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RESEARCH ARTICLE

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Nurse-led care for people with early rheumatoid arthritis: Interview study with thematic analysis

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Abstract

Aims: To develop an understanding of what comprises nurse-led care in early rheumatoid arthritis from the perspective of rheumatology nurse specialists in England.

Design: Qualitative study.

Methods: Semi-structured telephone interviews with rheumatology nurse specialists in England were conducted in Summer 2020. Interviews were audio-recorded, transcribed verbatim and analysed using reflexive thematic analysis.

Reporting follows the appropriate elements of consolidated criteria for reporting qualitative research.

Results: Sixteen nurses were recruited and interviews lasted 30–60 min. Four themes with 14 subthemes were identified.

A specialist service delivered by experienced rheumatology nurses: Specialist care is provided by experienced nurse specialists with a high degree of autonomy in the rheumatology multidisciplinary team context.

Addressing patients' complex care needs: Care is evidence-based and aims to start treatment, keep in treatment, educate and support. Access to psychology expertise is needed.

Care with compassion using person-centred, holistic and empathetic approaches: Nurses create patient relationships and a positive therapeutic environment. Nurse-led telephone advice lines are essential for treatment adjustment, patient support and empowerment.

Continued evaluation and development of the service: Consultations are reviewed, and patients are asked for feedback. The COVID-19 pandemic caused disruption, but changes streamlined procedures and improved documentation and communication.

Conclusion: Nurse-led care in early rheumatoid arthritis is a specialist service delivered with compassion, addressing complex care needs and using person-centred approaches. This study identifies key aspects of care in early disease from the nurse perspective.

KEYWORDS
early arthritis, interview, nurse specialist, nurse-led care, qualitative, RA, rheumatology

1 | BACKGROUND

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease, which causes pain, swollen joints and risk of bone erosion (Aletaha and Smolen, 2018). Guidelines for RA management recommend treat-to-target strategies with early detection of RA and start of intensive treatment with disease modifying anti-rheumatic drugs (DMARDs) until the state of remission or low disease activity is achieved (Combe et al., 2017; Smolen et al., 2020). In the current study, early RA is defined within 2 years from diagnosis (Burgers, Raza, and Mil, 2019; Luqmani et al., 2006). Treat-to-target strategies in early RA require close monitoring and support in treatment to control disease activity (NICE, 2018; Smolen et al., 2020), as well as social, emotional and psychological support.

Guidelines for RA management in the UK (NICE, 2018) recommend access to a named member of the multidisciplinary team (MDT) such as a specialist nurse. However, the role of the nurse in early RA has not been described in the guidelines. In the United Kingdom (UK), nurse-led care is established (BSR & NRAS, 2019; Ndosi et al., 2017). The European Alliance for Rheumatology Associations (EULAR) recommendations for the role of the nurse in inflammatory arthritis (Bech et al., 2020) summarise the contribution of rheumatology nursing in patient education, satisfaction with care, timely access to care, disease management, efficiency of care, psychosocial support and supporting self-management. While these recommendations are more detailed than the NICE guidelines, much of the underpinning research evidence includes patients with long-standing RA.

Research has shown that nurse-led care is just as effective as rheumatologist-led care for managing RA. This is based on randomised controlled trials (RCTs) comparing consultations provided by rheumatology nurse specialists to consultations provided by rheumatologists (Beauvais et al., 2022; Hoeper et al., 2021; Koksvik et al., 2013; Kwok et al., 2022; Larsson et al., 2014; Lopatina et al., 2021; Ndosi et al., 2014; Primdahl et al., 2014; Sørensen et al., 2015). The RCTs found that patients who received nurse-led care were more satisfied with their care and had similar health outcomes as patients who received care from a rheumatologist (Bech et al., 2020; de Thurah et al., 2017; Garner et al., 2017; Sezgin and Bektas, 2021). Where cost effectiveness was assessed, nurse-led care was associated with low cost and increased patient satisfaction (Larsson et al., 2015; Ndosi et al., 2014; Sørensen et al., 2015).

Despite its demonstrated effectiveness, the mechanisms underpinning nurse-led care have not been well studied. Previous qualitative studies have focused on separate aspects of nurse-led care such as patient education and self-management (Larsson et al., 2012; Primdahl, Wagner, and Hørslev-Petersen, 2011), interaction styles (Vinall-Collier et al., 2016), and person-centred care (Bala, 2017; Bala et al., 2012). Data on the contribution of nurse-led care in early RA are limited (Sweeney et al., 2020). The aim of this study was to understand what comprises nurse-led care in early RA from the perspective of rheumatology nurse specialists. The research question was: What comprises nurse-led care in early RA from the perspective of rheumatology clinical nurse specialists?

2 | METHODS

2.1 | Design

A pragmatist approach was taken, choosing the most appropriate method for the research question (Dures et al., 2011). This was a qualitative study using Reflexive Thematic Analysis (RTA) with inductive orientation (Braun & Clarke, 2022). The inductive orientation allowed for a data driven development of themes across the data set, thus allowing an understanding of what constitutes nurse-led care in early RA.

Semi structured interviews with rheumatology nurse specialists in England were used to provide qualitative in-depth data of individual participants' views and perspectives (Brinkmann & Kvale, 2015). The interviews were conducted via the telephone to accommodate participants' time constraints, regional spread, and enabling compliance with COVID-19 restrictions (Block & Erskine, 2012). An interview guide was developed based on the research question and informed by a prior systematic review of qualitative studies (Sweeney et al., 2020) and input from the research team comprising a rheumatology nurse specialist, senior researchers, a rheumatologist, a psychologist, and a patient research partner, with professional and personal experience in the research area. The interview guide and technique were tested in a pilot interview with a rheumatology specialist nurse.

2.2 | Patient research partner

The patient research partner was an integral member of the research team, contributing to all aspects of the study on collaboration basis, from research design, advising on recruitment, interview guide all the way to report. She provided valuable insights from the patient perspective, ensuring that the research was relevant and meaningful for patients with early RA.

2.3 | Recruitment

Information power was used to guide the sampling strategy (Malterud, Siersma, and Guassora, 2021). It was deemed important for the study to seek input from nurse specialists with varied roles and years of experience from different types of clinics across England. For this study, a sample size between 10 and 30 was deemed likely to provide sufficient rich data to answer the research question (Braun & Clarke, 2022; Brinkmann & Kvale, 2015). We continued with data collection until sufficient rich data (interviews lasting between 30 and 60 min) were gathered to answer the research question and therefore fill the gaps in our understanding of what comprises nurse-led care in early RA from the perspectives of rheumatology nurses. Participants were purposively sampled to reflect the varied range of nurse specialist roles in early RA across England, years of experience and types of clinics. Participants were recruited through professional networks, which included the Royal College of Nursing (RCN) Rheumatology Nursing Forum, RCN Advanced Practitioner Forum and social media platforms. Potential participants were invited to contact the researcher, who provided them with participant information, privacy information, and a consent form. Interested participants were invited for interviews.

2.4 | Inclusion and exclusion criteria

Participants were included if they were clinical nurse specialists, nurse practitioners, or rheumatology nurses, who ran nurse-led clinics for people with early RA in England. Excluded were nurses who did not run nurse-led care for people with early RA.

2.5 | Data collection

Data were collected by telephone interviews with rheumatology nurse specialists in the Summer of 2020, in England. The first author conducted the interviews. There was no established relationship between the researcher and participants. Interviews were conducted in private, and no repeat interviews took place. The researcher neither emphasised nor hid her professional background in rheumatology nursing but used her experience to ask follow-up questions. The interviews started with a short informal and unrecorded conversation, which included information about the interview process. Participants were informed when the recording started and ended. Demographic data were collected verbally. The first interview question was: "Based on your experience, how would you define nurse-led care?" The full interview topic guide is provided in Supplementary Table ST1.

2.6 | Ethical consideration

Ethics approval was granted by the University of the West of England (UWE) Research Ethics Committee: HAS.20.03.143. Potential participants were informed about the aims of this study. Participation was voluntary, and informed consent was obtained in writing and repeated orally prior to interviews. Interview transcripts were anonymised, and the received information was kept confidential. Research materials were stored in accordance with the Data Protection Act 2018 and General Data Protection Regulation (GDPR) requirements.

2.7 | Data analysis

Interviews were audio-recorded and transcribed verbatim. Data were analysed using inductive RTA according to Braun and Clarke (2022). The RTA process had six phases: Familiarisation with data; coding across the entire data set; generating initial themes, developing and reviewing themes; refining, defining and naming themes; and writing up (Braun & Clarke, 2022). The approach was flexible and generated data driven themes characterising early RA nurse-led care. The first author conducted the analysis. Word software was used to manage data, and tables were created to structure codes and develop themes.

2.8 | Rigour and reflexivity

The research team participated in the analysis discussions. The contribution of the patient research partner helped ensure the relevance of the research for patients with early RA. A research diary recorded reflections and summaries, and the research process was continuously discussed with the research team. Two authors independently checked a subset of transcripts for initial themes and naming of themes was discussed until agreement. The study is reported according to appropriate elements of the recommended Consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

3 | FINDINGS

The study included 16 rheumatology nurse specialists from nurse-led clinics in England. All interested and eligible participants were included, and none dropped out of the study. Interviews lasted 30–60 min. Fourteen participants worked at hospital rheumatology departments and two in community settings. Thirteen participants were rheumatology nurse specialists, two participants were rheumatology consultant nurses, and one participant was a nurse practitioner. Rheumatology experience ranged from 1 year to over 25 years, with roles ranging from new nurse specialists to nurse consultants, some with management responsibilities. Participants had varied professional backgrounds, especially from rheumatology and orthopaedic wards. Two participants had master's degrees, and some participants had acquired academic modules in rheumatology nursing, prescription and intra-articular injection technique. Five nurses were non-medical prescribers, and 11 were non-prescribers. A summary of participant characteristics is provided in Table 1.

Four connected but distinct themes were identified, which characterised nurse-led care in early RA from the perspective of rheumatology nurse specialists (Figure 1). An overview of themes and subthemes with codes and illustrative quotations is provided in Supplementary Table ST2.

3.1 | Theme 1: A specialist service delivered by experienced rheumatology nurses

This theme characterises nurse-led care in early RA as a specialist service delivered by experienced rheumatology nurses. Subthemes describe specialist training and experience, the importance of autonomy in clinical practice, and collaboration with the wider MDT.

3.1.1 | Specialist training and experience

> "When I first started, I had no idea how massive or how specialised [nurse-led] rheumatology is" (CNS16)
>
> "To have the experience and knowledge is absolutely critical" (CNS04).

Participants described nurse-led care in early RA as a specialised rheumatology practice requiring extensive knowledge, skill, and experience to plan and deliver care in cooperation with the MDT and the patients. According to participants, they received in-house training and were guided and supervised by colleagues, and they were gradually introduced to run their own consultations. However, availability, time and funding for further training and education were limited. Participants had attended conferences and courses provided by medical companies. However, it could be challenging to get time off from work in a busy clinic.

3.1.2 | Autonomy in clinical practice

> "We run our clinics independently" (CNS14).
>
> "We look after the patients from diagnosis" (CNS04).

Participants reported that they worked with a high degree of autonomy. Depending on the workplace, their experience and role in the clinic, they would independently run education clinics, clinics for escalation of medication, follow-up and review clinics as well as providing support via the telephone advice line. Participants reported that they managed patients' medication in early RA with introduction and escalation of DMARDs. Some participants were prescribers and could make treatment decisions. Participants who were non-prescribers had autonomy using treatment protocols, which allowed them to adjust DMARDs and administer Glucocorticoids according to defined criteria.

3.1.3 | Collaboration with the multidisciplinary team

> "I think knowing that you've got a Multidisciplinary team is really helpful" (CNS09).

TABLE 1 Summary of participant characteristics.

Participant	Role in clinic	Rheumatology experience	Work context
CNS01	Rheumatology nurse specialist	13 years	Hospital trust
CNS02	Rheumatology nurse specialist	28 years	Hospital trust
CNS03	Rheumatology consultant nurse	Over 25 years	Community trust
CNS04	Rheumatology nurse specialist	15 years	Hospital trust
CNS05	Nurse practitioner	25 years	General practice
CNS06	Rheumatology nurse specialist	24 years	Hospital trust
CNS07	Rheumatology nurse specialist	6–7 years	Hospital trust
CNS08	Rheumatology nurse specialist	14 years	Hospital trust
CNS09	Rheumatology nurse specialist	5 years	Hospital trust
CNS10	Rheumatology nurse specialist	11 years	Hospital trust
CNS11	Rheumatology nurse specialist	10 years	Hospital trust
CNS12	Rheumatology nurse specialist	10 years	Hospital trust
CNS13	Rheumatology nurse specialist	1 year	Hospital trust
CNS14	Rheumatology nurse specialist	6–7 years	Hospital trust
CNS15	Rheumatology consultant nurse	Over 25 years	Hospital trust
CNS16	Rheumatology nurse specialist	4–5 years	Hospital trust

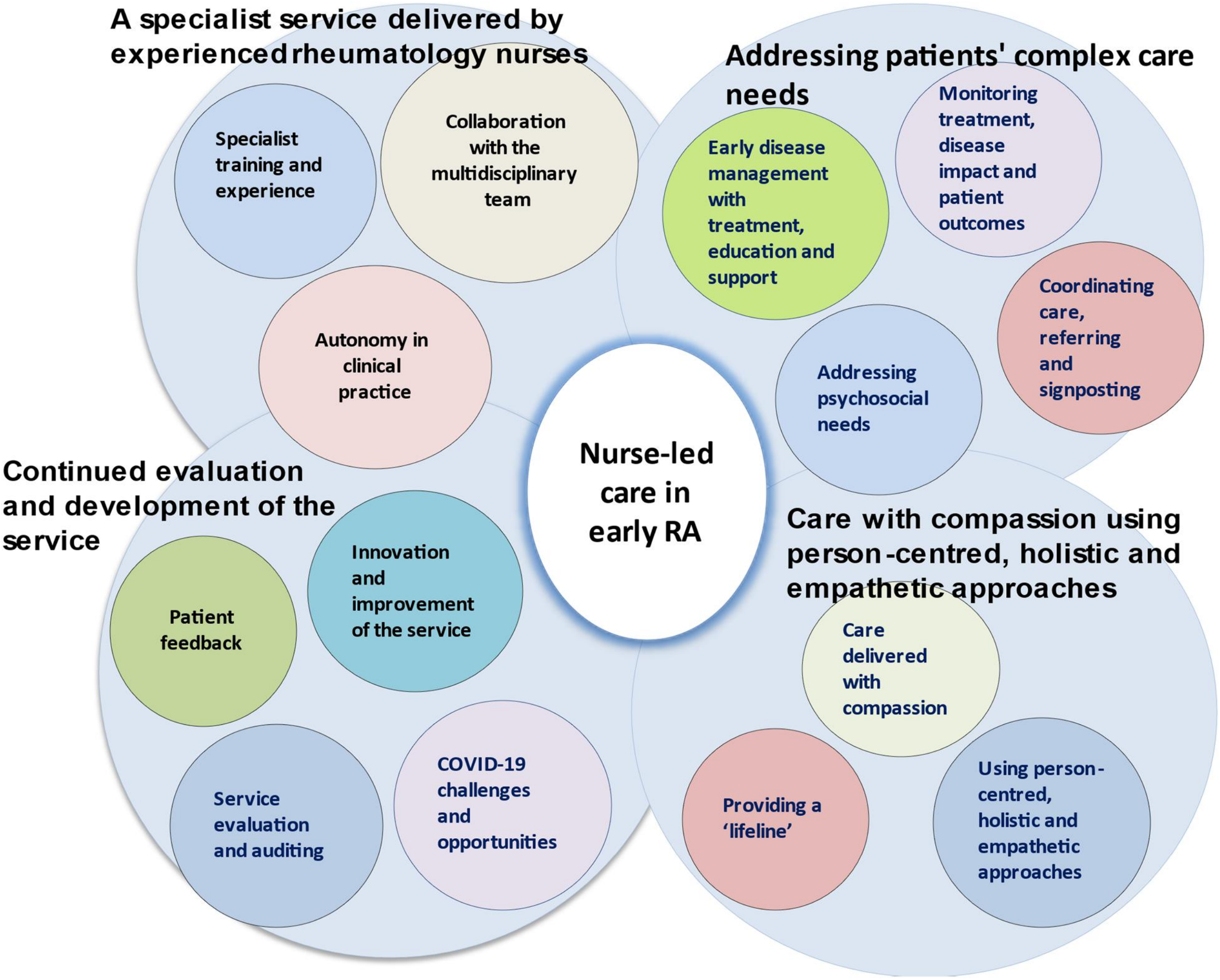

FIGURE 1 Themes and subthemes characterising early RA nurse-led care.

As participants managed medication in early RA, they reported that close collaboration between rheumatologists and nurse specialists was especially important to feel safe in their clinical practice.

Participants reported that they had good work relations with other members of the MDT, and the support from the MDT was seen as important. According to participants they worked closely together with colleagues as a team, relying on each other for advice and backup. They saw their practice as a collaboration and joint effort to provide good service for the patients in rheumatology.

3.2 | Theme 2: Addressing patients' complex care needs

The second theme captures the complex nature of early RA nurse-led care with subthemes describing aspects of care addressed in early RA. These subthemes include early disease management with the start of treatment and keeping in treatment; education and support; monitoring of treatment, disease impact and patient outcomes; addressing psychosocial needs; coordinating care; and referring and signposting.

3.2.1 | Early disease management with treatment, education, and support

> "So treat to target…escalating treatment as necessary, and addressing any concerns that the patients might have" (CNS14).

Participants reported that they were involved in providing RA management according to current international recommendations and national guidelines for early disease, which recommend early detection and start of treatment following a treat-to-target approach.

The aims of care were to: start treatment, keep in treatment, educate, and support. Participants reported that they introduced DMARD treatment at the first consultation after diagnosis.

3.2.2 | Monitoring treatment, disease impact and patient outcomes

> So looking at the efficacy of treatment, the response and how they feel. Have they improved?" (CNS04).

Participants reported that they monitored disease activity and disease impact using validated outcome measures and by asking questions during the consultation. Good outcomes were disease control, managing disease impact, medication and side effects, well-being and keeping in work.

Observation of the patients' movements as well as physical examination of the joints were seen as important for these assessments. Participants reported that they assessed disease activity and response to treatment. However, they emphasised the importance of getting 'the whole picture'. This included monitoring and addressing co-morbidities and lifestyle such as high-blood pressure and diabetes. Fatigue and anxiety were addressed by asking questions about the impact on everyday life.

3.2.3 | Coordinating care, referring and signposting

> "We have no access to psychotherapy, it is really rubbish basically. It is a difficult one" (CNS01).

According to participants, they coordinated care, referred to other health professionals and signposted patients to relevant services and charities.

Only a few participants had access to pain psychologists, Cognitive Behavioural Therapy (CBT) and fatigue management conducted by trained occupational therapists or nurses, either as access to a referral or as supervision. Participants agreed that access to psychology expertise was warranted as psychological issues were substantial in early RA. None mentioned referral for intimate or sex issues.

Shared Care Agreements with referral between rheumatology clinics and General Practice (GP) for DMARD prescriptions and follow up could be demanding. GPs looked after stable patients and referred unstable patients to rheumatology until they were stable. Prescriptions and blood tests needed double checking, and patients could be confused and unsure of whom to contact if needed.

3.2.4 | Addressing psychosocial needs

> "And whilst most of us have got some degree of understanding of…self-management, or psychology… we're not psychologists" (CNS02).

Participants reported that it could be very challenging for patients to be diagnosed with RA. They could experience shock, fear, anger, grief, and denial while feeling unwell with pain and fatigue.

It was seen as important to address the psychological side of the disease from the start, as concerns and worries could interfere with the patients' ability to take in information, start treatment and eventually stay in treatment. Education and a person-centred approach played an important part in easing the patients' distress and helped them to adapt. It was sought to give patients control at a time, when they could feel a loss of control, by providing education, strategies for setbacks and access to the telephone advice line with contact to the nurse specialists.

Participants reported that they provided psychological support but acknowledged that they were not experts. They listened to their patients and sought to support and encourage them that RA should not stop them from living a normal life. However, conversations about changes in lifestyle such as avoiding pregnancy and limiting alcohol intake because of the medical treatment could be sensitive and emotional. Issues about sex and intimate relationships could be challenging, and nurses felt awkward talking about these issues.

3.3 | Theme 3: Care with compassion using person-centred, holistic and empathetic approaches

The third theme captures the compassionate and person-centred approaches that nurse specialists use to deliver care. Subthemes describe the compassionate nature of early RA nurse-led care, where nurse specialists use a combination of person-centred, holistic, and emphatic approaches to provide early RA care. The provision of a lifeline for people with early RA, and what this aspect of care means for patients is described.

3.3.1 | Care delivered with compassion

> "It is a partnership and we're doing it together" (CNS14).

Participants felt they understood the patients. They had compassion for the patients and wanted to help the best they could. Participants reported that an essential aspect of early RA care was to establish a relationship with patients right from the start. This relationship was seen as crucial for effective and successful care. It encouraged patients to contact the nurse if they experienced symptoms, side effects, problems with medication, or had worries in general, so that these problems could be addressed, and solutions could be found without delay. According to participants, they assured patients they were not alone, and they were in it together from the start and throughout the journey.

3.3.2 | Using person-centred, holistic and empathetic approaches

> "Because it all relates. If the patients are stressed because they're not coping at work, then their arthritis isn't going to be so good. So everything relates to one another really" (CNS06).

Participants described how they used person-centred, holistic, and empathetic approaches to address patient needs in early RA. Describing their clinical practice, participants came across as being highly skilled in meeting patients at the different stages of their disease and centring the care on their complex care needs. Participants reported it was important to look at the whole person, as care was holistic, and everything was connected.

Participants highlighted the importance of actually listening to patients. According to participants, nurse specialists might consider that the most important issue for the patient was to get the disease under control, whereas the patient could want to be able to perform creative or social activities, such as knitting or being able to hold a grandchild.

3.3.3 | Providing a 'lifeline'

> "The Nurses are there for the patients and they know that" (CNS04).

Participants reported that they were the patients' primary contact at the rheumatology clinics, the first port of call. Participants described the nurse-led telephone advice line as the main link between patients and nurse specialists, which was essential for RA management and patient support.

The telephone advice line was reported to be of clinical importance as a tool for patient support as well as for monitoring the disease and adjusting treatment and care. The nurse-led telephone advice services thus provided a 'lifeline' for patients. If patients struggled, they could call and speak with a specialist who knew them and their RA well.

3.4 | Theme 4: Continued evaluation and development of the service

The fourth theme captures the aspect of the ongoing evaluation and development of rheumatology nurse-led care. Supporting subthemes describe aspects as patient feedback, and the use of patient feedback and audits to check if patient care needs are met, and to develop the service. The disruption caused by the COVID-19 pandemic as well as the challenges and opportunities caused by the pandemic are described.

3.4.1 | Patient feedback

> "It's really important to ask them initially what they expect to have from the consultation […] We've always had really good feedback in general…" (CNS02).

According to participants, it was seen as important to ask patients what they expected from the consultation with the nurse specialist. Some participants used focus forms for patients to fill in while they were waiting for their consultations. The form had suggestions of topics that patients might want to talk about and space for topics that were not on the list. Other clinics invited patients to write their own questions and show them to the nurse at the start of the consultation. At the end of the consultation, the nurse could then check with the patient if the topics had been addressed and questions answered or if follow-up was needed.

3.4.2 | Service evaluation and auditing

> "When you get them stable, when you get them into remission, when they're happy, when they're feeling well, I think there's lots of ways you can measure that" (CNS13).

Participants reported that their individual clinics and their services were evaluated to check if patients' care needs were met. Participants explained that there were many ways of measuring this such as disease control, management of the disease and its impact on everyday life, keeping in work, adjusting to the disease, and getting a normal life back. Patients would tell the nurse how they felt or send letters and messages to let the nurse know that they were well and improving.

Participants reported that they looked at patient cases from diagnosis until remission to check how pain had been managed and how education had worked. All cases were audited annually, and regular audits were conducted to get patient feedback on the current services or changes as well as feedback cards at the clinics. Patient partners and Patient Advisory Groups also provided feedback, which was reviewed at governance meetings. Nurse-led care generally had positive feedback on services.

3.4.3 | COVID-19 challenges and opportunities

> "At the moment [during the COVID-19 pandemic], most of our, appointments that we have are on the telephone, or we've got some video consultations as well" (CNS09).

Participants reported that despite the challenges imposed by the COVID-19 pandemic, the services adapted fast using telephone, video clinics and digital solutions, which streamlined procedures and improved documentation and communication. The telephone advice line became the main link between patients and nurse specialists. Face-to-face consultations were changed to telephone consultations, and only limited face-to-face appointments were available for patients who could not be managed via the telephone. Observation and physical examination were essential aspects of clinical assessment, but with telephone consultations, nurses had to rely on what patients told them. However, the disruption instigated the development of new processes of care and innovative solutions, and the COVID pandemic became a catalyst for changes in the service.

3.4.4 | Innovation and improvement of the service

> "I think things have changed […] And I don't' think they will go back to exactly as they were" (CNS02).

Participants reported that they developed video tutorials or written material which they posted to the patients. Telephone consultations were scheduled before and after receipt of these materials to ensure that information had been received and understood, and to give the patient an opportunity to ask questions. Participants developed protocols for telephone consultations, such as education clinics, escalation, follow-up, and review. The introduction of telephone clinics with designated day schedules improved the service regarding access, planning and documentation, and digital solutions streamlined booking systems, communication, and prescription of medication.

However, it was emphasised that some patients had to be seen in person depending on their specific needs. Patients with severe symptoms could require physical examination and assessment, some could lack access to wi-fi, adequate technology, or have limited computer skills. Participants agreed that telephone clinics worked well with access to face-to-face consultations according to needs.

4 | DISCUSSION

The current study provides an insight in the important role of the rheumatology specialist nurse in early RA. The findings show that nurse-led care in early RA is a specialist service delivered with compassion, addressing complex care needs, using person-centred approaches. This study identifies key aspects of care in early disease from the nurse perspective. Similar findings were reported by Oliver and Leary (Oliver & Leary, 2010, 2012), who documented the amount of workload and the complexity of the rheumatology nursing role. This complexity and the key skills and knowledge required to provide high-quality care to patients with early RA have been summarised in the competency framework for rheumatology nurses in the UK (RCN, 2020).

In this study, compassion was identified as an important aspect of early RA nurse-led care. Participants' thoughts, views, and clinical practice corresponded to compassion as described by Strauss et al. (2016). Strauss et al. (2016) proposed that compassion consists of five elements: recognising suffering, understanding the universality of human suffering, feeling for the person suffering, tolerating uncomfortable feelings, and motivation to act/acting to alleviate suffering. Similarly, kindness has been found to be important for positive patient experiences in cancer care (Berry et al., 2017). It has been characterised as 'a life vest in a sea of suffering', with six identified types of kindness: deep listening, empathy, generous acts, timely care, gentle honesty, and support for care givers (Berry et al., 2017). These elements resonated with data and the identified themes. Kindness, support, being understood and led at the beginning of disease are essential in early RA care (Sweeney et al., 2020).

Participants in this study reported that they managed patients from the start of disease throughout the RA journey with treatment, monitoring, education, and support. This is consistent with previous studies (Bech et al., 2020; Ndosi et al., 2011; Oliver & Leary, 2010, 2012) and a recent report on specialist nursing in rheumatology (BSR & NRAS, 2019). It was found in this study, that nurse access to education and training could be limited due to (lack of) time and funding, and complicated by pressures on the health service. This is consistent with the policy report, 'Specialist nursing in rheumatology: State of Play' (BSR & NRAS, 2019).

In our data, psychological support was seen as especially important in early RA and could help patients adjust to the disease. However, nurse specialists often were the only providers of psychological support without access to specialist referral or supervision. Few participants in the study had access to for example, pain psychologists, CBT, or fatigue interventions, which is consistent with the findings of a national audit (BSR and HQIP, 2022; Ndosi et al., 2017). Nurses understand that psychological issues need to be addressed but acknowledge that specialist support is needed.

Research on the psychological needs of patients with RA (Dures et al., 2016) found that the demand for psychological support was high, but only few patients were asked about social and emotional issues. Furthermore, patients were found to prefer support from rheumatology clinicians and in particular from the rheumatology nurses (Dures et al., 2016). The findings by Dures et *al*. (2016) suggest that nurses with appropriate training and experience could provide adequate psychological support in early RA, and that patients value this service. NICE guidelines recommend a four-stepped approach for psychological support in chronic disease (NICE, 2009). The two first steps can be delivered by nurses based on their professional experience and training. The provision of psychological support in early RA needs to be further explored to develop and improve the service. Introduction of psychologically informed health care may be a helpful approach (Dekker et al., 2023).

It was challenging for nurses to address issues about sex and intimate relationships. Recent research (Flurey, 2022) found that health professionals in rheumatology rarely addressed sexual health with patients despite considering it important. However, relevant training helped health professionals feel more comfortable about raising these issues with patients than staff without training (Flurey, 2022; Helland et al., 2013).

The findings of this research can inform clinical practice, nurse training, and future competence frameworks for the management of early RA.

5 | STRENGTHS AND LIMITATIONS

This study has some strengths. The interview method provided in-depth and rich data. Telephone interview accommodated participants from across England which helped obtain varied data. Telephone interviews might have offered some privacy and encouraged more open conversation compared to face-to-face or focus-group interviews. Using the interview-guide ensured that topics of interest were addressed, albeit allowing for prompt questions and discussion of other topics.

Inductive RTA (Braun & Clarke, 2022) allowed for the identification of themes across the entire data set. It also offered flexible guidelines for the analysis of data, which ensured that each phase of the analysis was addressed and reflected upon. In RTA, it is acknowledged that the researchers' interpretation of data is an important part of the research process. Each stage of the research process was discussed with co-authors and documented. It is possible that other researchers may obtain other and more varied data and results.

The study has some limitations. Only 16 nurse specialists participated. Participants were recruited in England and all participants were female. Whilst the data provided were rich and informed our research question, it is possible that more participants could have provided more nuanced data. For a broader investigation, research could be conducted with a wider population, using for example, survey methods.

This research was conducted at the outbreak of the COVID-19 pandemic, and face-to-face interviews were prohibited. It is possible that a face-to-face interview could have provided richer data. However, using telephone-interviews with all participants brought consistency in the research, and it was possible to reach participants at long geographical distances and at a time that suited them.

This study provided key aspects of care in early RA seen from the nurse perspective and can inform a model of care in early RA. More research is needed to get the patient perspective of the identified aspects of care, and to understand how early RA nurse-led care meets the needs of patients.

6 | CONCLUSION

This interview study identified themes and subthemes that described early RA nurse-led care as a specialist service delivered with compassion, addressing patients complex care needs using person-centred, holistic, and empathetic approaches with continued development and improvement of the service. The COVID-19 pandemic caused a disruption of the service but contributed to innovation and improvements as a catalyst for change. As psychosocial issues were found to play a major role in early RA care and could have an impact on the management of the disease, the lack of access to specialist psychology referral and supervision was highlighted. However, participants experienced that their patients were supportive of rheumatology nurse-led care in early RA. More research is needed to get the patient perspective of identified key aspects of early RA nurse-led care.

AUTHOR CONTRIBUTION

Anne-Marie Tetsche Sweeney: Conceptualisation, Investigation, Formal analysis, Writing – Original draft, Writing – Review & Editing. **Mwidimi Ndosi:** Conceptualisation, Supervision, Writing – Review & Editing. **Caroline A. Flurey:** Conceptualisation, Methodology, Supervision, Writing - Review & Editing. **Candy S. McCabe:** Conceptualisation, Supervision, Writing – Review & Editing. **Joanna C. Robson:** Conceptualisation, Supervision, Writing – Review & Editing. **Pamela Richards:** Conceptualisation, Supervision, Writing – Review & Editing.

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

Research data are not shared.

ETHICS STATEMENT

Ethics approval was granted by the University of the West of England (UWE) Research Ethics Committee: HAS.20.03.143.

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REFERENCES

Aletaha, D., & Josef, S. S. (2018). Diagnosis and management of rheumatoid arthritis: A review. *JAMA*, *320*(13), 1360–1372. https://doi.org/10.1001/jama.2018.13103

Bala, S.-V. (2017). *'Person-Centered care in nurse-led outpatient rheumatology clinics. From experience to measurement'. PhD disertation*. Faculty of Medicine, Lund University.

Bala, S.-V., Samuelson, K., Hagell, P., Svensson, B., Fridlund, B., & Hesselgard, K. (2012). The experience of care at nurse-led rheumatology clinics. *Musculoskeletal Care*, *10*(4), 202–211. https://doi.org/10.1002/msc.1021

Beauvais, C., Fayet, F., Rousseau, A., Sordet, C., Pouplin, S., Maugars, Y., Rose Marie, P., Savel, C., Ségard, V., Godon, B., L'amour, C., Perdriger, A., Brin, F., Peyrard, P., Chalier, F., Pallot-Prades, B., Tuffet, S., Griffoul, I., & Gossec, L. (2022). Efficacy of a nurse-led patient education intervention in promoting safety skills of patients with inflammatory arthritis treated with biologics: A multicentre randomised clinical trial. *RMD Open*, *8*(1), e001828. https://doi.org/10.1136/rmdopen-2021-001828

Bech, B., Primdahl, J., van Tubergen, A., Voshaar, M., HeidiZangi, A. L. B., Carina, B., Boryana, B., Boteva, B., Carubbi, F., Fayet, F., Ferreira, R. J. O., Hoeper, K., Kocher, A., Kukkurainen, M. L., Lion, V., Minnock, P., Moretti, A., Ndosi, M., Pavic Nikolic, M., & van Eijk-Hustings, Y. (2020). 2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Annals of the Rheumatic Diseases*, *79*(1), 61–68. https://doi.org/10.1136/annrheumdis-2019-215458

Berry, L. L., Tracey S, D., Robert A, C., & Awdish, R. L. A. (2017). Role of kindness in cancer care. *Journal of Oncology Practice*, *13*(11), 744–750. https://doi.org/10.1200/JOP.2017.026195

Block, E. S., & Erskine, L. (2012). Interviewing by telephone: Specific considerations, opportunities, and challenges. *International Journal of Qualitative Methods*, *11*(4), 428–445. https://doi.org/10.1177/160940691201100409

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide to understand and doing*. SAGE.

Brinkmann, S., & Kvale, S. (2015). *InterViews*. SAGE Publications.

BSR, and NRAS. 2019. Specialist nursing in rheumatology - the state of play.

Burgers, L. E., Raza, K., & van der Helm-van Mil, A. H. (2019). Window of opportunity in rheumatoid arthritis – Definitions and supporting evidence: From old to new perspectives. *RMD Open*, *5*(1), e000870. https://doi.org/10.1136/rmdopen-2018-000870

Combe, B., Landewe, R., Daien, C. I., Hua, C., Aletaha, D., Bakkers, M., Brodin, N., Burmester, G. R., Codreanu, C., Conway, R., Dougados, M., Paul, E., Ferraccioli, G., Fonseca, J., Raza, K., Silva-Fernández, L., Josef S, S., Diana, S., Szekanecz, Z., … van Vollenhoven, R. (2017). 2016 update of the EULAR recommendations for the management of early arthritis. *Annals of the Rheumatic Diseases*, *76*(6), 948–959. https://doi.org/10.1136/annrheumdis-2016-210602

Dekker, J., Sears, S. F., Pernilla, Å., & Katherine, B. (2023). Translational Behavioral Medicine ibac105. https://doi.org/10.1093/tbm/ibac105. Psychologically informed health care.

de Thurah, A., Appel Esbensen, B., Ida Kristiane, R., Tove Faber, F., & Primdahl, J. (2017). Efficacy of embedded nurse-led versus conventional physician-led follow-up in rheumatoid arthritis: A systematic review and meta-analysis. *RMD Open*, *3*(2), e000481. https://doi.org/10.1136/rmdopen-2017-000481

Dures, E., Almeida, C., Caesley, J., Peterson, A., Ambler, N., Morris, M., Pollock, J., & Hewlett, S. (2016). Patient preferences for psychological support in inflammatory arthritis: A multicentre survey. *Annals of the Rheumatic Diseases*, *75*(1), 142–147. https://doi.org/10.1136/annrheumdis-2014-205636

Dures, E., Rumsey, N., Morris, M., & Gleeson, K. (2011). Mixed methods in health psychology: Theoretical and practical considerations of the third paradigm. *Journal of Health Psychology*, *16*(2), 332–341. https://doi.org/10.1177/1359105310377537

Flurey, C. A. (2022). Let's talk about sex, rheumatology. *Nature Reviews Rheumatology*, *18*(2), 65–66. https://doi.org/10.1038/s41584-021-00722-y

Garner, S., Lopatina, E., Rankin, J. A., & Marshall, D. A. (2017). Nurse-led care for patients with rheumatoid arthritis: A systematic review of the effect on quality of care. *Journal of Rheumatology*, *44*(6), 757–765. https://doi.org/10.3899/jrheum.160535

Helland, Y., Garratt, A., Kjeken, I., Kvien, T. K., & Dagfinrud, H. (2013). Current practice and barriers to the management of sexual issues in rheumatology: Results of a survey of health professionals. *Scandinavian Journal of Rheumatology*, *42*(1), 20–26. https://doi.org/10.3109/03009742.2012.709274

Hoeper, J. R., Zeidler, J., Meyer, S. E., Gauler, G., Steffens-Korbanka, P., Welcker, M., Wendler, J., Schuch, F., von Hinüber, U., Schwarting, A., Witte, T., Meyer-Olson, D., & Hoeper, K. (2021). Effect of nurse-led care on outcomes in patients with ACPA/RF-positive rheumatoid arthritis with active disease undergoing treat-to-target: A multicentre randomised controlled trial. *RMD Open*, *7*(1), e001627. https://doi.org/10.1136/rmdopen-2021-001627

Koksvik, H. S., Kåre Birger, H., Rødevand, E., Mowinckel, P., Kvien, T. K., & Zangi, H. A. (2013). Patient satisfaction with nursing consultations in a rheumatology outpatient clinic: A 21-month randomised controlled trial in patients with inflammatory arthritides. *Annals of the Rheumatic Diseases*, *72*(6), 836–843. https://doi.org/10.1136/annrheumdis-2012-202296

Kwok, S.-K., Lai-Man, T., Tsang, H.-L., Chung, Ho-Y., Chung, M.-Ho, Ho, C. T. K., Lau, C.-S., & Cheung, T. T. (2022). Nurse-led consultation for patients with rheumatoid arthritis at low disease activity: A randomized noninferiority trial. *Arthritis Care & Research*, *74*(10), 1736–1744. https://doi.org/10.1002/acr.24625

Larsson, I., Bergman, S., Fridlund, B., & Arvidsson, B. (2012). Patients' experiences of a nurse-led rheumatology clinic in Sweden: A qualitative study. *Nursing and Health Sciences*, *14*(4), 501–507. https://doi.org/10.1111/j.1442-2018.2012.00723.x

Larsson, I., Fridlund, B., Arvidsson, B., Teleman, A., & Bergman, S. (2014). Randomized controlled trial of a nurse-led rheumatology clinic for monitoring biological Therapy. *Journal of Advanced Nursing*, *70*(1), 164–175. https://doi.org/10.1111/jan.12183

Larsson, I., Fridlund, B., Arvidsson, B., Teleman, A., Svedberg, P., & Bergman, S. (2015). A nurse-led rheumatology clinic versus rheumatologist-led clinic in monitoring of patients with chronic inflammatory arthritis undergoing biological Therapy: A cost comparison study in a randomised controlled trial. *BMC Musculoskeletal Disorders*, *16*(1), 354. https://doi.org/10.1186/s12891-015-0817-6

Lopatina, E., Marshall, D. A., Le Clercq, S. A., Noseworthy, T. W., Suter, E., De la Rossa Jaimes, C., Lauf, A. M., Mosher, D. P., & Barber, C. E. H. (2021). Nurse-led care for stable patients with rheumatoid arthritis: Quality of care in routine practice compared to the traditional rheumatologist-led model. *Rheumatology and Therapy*, *8*(3), 1263–1285. https://doi.org/10.1007/s40744-021-00339-3

Luqmani, R., Hennell, S., Estrach, C., Birrell, F., Bosworth, A., Davenport, G., Fokke, C., Goodson, N., Jeffreson, P., Lamb, E., Mohammed, R., Oliver, S., Stableford, Z., Walsh, D., Washbrook, C., & Webb, F. (2006). British society for rheumatology and British health professionals in rheumatology guideline for the management of rheumatoid arthritis (the first two years). *Rheumatology*, *45*(9), 1167–1169. https://doi.org/10.1093/rheumatology/kel215a

Malterud, K., & Siersma, V., & Ann Dorrit, G. (2021). Information power: Sample content and size in qualitative studies. In *Qualitative research in psychology: Expanding perspectives in methodology and design* (2nd ed., pp. 67–81). American Psychological Association.

Ndosi, M., Ferguson, R., Backhouse, M. R., Bearne, L., Ainsworth, P., Roach, A., Dennison, E., & Cherry, L. (2017). National variation in the composition of rheumatology multidisciplinary teams: A cross-sectional study. *Rheumatology International*, *37*(9), 1453–1459. https://doi.org/10.1007/s00296-017-3751-0

Ndosi, M., Lewis, M., Hale, C., Quinn, H., Ryan, S., Paul, E., Bird, H., & Hill, J. (2014). The outcome and cost-effectiveness of nurse-led care in people with rheumatoid arthritis: A multicentre randomised controlled trial. *Annals of the Rheumatic Diseases*, *73*(11), 1975–1982. https://doi.org/10.1136/annrheumdis-2013-203403

Ndosi, M., Vinall, K., Hale, C., Bird, H., & Hill, J. (2011). The effectiveness of nurse-led care in people with rheumatoid arthritis: A systematic review. *International Journal of Nursing Studies*, *48*(5), 642–654. https://doi.org/10.1016/j.ijnurstu.2011.02.007

NICE. (2009). Depression in adults with a chronic physical health problem: Recognition and management. Retrieved 30 March 2020 (Retrieved from https://www.nice.org.uk/guidance/cg91/chapter/1-Guidance#stepped-care

NICE. (2018). NICE guideline. Rheumatoid arthritis in adults: Management. Retrieved from https://www.nice.org.uk/guidance/ng100

Oliver, S., & Leary, A. (2010). The value of the nurse specialists' role: Pandora initial findings. *Musculoskeletal Care*, *8*(3), 175–177. https://doi.org/10.1002/msc.186

Oliver, S., & Leary, A. (2012). Return on investment: Workload, complexity and value of the CNS. *British Journal of Nursing*, *21*(1), 32–37. https://doi.org/10.12968/bjon.2012.21.1.32

Primdahl, J., Jan, S., Horn, H. C., Petersen, R., & Hørslev-Petersen, K. (2014). Shared care or nursing consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis outpatients with low disease activity—Patient outcomes from a 2-year, randomised controlled trial. *Annals of the Rheumatic Diseases*, *73*(2), 357–364. https://doi.org/10.1136/annrheumdis-2012-202695

Primdahl, J., Wagner, L., & Kim, H.P. (2011). Being an outpatient with rheumatoid arthritis – A focus group study on patients' self-efficacy and experiences from participation in a short course and one of three different outpatient settings. *Scandinavian Journal of Caring Sciences*, *25*(2), 394–403. https://doi.org/10.1111/j.1471-6712.2010.00854.x

RCN (2020). A competency framework for rheumatology nurses.

Sezgin, M. G., Gozde, M., & Bektas, H. (2021). The effect of nurse-led care on fatigue in patients with rheumatoid arthritis: A systematic review and meta-analysis of randomised controlled studies. *Journal of Clinical Nursing*, *31*(7–8), 832–842. https://doi.org/10.1111/jocn.16003

Smolen, J. S., Landewé, R. B. M., Bijlsma, J. W. J., Burmester, G. R., Dougados, M., Kerschbaumer, A., McInnes, I. B., Sepriano, A., van Vollenhoven, R. F., de Wit, M., Aletaha, D., Aringer, M., Askling, J., Balsa, A., Boers, M., den Broeder, A. A., Buch, M. H., Buttgereit, F., Caporali, R., & van der Heijde, D. (2020). EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2019 update. *Annals of the Rheumatic Diseases*, *79*(6), 685–699. https://doi.org/10.1136/annrheumdis-2019-216655

Sørensen, J., Primdahl, J., Horn, H. C., & Hørslev-Petersen, K. (2015). Shared care or nurse consultations as an alternative to rheumatologist follow-up for rheumatoid arthritis (RA) outpatients with stable low disease-activity RA: Cost-effectiveness based on a 2-year randomized trial. *Scandinavian Journal of Rheumatology*, *44*(1), 13–21. https://doi.org/10.3109/03009742.2014.928945

Strauss, C., Taylor, B. L., Gu, J., Kuyken, W., Baer, R., Jones, F., & Cavanagh, K. (2016). What is compassion and how can we measure it? A review of definitions and measures. *Clinical Psychology Review*, *47*, 15–27. https://doi.org/10.1016/j.cpr.2016.05.004

Sweeney, A.-M. T., McCabe, C., Flurey, C. A., Robson, J. C., Berry, A., Richards, P., & Ndosi, M. (2020). The patient perspective of nurse-led care in early rheumatoid arthritis: A systematic review of qualitative studies with thematic analysis. *Journal of Clinical Nursing*, *0*(0), 1–16. https://doi.org/10.1111/jocn.15531

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Vinall-Collier, K., Madill, A., & Firth, J. (2016). A multi-centre study of interactional style in nurse specialist- and physician-led rheumatology clinics in the UK. *International Journal of Nursing Studies*, *59*, 41–50. https://doi.org/10.1016/j.ijnurstu.2016.02.009

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