise the sensitivity of the search, alternative key terms were identified and the 'explode' or 'expand' functions and truncations (*) were applied. For example, for rheumatoid arthritis, the following key terms were used:

‘rheumatoid arthritis’, ‘RA’, ‘chronic arthritis’, ‘arthritis’, ‘early arthritis’ and ‘inflammatory arthritis’. Also, the key terms within each concept were combined with ‘OR’. The three term concepts were eventually combined with ‘AND’ to increase the specificity of the search. The full search strategy in MEDLINE is presented in Table 1.

Study selection

Screening for eligibility

One reviewer performed the search and made the initial selection based on titles and abstracts. Identified records were exported from the databases and merged using ENDNOTE® software. Duplicates were removed and the remaining records were screened. The first reviewer screened the titles of records against inclusion and exclusion criteria. Records that were irrelevant regarding diagnosis, population and topic were excluded. Ten percent of the records were screened by the second reviewer and discrepancies were discussed until agreement was reached. Abstracts and full texts of the remaining records were screened for relevance according to inclusion and exclusion criteria by two reviewers working independently. Tables were created with fields for author, year, design, topic, population and notes from each reviewer and marked: ‘Yes’, ‘No’ or ‘Maybe’ for inclusion. An inclusive approach was chosen as the search term included ‘inflammatory arthritis’ which meant that some studies had participants with chronic inflammatory arthritis and poly-arthritis, including RA. Where there were doubts or conflicting opinions, a third reviewer was invited and the issues were discussed until agreement was reached.

Data collection process

A data extraction form was created which included records and data extraction fields, based on the protocol. Data were extracted with an ‘inclusive approach’ which involves abstracting both participant (first order) quotes and author findings (themes or second order quotes) from primary studies to avoid omitting findings of potential value to the synthesis (Noyes et al., 2018; Noyes & Lewin, 2011). Original author findings (themes) and individual participant quotes were extracted from the primary studies in the findings or results sections and from the discussion and conclusion sections, depending on the individual reporting style (Noyes et al., 2018; Noyes & Lewin, 2011; Thomas & Harden, 2008). The first reviewer extracted all data, which was checked by the second reviewer. Any discrepancies were discussed until consensus was reached (Thomas & Harden, 2008).

Quality Assessment of studies included in the review

The Joanna Briggs Institute (JBI) checklist (Martin, 2017) was used for quality assessment as it was developed specifically to assess the methodological quality of primary studies (Hannes et al., 2010;

Porrit et al., 2014). Each included study was assessed against the ten items and rated as ‘yes’, ‘no’ or ‘not clear’. The first reviewer carried out the assessment and this was checked by the second reviewer. Where there were differences in opinion, these were discussed until consensus was reached.

Data synthesis

A thematic synthesis was used according to Thomas and Harden’s framework (Thomas & Harden, 2008) and as suggested by Booth and colleagues (Booth et al., 2016) when the aim is to synthesise and describe varied themes across studies with varied qualitative methodologies. This involved bringing together and integrating findings from primary qualitative studies by identifying themes which were then synthesised into new combined main and sub-themes. The first stage was free line-by-line coding of findings from primary studies into related areas. The second stage was to construct ‘descriptive’ themes across studies, and the third stage was to develop ‘analytical’ themes related to the research question (Thomas & Harden, 2008). Tables were created to manage coding and themes. The first reviewer carried out the thematic synthesis, and the process and results were discussed with the second reviewer. The findings were finally reviewed by the team.

Results

The search identified 1034 records in total. After removing duplicates and irrelevant titles, 125 studies were screened and assessed for eligibility. Eight studies were included in the thematic synthesis. The process of identification, screening and eligibility checking is summarised in Figure 1.

Characteristics of the included studies

Included studies were conducted in the UK (Ryan et al., 2013), Sweden (Bala et al., 2012, 2017; Larsson et al., 2012; Sjo & Bergsten, 2018), the Netherlands (Arends et al., 2017; van Eijk-Hustings et al., 2013) and Denmark (Primdahl et al., 2011). They used a range of qualitative designs.

Primdahl et al. (2011) in Denmark conducted six focus group interviews with thirty three participants (disease duration of four to thirteen years) attending one of three different RA outpatient settings: planned medical consultations, shared care setting with no planned consultations or planned nursing consultations every three months. A hermeneutic phenomenological approach was used.

Bala et al. (2012) aimed to describe how people with RA experienced the care provided by Swedish nurse-led rheumatology outpatient clinics. They conducted interviews with eighteen participants with RA, five participants had disease duration under two years. Data were analysed using a qualitative content analysis.

Larsson et al. (2012) also in Sweden, aimed at describing patients' experiences of a nurse-led rheumatology clinic for those undergoing biological therapy. They recruited twenty patients with inflammatory arthritis (thirteen with RA, seven with other types of arthritis) visiting a rheumatology nurse-led clinic. Data were collected by interviews and were analysed using content analysis with an inductive approach. Disease duration for those with RA was three to forty years.

Ryan et al. (2013) in the UK explored the perceptions and experiences of people with osteo-arthritis (OA) and RA regarding the knowledge and skills they wanted nurses and allied health professionals to have to manage their care needs. They conducted two separate focus groups with patients with OA and RA. Eight patients with RA participated, and five with OA. Data were analysed using content analysis and separate themes were presented for patients with OA and RA. Disease duration for the participants with RA was five to thirty one years.

van Eijk-Hustings et al. (2013) in the Netherlands conducted four focus group interviews with twenty patients, of whom eighteen had RA. The aim was to explore needs and expectations of rheumatology nursing care in patients with chronic inflammatory arthritis (CIA) from three medical clinics, eighteen with RA, two with ankylosing spondylitis (AS); Emerging subjects were categorised into themes which were verified in a fourth interview (van Eijk-Hustings et al., 2013). Patients with RA had disease duration of one and a half to forty two years.

Bala et al. (2017) in Sweden aimed to describe and understand the meaning of living with persistent rheumatoid arthritis. A descriptive design based on a hermeneutic phenomenological method was used, and ten adults with persistent RA with six to twenty years disease duration were interviewed. The interviews were analysed according to van Manen’s methodology.

Arends et al. (2017) in the Netherlands conducted a mixed method study to evaluate a goal management intervention for participants with poly-arthritis and anxiety. Participants were interviewed about their experiences with the programme, eighteen had RA with disease duration from one to forty-seven years.

Sjo et al. (2018) in Sweden conducted an interview study with fifteen participants with the aim to describe the experience of patients with RA attending person-centred, nurse-led clinics over a twelve month period. The interviews were analysed using the phenomeno-graphic method. Disease duration was two to forty years. Two participants had two years disease duration.
A summary of included studies is provided in Table 2.

Quality of research in the included studies

The quality of research varied across the included studies. One study (Bala et al., 2017) rated 'yes' in all ten JBI items (Martin, 2017) and was considered of high quality. Six studies (Bala et al., 2012, 2017; Larsson et al., 2012; Primdahl et al., 2011; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013) rated 'yes' in items 1 to 5 about congruity between methodology and stated philosophy, research question or objective, data collection method, analysis of data and interpretation of results. Two studies (Arends et al., 2017; Ryan et al., 2013) were rated as 'not clear' in item 1, and 'yes' in items 2 to 5. Other quality issues were related to (i) not locating researchers culturally and theoretically (item 6) (Arends et al., 2017; Bala et al., 2012; Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013), and (ii) not clearly addressing their possible influence on the research (item 7) (Arends et al., 2017).The rest of the quality items rated well. These included: participants and their voices (item 8) were adequately represented, the research was ethical (item 9), and conclusions drawn in studies were flowing from analysis or interpretation of the data (item 10). All the eight studies were deemed of acceptable quality to provide insights on patient perspective of nurse-led care in RA. A summary of quality assessment is presented in Table 3.

Synthesis of findings.

Three main themes were identified from the synthesis describing nurse-led care from the perspective of patients with RA: 'Providing knowledge and skill', 'Using a person-centred approach', and 'Meeting patients' care needs'. These themes were interconnected with some overlap and encompassed three aspects of nurse-led care as experienced by patients, focusing on what the nurses provided, how they did this and how it made people with RA feel. The main themes were supported by descriptive subthemes and illustrated with quotes from the original studies. Both individual participant quotes and aggregated author findings were used as data to identify and illustrate themes. Patient quotes were weighed over original author quotes, and clearly marked. Themes and subthemes are presented in Figure 2 (and in Supplementary Table S2 available online).

Providing knowledge and skill

This theme captures patients' experience of the knowledge and skill that rheumatology nurses provided in RA rheumatology nurse-led clinics. It is supported by subthemes describing patients' experience of the nurses' professionalism in the planning and execution of care.

Professional knowledge and nurse expertise

> *'It involves professionalism, which in itself provides a sense of security. You feel that these nurses know what they are doing' (Patient) (Larsson et al., 2012).*

Patients across studies had met knowledge and skill when experiencing rheumatology nurse-led care in nurse-led clinics (Bala et al., 2012, 2017; Larsson et al., 2012; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). Patients experienced competence when the rheumatology nurse assessed disease activity by examining tender and swollen joints and by checking laboratory tests (Larsson et al., 2012). The nurse's professional knowledge of the disease and treatment thus created a sense of security and confidence (Larsson et al., 2012). It was found, that the nurses' specific knowledge, and their practical and teaching skills, were instrumental for a positive experience of care (Bala et al., 2012).

> *Knowledge and skill were considered very important for a positive experience of care. These factors meant that participants became well informed about their illness, medication and self-care (Original author) (Bala et al., 2012).*

Patients thus experienced that the nurses were specialists in their field and would check with the rheumatologist when necessary (Primdahl et al., 2011; Sjo & Bergsten, 2018). Getting the opportunity to ask the nurse about treatment and the implications of the disease meant that patients felt more confident and therefore would adhere to the planned treatment (Sjo & Bergsten, 2018).

Collaboration and planning of care

> *(…) Both the nurse and the doctor are highly specialized, so I never think that the nurse I'm meeting will be lacking in competence—that has never occurred to me… I know that if the nurse felt uncertain, she would check with a doctor, she wouldn't just chance it (Patient, RA 5 years duration) (Sjo and Bergsten, 2018).*

Patients attending rheumatology nurse-led clinics had experienced well organised, coordinated care, which was managed by knowledgeable professionals, who collaborated and communicated with each other and the multidisciplinary team (Larsson et al., 2012; Primdahl et al., 2011; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). It was appreciated that the nurses were well informed about the individual patient's case history (Bala et al., 2012). Patients valued that the nurses were interested in their situation, were focused on conveying knowledge, support and trust and in making careful plans for further follow-ups (Bala et al., 2012). This made them feel that the nurses were interested and wanted to help (Bala et al., 2012). Patients experienced good service and coordination of services when they had access to blood tests and X-rays in connection with their clinic appointments and therefore could avoid tiring waiting times (Bala et al., 2017).

> *Good service and a good coordination of services were experienced when one could leave blood samples and be X-rayed in conjunction with appointments, which meant avoiding a tiring wait (Original author) (Bala et al., 2017).*

Patients emphasised the importance of the collaboration between nurses and rheumatologists (Primdahl et al., 2011; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013), and being able to see both professionals on a regular basis was found to make care optimal and complete (Larsson et al., 2012). The nurses assessed when the patient needed to see a specialist, and patients perceived that the nurse's care complemented that of the rheumatologist and added a new dimension (Larsson et al., 2012).

Information and education

> *The care that focused on patient education (individually or in groups) was described as competent because the nurses were proficient teachers in both theoretical and practical subjects [...] (Original author) (Bala et al., 2012).*

Participants valued when nurses shared information and education about the disease as well as how to cope and self-manage (Bala et al., 2012, 2017). Examples were how to act if infection occurred (van Eijk-Hustings et al., 2013), support in self administration of medication (Bala et al., 2012) and information about medical treatment (Bala et al., 2012). A patient with early RA had been introduced to self-administration of her medication and had despite her own doubts managed to inject herself by the support of the nurse (Bala et al., 2012). This had supported the patient's empowerment and self-confidence. Another patient with early RA praised the way the nurse had provided information about RA at a time when everything about the disease was new and unknown (Bala et al., 2012).

> *She was very good at informing me, so I have only praise for this ... because I have never had it like this before' (P3. Patient, RA 1 year duration) (Bala et al., 2012).*

Patients reported that consultations with the rheumatology nurse facilitated involvement and influence on decision making (Sjo & Bergsten, 2018). They also expressed, that the nurse–patient encounter could be a learning opportunity for both parties and contributed to the patients' sense of participation (Larsson et al., 2012).

Regarding patient expectations, patients appreciated that nurses or allied healthcare professionals from the rheumatology team looked after pain and suggested pain interventions, because they knew the disease. They would also like that the nurse informed them about relaxation, exercise and referral to physiotherapist, which they felt could help them manage the disease (Ryan et al., 2013). Patients in two Dutch studies (Arends et al., 2017; van Eijk-Hustings et al., 2013) would like the rheumatology nurses to provide understandable, tailored information and education about their disease, its treatment and management whenever it was needed.

Using a person-centred approach

This theme captures the person-centred approach that patients meet in RA nurse-led care. Subthemes describe aspects of this approach involving empathy and communication skills, which create a good therapeutic environment and make the patients feel understood and cared for.

Person-centeredness and empathy

> *'She is very sensitive. She can see if I am feeling bad and comes straight to me and asks: "How are you today?" ...You are treated and taken seriously' (P17. Patient, RA 1 year duration) (Bala et al., 2012).*

Patients across studies appreciated the person-centred approach when attending a nurse-led rheumatology clinic (Arends et al., 2017; Bala et al., 2012, 2017; Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). Positive experiences of the nurse-patient encounter were related to the nurses' ability to have a holistic and empathic approach, being sensitive, and showing interest and involvement in the individual patients' circumstances (Arends et al., 2017; Bala et al., 2012, 2017; Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). Patients emphasised that the key thing was that the nurse not only knew about the disease, but also had empathy with what it meant to be in the situation (Ryan et al., 2013). It was reported how patients felt they could talk with the nurse about all their problems, that the nurse was a good listener which made patients feel well, acknowledged and seen as a whole person (Bala et al., 2012; van Eijk-Hustings et al., 2013). Patients thus appreciated being recognised when they contacted the clinic and feeling seen, heard and believed (Bala et al., 2012). This was reported to create feelings of trust and hope (Bala et al., 2012).

> *'You feel that she is interested in my problem and that she really wants to help. It is extremely important to feel that they really are there for me' (P4. Patient, RA 1 ½ years duration) (Bala et al., 2012).*

Communication and therapeutic environment

> *'It is their warmth and kindness, and one feels welcome ... it's this gentle, civil manner so one feels that they care' (Patient) (Bala et al., 2012).*

Patients highlighted the rheumatology nurses' good communication skills and the friendly environment as important for their experience of feeling cared for (Bala et al., 2012). Openness and clear two-way communication were perceived as essential for good encounters (Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013), and helped patients feel welcome and taken care of (Bala et al., 2012).

> *I think somebody should be clear, not too soft. You know, I value the adequate communication. And as I say: it doesn't have to be too soft, it has to be pure and simple (Patient, Female, RA, 59 years old) (van Eijk-Hustings et al., 2013).*

Patients expressed that it was easier to contact the nurses than the rheumatologist if they had a problem, because they knew that the nurses were easy to talk to and were easy to contact by telephone (Bala et al., 2017; Primdahl et al., 2011; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013).

> *Support from the nurses and that they were accessible every day for free telephone advice provided a greater sense of well-being and security as well as quick solutions and time-saving (Original author) (Bala et al., 2017).*

Easy access meant that patients every day could contact the nurse on the free telephone helpline for support or appointments with relevant members of the healthcare team (Bala et al., 2017). Patients valued quick solutions and feedback without additional suffering and exhausting waiting times (Bala et al., 2017; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013).

Meeting patients' care needs

This theme captures how nurse-led care is received by patients, what it makes them feel and the experience of having care needs met. Subthemes describe experiences of being empowered and psychologically supported and of feeling secure and confident.

Empowerment and psychological support

> *'The thought of sticking a needle into my own stomach... it felt a bit like I would never manage to do that. However, they have been absolutely wonderful here ... and now I can do it myself' (P2. Patient, RA 1 ½ year duration) (Bala et al., 2012).*

Patients across studies expressed the importance of being able to get support and advice from the rheumatology nurse (Arends et al., 2017; Bala et al., 2012, 2017; Larsson et al., 2012; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). The unpredictability of the disease meant, that patients could experience flares, pain and feeling down and depressed (Larsson et al., 2012; Ryan et al., 2013). Patients described the support they needed as 'a listening ear' (van Eijk-Hustings et al., 2013) and 'sounding board'(Larsson et al., 2012) to whom they could pose questions and get support when facing problems. Being taken seriously by the nurse made patients feel strengthened and empowered to make their own assessments and decisions, and self-manage (Larsson et al., 2012; Ryan et al., 2013). A patient with early RA had thus felt empowered to self-administer an injection (Bala et al., 2012). Increased contact with a rheumatology nurse during challenging times was important and could support the patients in gaining insight into themselves and their disease (Sjo & Bergsten, 2018). This involved reflecting on patterns of behaviour and learning to take care of oneself by focusing on well-being and set boundaries for other's and own expectations (Sjo & Bergsten, 2018).

> *Making a personal journey. What made this "journey" possible was the targets set during the encounters with the nurse, which had a focus on, as far as possible, well-being, and the fact that the meetings took place at regular intervals. This enabled participants to gain greater insight into both themselves and their disease (Original author) (Sjo and Bergsten, 2018).*

Security and confidence

> *My best contact was the nurse. If the drugs are not working you can just call her up and she will call you back. She's empathic, kind, practical and she'll sort things out (Patient, RA 10 years duration) (Ryan et al., 2013).*

Patients reported that access to support from the rheumatology nurse gave them a feeling of security, trust and confidence that the nurse would help them finding a way forward (Bala et al., 2012; Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2013; van Eijk-Hustings et al., 2013). This involved feeling confident that professional help and support was available when needed, and that a solution acceptable to the patient would be found without delay (Bala, 2017). Patients thus felt confident that they could contact the nurse if they had a problem with their medication, since the nurse would understand and help them find a solution to manage the problem (Ryan et al., 2013). Patients reported, that they had experienced being taken seriously and feeling cared for and secure in contact with nurses in nurse-led care clinics (Bala et al., 2012, 2017; Larsson et al., 2012; Primdahl et al., 2011; Ryan et al., 2013; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013). Patients also reported that being recognised and understood when contacting the clinic led to feelings of trust, hope and participation (Bala et al., 2012). The combination of a friendly way of meeting patients with understanding and respect added value to rheumatology care and constituted complete care (Larsson et al., 2012).

> *They appreciated being recognized when they contacted the clinic, and feeling that they were seen, heard and believed increased their feelings of trust and hope (Original author) (Bala et al., 2012).*
>
> *It was also found that the encounters with the nurse led to a sense of security, familiarity and participation and added value to rheumatology care (Original author) (Larsson et al., 2012).*

DISCUSSION

This review aimed at exploring the patient perspective of nurse-led care in early RA. This is the time when patients who have started intensive immunosuppressive treatments require tight monitoring and holistic support from nurse-led clinics. The findings from the included studies presented perspectives of patients with RA, seeing nurse-led care as providing knowledge and skill, using a person-centred and emphatic approach and that patients' holistic care needs were being met. Nurse-led care in RA included easy access via telephone helpline, consultations, disease assessment, planning of care, education and information, supporting self-management, and referral to rheumatologist and the multi-disciplinary team.

Patients valued the skill and expertise of the rheumatology nurses, their accessibility and good communication skills and also their collaboration with the rheumatologist. Patients perceived that the nurse's care complemented that of the rheumatologist and added a new dimension (Larsson et al., 2012). This is consistent with findings in a systematic review by Mohammed and colleagues (Mohammed et al., 2016) which explored the patient perspective of health care quality. Their study found that in chronic diseases, patient–provider communication was the most commonly reported indicator of quality, followed by provider accessibility and provider–provider communication (Mohammed et al., 2016).

In this review, patients described the rheumatology nurse as being a specialist with professional knowledge and skill. The EULAR recommendations for the role of the nurse (Bech et al., 2019) state that nurses should have access to and undertake continuous education in the specialty of rheumatology to improve and maintain knowledge and skills and be encouraged to undertake extended roles after specialised training and according to national regulations (Bech et al., 2019). Education is thus important in order to undertake and maintain extended roles in rheumatology nursing. However, a recent UK nation-wide survey of rheumatology clinical nurse specialists carried out by the British Society for Rheumatology (BSR & NRAS, 2019) has shown that there is lack of succession planning in the specialty and it is difficult for nurses to get access to specialist training and education due to lack of time, funding and suitable study programmes. Rheumatology nursing is reported to be under high demand and in need of more specialist nurses to meet patients care needs (BSR & NRAS, 2019). A competency framework for rheumatology nurses in the UK (RCN, 2020) was recently published, acknowledging the highly complex role of the rheumatology nurse. It focused on knowledge and skill in RA management, which will help secure professional clinical standards. While it did not clearly address nurse-led care in early RA the current innovation in treatments and evolution of delivery of care will inevitably call for even higher levels of professionalism and skills in order to meet changing needs of patients with early RA

Our findings highlighted the importance of the person-centered and emphatic approach used by the rheumatology nurses. An established relationship between nurse and patient was found to make it easier for patients to contact the clinic for support, when they had questions or problems with managing the disease and created a feeling of trust and security. This aspect of rheumatology nursing is important. National audits in the United Kingdom (HQIP, 2016, 2019) showed that more patients with RA started and adhered to medical treatment when they had access to a rheumatology nurse. Access and continuous contact to a rheumatology nurse were thus found to improve treatment outcomes in RA (HQIP, 2016, 2019).

The importance of a person-centred approach in RA rheumatology care was also emphasised by Voshaar et al. (2015). Their review of the evidence of patient-centered care in established RA showed that involving the patients as individuals, with unique needs, concerns and preferences, had relevant impact on treatment outcomes as safety and effectiveness (Voshaar et al., 2015). Furthermore, the patient-centred care approach empowered patients to take personal responsibility for their treatment (Voshaar et al., 2015). Person-centred care in RA rheumatology care was explored and conceptualised by Bala and colleagues (Bala, Forslind, Fridlund, & Hagell, 2018; Bala, Forslind, Fridlund, Samuelson, et al., 2018), who developed a framework to conceptualise outpatient person-centred care, comprising five domains: social environment, personalisation, shared decision-making, empowerment and communication. These concepts resembled themes identified in this review and suggest that the person-centred care concept is essential in defining the key ingredient of nurse-led care in early RA.

Nurses' communication styles also seem to contribute to patient participation in their care and favourable patient outcomes. Vinall-Collier et al. (2016) conducted a multi-centre study of interactional style in nurse specialist and physician-led rheumatology clinics in UK. Their research illuminated differences as 'socio-emotional' versus 'task-focussed', and highlighted the value of the nurse specialists' socio-emotional communication skills to enhance patient participation. Nurse specialists and their patients were found to work together in consultations and to engage significantly more in the socio-emotional activity of 'building a relationship'. Interviews also revealed that continuity of practitioner was highly valued by patients, as it offered the benefits of an established relationship and of emotional support beyond that of the clinical encounter. This helped foster familiarity not only with their particular medical history, but also their individual personal circumstances, which encouraged patient participation. It was thus found, that socio-emotional communication and relationship-building appeared to have clinical relevance in relation to measurable outcomes of quality of care (Vinall-Collier et al., 2016).

Patients in this review valued empowerment and psychological support provided by nurses. However, there were reports that patients needed increased psychological support when experiencing pain and flares (Ryan et al., 2013; Sjo & Bergsten, 2018). The connection between pain and feeling depressed was emphasised by patients in a British study (Ryan et al., 2013), who compared their needs to those of patients with cancer.

The demand for psychological support is high in inflammatory arthritis, but a UK study (Dures et al., 2016) suggests that few patients are being asked about social and emotional issues. Patients would in particular like to have support to manage the impact of their disease in relation to symptoms such as pain and fatigue, emotions, and work and leisure. They preferred support from rheumatology clinicians and in particular from the rheumatology nurses (Dures et al., 2016). Provision of psychological support by nurses and other trained health professionals is supported by the NICE guideline for depression in long-term chronic conditions (NICE, 2009).

While there is robust evidence of effectiveness of nurse-led care in RA, the mechanism by which nurse-led care has its effects has not been well studied. This review of qualitative studies describing patient experience and their perspective of nurse-led care has shed some light on how patients with RA perceive this service. The findings have highlighted the professionalism of nurses in the RA management, their person-centred approach to care, and how this meets holistic needs of patients. A qualitative study with rheumatology nurses who see patients in early RA would help complement the findings of this review.

Strengths and limitations

This review has three key strengths: First, a thorough process was taken to register the methods prospectively to ensure a transparent and systematic process was followed in the review. Second, the thematic synthesis brought together and combined themes from varied qualitative studies with varied designs including both ‘first order’ participant quotes and ‘second order’ author interpretations which ensured important findings were not omitted. Third, transparency and rigour were sought by describing, illustrating and checking the various steps in the research process with the second reviewer and the review team.

This review has some limitations: First, one reviewer carried out the search for eligible studies, quality assessment, data extraction and the data analysis process. However, each stage was checked by one or more reviewers to minimise errors and maximise the credibility of the findings. Second, only four studies (Arends et al., 2017; Bala et al., 2012; Sjo & Bergsten, 2018; van Eijk-Hustings et al., 2013) included participants with up to 2 years duration of RA so the evidence is limited in informing nurse-led care in early RA. As studies with early RA were limited, the remit of the review was widened to include all stages of the disease trajectory, as reported in the original studies. Third, some studies with both RA and non-RA conditions were included in the review, but only if they clearly separated the findings of those with RA (Ryan et al., 2013), clearly labelled quotes of patients with RA (Arends et al., 2017; van Eijk-Hustings et al., 2013), or the vast majority of patients had RA (Larsson et al., 2012). This means there is possibility that primary authors interpretations may be influenced by the totality of the findings, including those of non-RA conditions in one study (Larsson et al., 2012). However, the impact of this is likely to be minimal. Fourth, studies using different qualitative methodologies were included in this review and this may have an impact on the synthesis of findings. However, this was minimised by (i) describing all included studies and (ii) quality assessment of the included studies, including author impact on the research, (iii) weighing patient (first order) quotes over original author (second order) quotes and (iv) consistency of themes across the studies which supports the credibility of the findings. Fifth, despite efforts of systematically detecting relevant data from the identified publications, it is possible that not all data were included, as researchers in the primary studies may have left out other aspects and quotes that could have added more detail and richness to the data. To thoroughly explore the patient perspective on nurse-led care in early RA more qualitative studies are needed focusing on early RA.

This review found a dearth in literature regarding nurse-led care in early RA and the patient perspective of this. The findings of this review could help inform future research looking into rheumatology nurse-led care in early RA and exploring patients' experiences and the views of the rheumatology nurses who are the service providers. There is also a need for exploring how nurse-led interventions can help and support patients in achieving and sustaining remission.

Conclusion

To our understanding, this is the first systematic review to report on nurse-led care from the perspective of patients with early RA. Patients are very supportive of rheumatology nurse-led care, and the findings outline key ingredients of nurse-led care that are important to patients with RA. Patients thus value the provision of professional expertise and the use of a person-centred approach, which give them a sense of security and confidence and meet their holistic care needs. More qualitative studies of nurse-led care in early RA are needed.

Relevance to clinical practice

This review presents patients' perspective of nurse-led care in early RA and is therefore highly relevant to informing clinical practice. The findings can be used to inform practice at the nurse practitioner level, department level and contribute to national standards of care. Rheumatology nursing is provided by nurses with different skill sets, from registered practitioners, advanced level practitioners to consultant level practitioners in some countries. Nurses can use the findings to plan their own professional development. For example, nurses' personal development plans could include gaining new skills to provide psychological support for patients with RA. At departmental level, the findings such as coordination of care and personal centredness can be used in audits and service improvement. These could also be used in training new rheumatology nurses and contribute to competence frameworks for rheumatology nursing.

What does this paper contribute to the wider global community?

- This paper reports research findings on patients' perspective of nurse-led care in early rheumatoid arthritis.
- Patients with early and established rheumatoid arthritis value nurse-led care, and they view this as characterised by professionalism, person-centeredness and meeting their holistic care needs.
- The findings can inform professional development, service improvement and evaluation, and competence frameworks for rheumatology nursing.

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Author contributions

All authors have actively contributed to the work and meet the International Committee of Medical Journal Editors criteria for authorship. AMTS, CSM, CF, JR, PR and MN were involved in the study design. AMTS, AB and MN were involved in acquisition of data. All authors were involved in drafting the manuscript or revising it critically for important intellectual content, read and approved the final version to be submitted.

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Figures

Figure 1. Flow diagram showing the process of identification, screening and eligibility checking

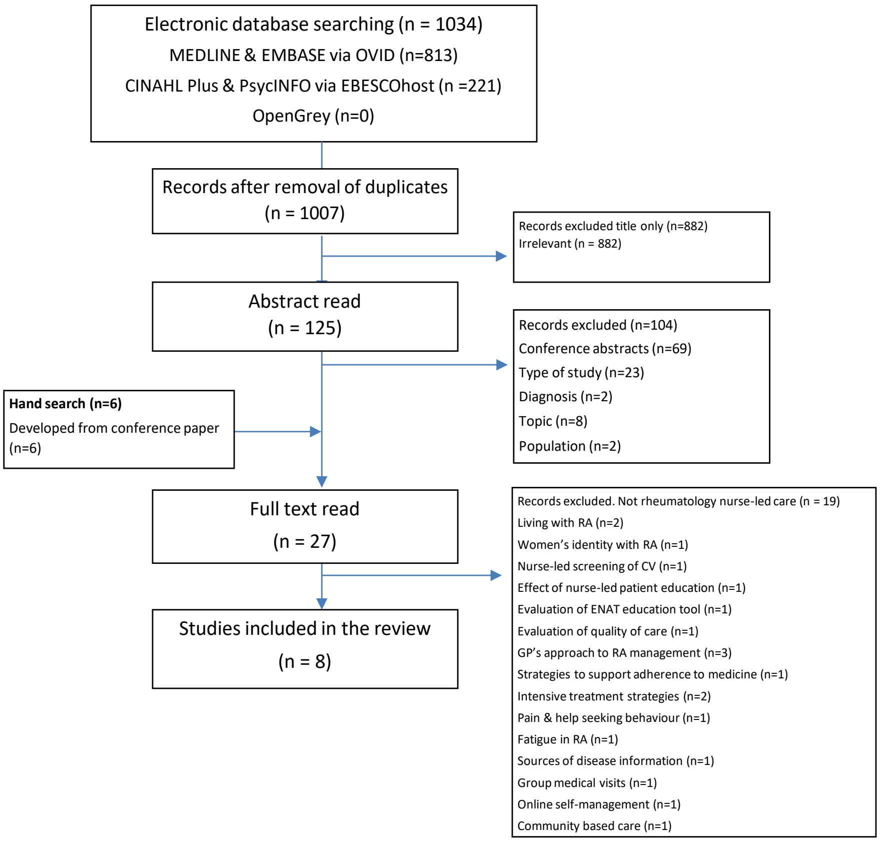
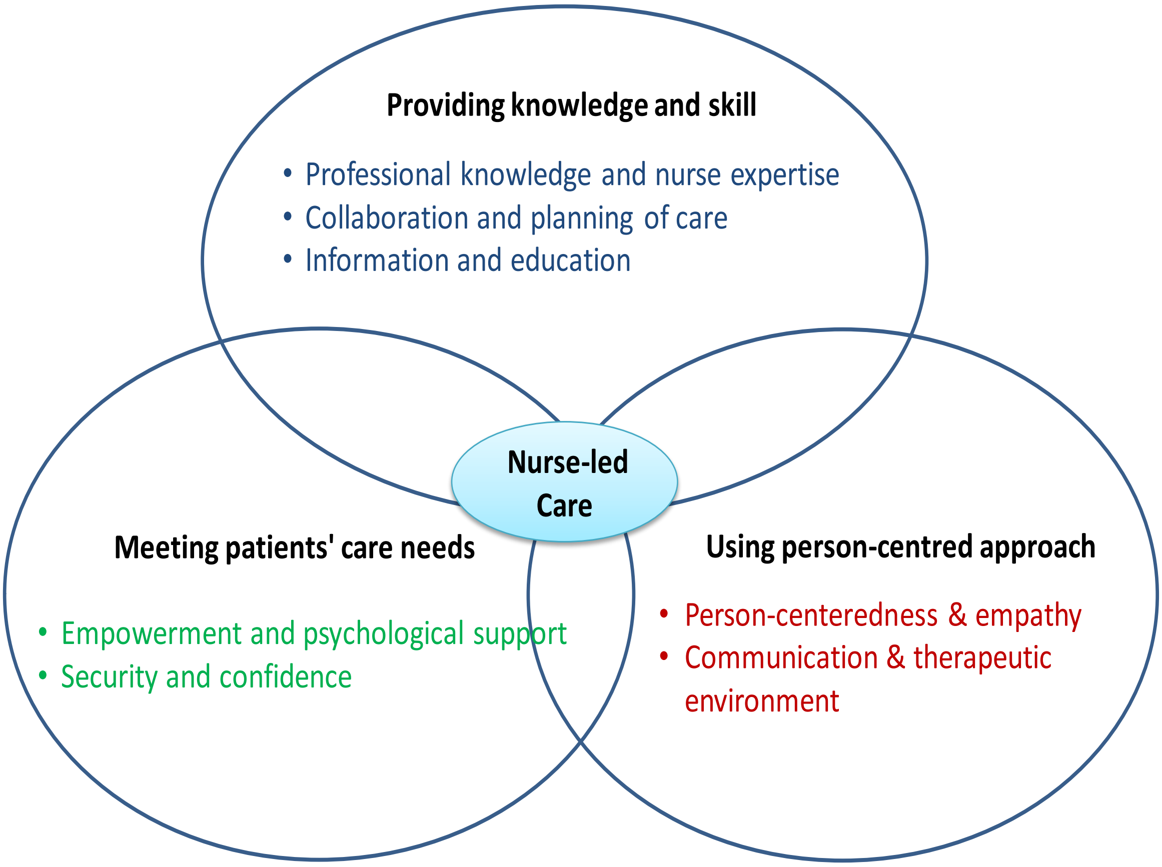


Figure 2. The identified themes and subthemes



Tables

Table 1: The search strategy

1 (experiences or expectations or perception or views or needs).af. (1095047)
2 exp "rheumatoid arthritis"/ (208054)
3 exp "chronic arthritis"/ (2090)
4 exp arthritis/ (474912)
5 ("rheumatoid arthritis" or RA or "chronic arthritis" or arthritis or "early arthritis" or "inflammatory arthritis").af. (427537)
6 2 or 3 or 4 or 5 (585234)
7 exp nurse/ (168332)
8 exp nursing/ (383237)
9 exp "registered nurse"/ (3529)
10 exp "nurse practitioner"/ (23849)
11 exp "nurse clinician"/ (1784)
12 exp "clinical nurse specialist"/ (1784)
13 exp "physician assistant"/ (7392)
14 exp telephone/ (35668)
15 ("nurse led care" or nurs* or "rheumatology nurs*" or "rheumatology provider" or "nurse practi*" or "nurse practice" or "qualified nurse" or "expert nurse" or "advanced practice nurse" or "nurse consultant" or "nurse counsel").af. (974872)
16 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 (1010383)
17 1 and 6 and 16 (1160)
18 limit 17 to "all adult (19 plus years)" [Limit not valid in Embase; records were retained] (1160)
19 limit 18 to english language (1122)
20 limit 19 to human (1046)
21 limit 20 to yr="2010 -Current" (813)
22 limit 21 to humans (813)

Table2. Summary of included studies

References	Country	Diagnosis/ Disease duration (years)	Sample size	Sex/age	Sampling	Data collection	Data analysis	Main themes
ARENDS, 2017(Arends et al., 2017)	Netherlands	Poly-arthritis (Polymyalgia/Temporal Arthritis/Spondyloarthropathy/ SLE and other systemic diseases) & anxiety/1–41 years	RA: 18 Polymyalgia and Temporal Arteriitis: 2 Spondyloarthropathy: 3 SLE and other systemic diseases: 1	Female: 18 Male: 6/ Age: 24-73 years	Stratified purposeful sampling	Interview	Thematic analysis of content	Nurse as trainer in group self- management intervention.
BALA, 2017 (Bala et al., 2017)	Sweden	Persistent RA/ 6–20 years	Persistent RA: 10	Female: 5 Male: 5/ Age: 56-78 years	Strategic sampling	Interview	Hermeneutic phenomenological analysis as described by van Manen (1997)	Living with persistent RA.
BALA, 2012(Bala et al., 2012)	Sweden	RA/ 1-58 years	RA:18	Female: 17 Male: 1/ Age: adults	Purposeful sampling	Interview	Stepwise analysis in accordance with Burnard (1991)	Optimal care at nurse-led rheumatology clinic.
LARSSON, 2012(Larsson et al., 2012)	Sweden	RA, psoriatic arthritis (PsA), undifferentiated spondylo-arthritis (AS)/ 3–40 years	RA: 13 PSA: 4 Undiff AS: 3	Female: 10 Male: 10/ Age: 34-76 years	Strategic sampling	Interview	Qualitative content analysis	Nurse consultation replacing rheumatologist consultation.
PRIMDAHL, 2011(Primdahl et al., 2011)	Denmark	RA/ 4–13 years + 1	RA: 33	Female: 23 Male: 10/ Age: 39-78	Strategic sampling	Focus group interview	Phenomenological meaning analysis according to Giorgi (1975)	Being an RA outpatient.
RYAN, 2013(Ryan et al., 2013)	United Kingdom	RA, osteoarthritis (OA)/ RA: 5-31 years	RA: 8 OA: 5	RA: Female: 6 Male: 2/ Age: 42-67	Purposeful sampling	Focus group interview (RA/OA separate)	Qualitative content analysis	Nurse knowledge and skill to support care needs.
SJÖ, 2018(Sjo and Bergsten, 2018)	Sweden	RA/ 2 - 40 years	RA: 15	Female; 14 Male: 1/Age: 21-79	Strategic sampling	Interview	Phenomenographic method	Frequent regular consultations with rheumatology nurses.
VAN EIJK-HUSTINGS, 2013(van Eijk-Hustings et al., 2013)	Netherlands	Chronic inflammatory arthritis: RA & ankylosing spondylitis (AS)/ 1.5–42 years	RA: 18 AS: 2	Female: 15 Male: 5 Age: 18-90	Purposeful sampling	Focus group	Content analysis followed by consensus meetings according to Krueger (2009)	Patient needs and expectations of rheumatology nursing care.

Table 3. Summary of JBI quality assessment

Reference	1. Is there congruity between the stated philosophical perspective and the research methodology?	2. Is there congruity between the research methodology and the research question or objectives?	3. Is there congruity between the research methodology and the methods used to collect data?	4. Is there congruity between the research methodology and the representation and analysis of data?	5. Is there congruity between the research methodology and the interpretation of results?	6. Is there a statement locating the researcher culturally or theoretically?	7. Is the influence of the researcher on the research, and vice-versa, addressed?	8. Are participants, and their voices, adequately represented?	9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
ARENDS 2017(Arends et al., 2017)	Not clear	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
BALA, 2017(Bala et al., 2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
BALA, 2012(Bala et al., 2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
LARSSON, 2012(Larsson et al., 2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
PRIMDAHL, 2011(Primdahl et al., 2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
RYAN, 2013(Ryan et al., 2013)	Not clear	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
SJÖ, 2018(Sjo and Bergsten, 2018)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
VAN EIJK-HUSTINGS, 2013(van Eijk-Hustings et al., 2013)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Supplementary tables

Supplementary Table S1: Databases searched

Name of database	Platform/provider	Date limits
MEDLINE. Medical Literature Analysis and Retrieval System Online	OVID	Year 2010 - 01.03.2019
EMBASE. Excerpta Medica Database	OVID	Year 2010 - 01.03.2019
CINAHL Plus. Cumulative Index of Nursing and Allied Health Literature	EBSCOhost	Year 2010 - 05.03.2019
PsycINFO. Comprehensive international bibliographic database of psychology	EBSCOhost	Year 2010 - 05.03.2019
OpenGrey. System for Information on Grey Literature in Europe	opengrey.eu	Year 2010 -01.03.2019

Supplementary Table S2. Themes, sub-themes and illustrative quotations

Theme:	**Providing knowledge and skill**
Subthemes	**Illustrative quotations, including codes in bold**
Professional knowledge & **nurse expertice**	It **involves professionalism**, which in itself provides a sense of security. You feel that these **nurses know what they are doing** (Patient) (Larsson et al., 2012). When I came here**, I felt that here there was a very solid knowledge of rheumatology . . . the knowledge was deep** and **meant that you got a feeling of trust** (P6, Patient Female, RA 10 years duration) (Bala et al., 2012). (…)**Both the nurse and the doctor are highly specialized**, so I never think that the nurse I'm meeting will be lacking in competence—that has never occurred to me… I know **that if the nurse felt uncertain**, she would **check with a doctor**, she wouldn't just chance it (I. 12. Patient Female, RA 5 years duration) (Sjo and Bergsten, 2018). When I had **had the opportunity to talk to her and pose all my questions**… that is what **has made me take the medications** (I. 6. Patient Female, RA 11 years duration) (Sjo & Bergsten, 2018). **When the participants were at the clinics**, the **nurses showed** that **they were well informed about participants' case history, interested in their present situation, focused on conveying knowledge**, support and trust, **and made careful plans for further follow-ups** (Original author) (Bala et al., 2012). **Knowledge and skill were considered very important for a positive experience of care**. These factors meant that

	participants became well informed about their illness, medication and self-care (Original author) (Bala et al., 2012). '**She was very good at informing me**, **so I have only praise for this** ... because **I have never had it like this before'** (P 3, Patient Female, RA 1 year) (Bala et al., 2012). **Professional approach.** Participants felt that their care was person centred and characterized by empathy, **knowledge and skill, as well as support** (Original author) (Bala et al., 2012). The nurses were described as sensitive, sympathetic and attentive. Their **expertise, specific knowledge of rheumatology and rheumatology care was greatly valued**. **The care was based on each participant's unique disease experience and needs**, and was therefore **described as competent** (Original author) (Bala et al., 2012). The participants experienced **competence** in the encounter with the nurse, when she/he **assessed disease activity** by **examining tender, swollen joints and checking laboratory tests**. They stated that the nurse's **knowledge of the disease and treatment** created a **sense of security** (Original author) (Larsson et al., 2012). **The rheumatology care is important for me**, absolutely! **You feel safer in some way if you have that contact and ring them** ...because **at the GP office they can't do much anyway**. **It's difficult to find a doctor to empty [drain] a knee or** a shoulder (Patient Male, RA 20 years duration) (Bala et al., 2017).
Collaboration & planning of care	**Good service** and a **good coordination of services** were experienced when one **could leave blood samples and be X-rayed in conjunction with appointments**, which meant **avoiding a tiring wait** (Original author) (Bala et al., 2017).

When the participants were at the clinics, the nurses showed that they were **well informed about participants' case history**, **interested in their present situation**, **focused on conveying knowledge, support and trust**, and **made careful plans for further follow-ups** (Original author) (Bala et al., 2012).

'You feel that **she is interested in my problem** and that she **really wants to help**. It is **extremely important to feel that they really are there for me'** (P4. Patient Female, RA. 1 ½ years duration) (Bala et al., 2012).

They expressed confidence in the nurse's competence and that **the nurse would refer them to a hospital doctor when needed** (Original author) (Primdahl et al., 2011).

The nurse assessed when the patient needed to see a specialist, thus the importance of **collaboration between the two professional categories** was emphasized (Original author) (Larsson et al., 2012).

The participants perceived that the **nurse's care complemented that of the rheumatologist** and **added a new dimension** (Original author) (Larsson et al., 2012).

(…)**Both the nurse and the doctor are highly specialized**, so I never think that the nurse I'm meeting will be lacking in competence—that has never occurred to me… I know **that if the nurse felt uncertain**, she would **check with a doctor**, she wouldn't just chance it (I. 12. Patient Female, RA 5 years duration) (Sjo and Bergsten, 2018).

Information & education	The care was also appreciated when the **nurse provided support in handling anxiety and fear as a result of the course of the disease, test results, medication side effects and self-administration of subcutaneous injections**. It **helped participants to gain control of the situation** (Original author) (Bala et al., 2012). The thought of **sticking a needle into my own stomach**... it **felt a bit like I would never manage to do that**. However, they have been absolutely wonderful here **... and now I can do it myself’** (P2. Patient Female, RA 1½ years duration) (Bala et al., 2012). If **someone explains to me that it is important** that you do this and that, **then I do it**. **If I read a brochure, it is easy for me to believe a half truth,** but **if the nurse says, “it would be a benefit for you”, then you perceive it completely differently’** (P1, Patient Male, RA 16 years duration) (Bala et al., 2012). There were also participants who **wished for more commitment from the nurses because on some occasions their questions were not answered** and they **did not get the support they expected** (Original author) (Bala et al., 2012). **Knowledge and skill were considered very important for a positive experience of care**. These **factors meant that participants became well informed about their illness, medication and self-care** (Original author) (Bala et al., 2012). The **care that focused on patient education** (individually or in groups) was **described as competent because the nurses were proficient teachers in both theoretical and practical su**bjects [...] (Original author) (Bala et al., 2012). [. . .] **It was easy to learn from them** (P 13, Patient Female, RA 21/2 years duration) (Bala et al., 2012).

	She was very **good at informing** me, so I have only praise for this ... because I **have never had it like this before**’ (P3. Patient Female, RA 1 years duration) (Bala et al., 2012).
	Encounters with the rheumatology nurse were experienced as **facilitating involvement** and **influence on decisions made** (Original author) (Sjo and Bergsten, 2018).
	I **want to keep mobile** and find **out what exercises I can do** but I **have never been told this or offered to see a physiotherapist** who would be able to **help me manage my arthritis** (FG2:3, Patient Female, RA 13 years duration) (Ryan et al., 2013).
	I **would like the team and especially the nurse to be able to coach me into being a full player in the partnership**. It’s **coaching about facts and information** and **also empowering people to be able to self-manage** (FG2:5, Patient Male, RA 5 years duration) (Ryan et al., 2013).
Theme:	**Using a person-centred approach**
Subthemes	**Illustrative quotes, including codes in bold**
Person-centeredness & empathy	**Empathy was related to the fact that the nurses took participants’ needs seriously** (Original author) (Bala et al., 2012). **She is very sensitive**. She **can see if I am feeling bad** and **comes straight to me** and **asks: “How are you today?”...** You are **treated and taken seriously**’ (P17. Patient Female, RA 1 years duration) (Bala et al., 2012).

	'You feel that **she is interested in my problem** and that she **really wants to help**. It is **extremely important to feel that they really are there for me'** (P4. Patient Female, RA. 1 ½ years duration) (Bala et al., 2012).
	The key thing is that **the nurse knows not only about the disease but has a degree of empathy** with **what it means to the individual** (FG2:P5, Patient Male, RA 5 years duration) (Ryan et al., 2013).
	Professional approach. **Participants felt that their care was person centred and characterized by empathy**, knowledge and skill, as well as support (Original author) (Bala et al., 2012).
	The nurses were described as sensitive, **sympathetic and attentive**. Their expertise, specific knowledge of rheumatology and rheumatology care was greatly valued (Original author) (Bala et al., 2012).
	The care was based on each participant's unique disease experience and needs, and was therefore described as competent (Original author) (Bala et al., 2012).
	To my mind, a **friendly manner**, **understanding your problems**, and **being taken seriously** constitute **complete care** (Patient) (Larsson et al., 2012).
	People do not understand. I could **talk with the nurse about all my problems**. That **made me feel well**. And **she has listened very well (**Patient, Female, RA, 47 years old) (van Eijk-Hustings et al., 2013).
	These were statements regarding opinions about **the 'personality' of the nurse**, for example, "**the nurse is easy to**

	talk to”, “the nurse is **empathic**”, “**the nurse considers me as a whole**” (Original author) (van Eijk-Hustings et al., 2013). They **appreciated being recognized when they contacted the clinic,** and **feeling that they were seen**, **heard and believed increased their feelings of trust and hope** (Original author) (Bala et al., 2012). **If you want to talk because you are feeling a bit down or sad**, **you don’t talk to a rheumatologist about such matters**. **It’s much easier to tell a nurse** (Patient) (Larsson et al., 2012).
Communication & therapeutic environment	It is their **warmth and kindness, and one feels welcome** [...] (P12. Patient Female, RA 7 years duration) (Bala et al., 2012). It’s **this gentle, civil ma**nner so **one feels that they care** (P 12. Patient Female, RA 7 years duration) (Bala et al., 2012). [. . .] **accessibility is of course fundamental** . . . **that it is easy for me to come to her** . . . there is **good accessibility**. This is what I feel (P18, Patient Female, RA 3 years duration) (Bala et al., 2012). [. . .] since I have been **visiting this clinic for so many years**, **we know each other**. . . so there is a **family atmosphere** . . . and **I think this is important** (P 14, Patient Female, RA 15 years duration) (Bala et al., 2012)- You feel that **she is interested in my problem** and that she **really wants to help**. It is **extremely important to feel that they really are there for me’** (P4. Patient Female, RA. 1 ½ years duration) (Bala et al., 2012).

	I think **somebody should be clear, not too soft**. You know, **I value the adequate communication**. And as I say: it doesn't have to be too soft, it has to be pure and simple (Patient, Female, RA, 59 years old) (van Eijk-Hustings et al., 2013).
	A **warm encounter** helped participants to **feel welcome** and **taken care of** (Original author) (Bala et al., 2012).
	To my mind, a **friendly manner**, **understanding your problems**, and **being taken seriously** constitute **complete care** (Patient) (Larsson et al., 2012).
	[. . .] I have a very **good doctor** . . . but **you don't say as much to her as you do to a nurse**. You form a **different relationship**, I think. You are more **on the same level with a nurse than you are with a doctor** . . . that's **why this intermediary is so very important** (P8, Patient Female, RA 15 years duration) (Bala et al., 2012).
	People do not understand. I could **talk with the nurse about all my problems**. That **made me feel well**. And she has listened very well (Patient, Female, RA, 47 years old) (van Eijk-Hustings et al., 2013).
	Support from the nurses and that they were **accessible every day for free telephone advice** provided a **greater sense of well-being and security** as well as **quick solutions** and **time-saving** (Original author) (Bala et al., 2017).
	My **best contact was the nurse**. **If the drugs are not working you can just call her up** and **she will call you back**. She's **empathic, kind, practical** and **she'll sort things out** (FG2:P8, Patient Female, RA 10 years duration) (Ryan et al., 2013).

	The **rheumatology care is important for me**, absolutely! You **feel safer** in some way **if you have that contact and ring them** . . . because at the GP office they can't do much anyway. It's difficult to find a doctor to empty [drain] a knee or a shoulder (Patient Male, RA 20 years duration) (Bala et al., 2017). If you want **to talk because you are feeling a bit down or sad**, **you don't talk to a rheumatologist about such matters**. It's **much easier to tell a nurse** (Patient) (Larsson et al., 2012). They **appreciated being recognized when they contacted the clinic,** and **feeling that they were seen**, **heard and believed increased their feelings of trust and hope** (Original author) (Bala et al., 2012).
Theme:	**Meeting patients' care needs**
Subthemes	**Illustrative quotes, including codes in bold**
Empowerment & psychological support	People do not understand. I could **talk with the nurse about all my problems**. That **made me feel well**. And she has listened very well (Patient, Female, RA, 47 years old) (van Eijk-Hustings et al., 2013). To my mind, a **friendly manner**, **understanding your problems**, and **being taken seriously** constitute **complete care** (Patient) (Larsson et al., 2012). 'You feel that **she is interested in my problem** and that she **really wants to help**. It is **extremely important to feel that they really are there for me'** (P4. Patient Female, RA 1 ½ years duration) (Bala et al., 2012). The thought of **sticking a needle into my own stomach**... it **felt a bit like I would never manage to do that**. However, they have been absolutely wonderful here **... and now I can**

	do it myself' (P2. Patient Female, RA 1½ years duration) (Bala et al., 2012).
	If you want **to talk because you are feeling a bit down or sad**, **you don't talk to a rheumatologist about such ma**tters. **It's much easier to tell a nurse** (Patient) (Larsson et al., 2012).
	Support from the nurses and that they were **accessible every day for free telephone advice** provided a greater **sense of well-being and security** as well as **quick solutions** and **time-saving** (Original author) (Bala et al., 2017).
	One woman described having **increased personal contact with the nurse during a period when she was in need of support** (Original author) (Sjo & Bergsten, 2018).
	For me, this was perfect… It was **absolutely super to have such support**…actually… **having her was a fantastic support**…and so **often…she phoned me at home and I phoned her**…**it was fantastic** (I. 8, Patient Female, RA 40 years duration) (Sjo & Bergsten, 2018)
	Making a personal journey. What made this "journey" possible was the **targets set** during the encounters with the nurse, which had **a focus on, as far as possible, well-being**, and the fact that the **meetings took place at regular intervals**. This enabled participants to **gain greater insight into both themselves and their disease** (Original author) (Sjo and Bergsten, 2018).
	And because **you're in pain it makes you feel depressed**, it's **the ongoing 24/7 pain that is very depressing** and you **need someone to talk about it**. It **would be nice to the nurse could do this** (FG2: P4, Patient Female, RA 23 years duration) (Ryan et al., 2013).

	You **never get over RA**, lots of **people with cancer are offered counselling**, **RA is not offered the same support I would like the nurse to be able to help with this** (FG2: 1, Patient Female, RA 31 years duration) (Ryan et al., 2013). One of the interviewees reported that her **trainer did not sufficiently master the content of the training to make everything understandable** for all participants (Original author) (Arends et al., 2017). There were also signals that **the training did not meet the expectations of all participants**. For instance, nine participants **had expected to passively receive practical and medical information during the training** (Original author) (Arends et al., 2017). Also **with the help of [the trainer], who can offer the necessary support and motivation**, who **can sometimes help you get a grip on situations in which you get stranded, financially as well as physically**. This **may not be dealt with in depth during the course**, but **at least it is clear where you can turn to for further support** (P14, D, male, 55y, RA) (Arends et al., 2017).
Security & confidence	When the participants were at the clinics, the nurses showed that they were **well informed about participants' case history, interested in their present situation, focused on conveying knowledge, support and trust**, and made **careful plans for further follow-ups** (Original author) (Bala et al., 2012)**.** '**You feel that she is interested in my problem** and that **she really wants to help**. **It is extremely important to feel that they really are there for me**' (P4, Patient Female, RA 1 ½ years duration) (Bala et al., 2012). The participants felt that **the encounter with the nurse led to a sense of security, familiarity, and participation** that

	contributed and **added value to rheumatology care** (Original author) (Larsson et al., 2012).
	My **best contact was the nurse**. **If the drugs are not working you can just call her up** and **she will call you back**. She's **empathic, kind, practical** and **she'll sort things out** (FG2:P8, Patient Female, RA 10 years duration) (Ryan et al., 2013).
	They appreciated being **recognized when they contacted the clinic,** and **feeling that they were seen**, **heard and believed** increased their **feelings of trust and hope** (Original author) (Bala et al., 2012). It involves **professionalis**m, which in itself **provides a sense of security**. You feel that these **nurses know what they are doing** (Patient) (Larsson et al., 2012). To my mind, a **friendly manner**, **understanding your problems**, and **being taken seriously constitute complete care** (Patient) (Larsson et al., 2012). It was also found that **the encounters with the nurse led to a sense of security, familiarity and participation and added value to rheumatology car**e (Original author) (Larsson et al., 2012).
	I feel safe . . . **I rely a lot on them**! I think that **what they say is good, and I try to take it in** . . . **they are very responsive and open to my illness** as well **as to me as a person**, and **that is why I have so much confidence in them**' (P13, Patient Female. RA 2 ½ years duration) (Bala et al., 2012).
	The **rheumatology care is important for me**, absolutely! You **feel safer** in some way **if you have that contact and ring them** . . . because at the GP office they can't do much anyway**. It's difficult to find a doctor to empty [drain] a knee or a shoulde**r (Patient Male, RA 20 years duration) (Bala et al., 2017).