Defining and refining nurse-led care for people with early rheumatoid arthritis

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Abstract

Nurse-led care in rheumatoid arthritis (RA) has been shown to be effective. However, the role of the nurse in early RA is not well-defined, and it is not known how well care needs are met in early RA nurse-led care. This PhD research aims to provide new knowledge in understanding nurse-led care in early RA and to propose a model of early RA care.

Three studies were conducted using a sequential exploratory mixed method approach: a systematic review of qualitative studies, an interview study with rheumatology nurse specialists, and a cross-sectional survey with patients in early RA. Evidence from the three studies was compared with EULAR recommendations for the role of the nurse, EULAR recommendations for management of early RA, and with an earlier model of rheumatology nursing care.

The systematic review found that patients valued nurse-led care. It was characterised by professionalism, person-centeredness, and a capacity to address holistic care needs. However, only few studies specifically included the perspective of patients with early RA. The interview study with rheumatology nurse specialists found that nurse-led care in early RA is a specialist service that is delivered with compassion and addresses complex and holistic care needs using person-centred approaches. Innovation and service improvement are part of the role. The study provided a provisional model of nurse-led care in early RA. In the patient survey, questionnaire items representing the provisional model of care were assessed as highly important. Analysis of participant comments generated themes of patient needs such as being listened to, involved, and informed.

The synthesis of evidence generated a novel model of nurse-led care in early RA with the potential to meet patients’ complex and holistic care needs. The research contributes to knowledge about rheumatology nursing and can inform practice, training, and further research.

List of abbreviations and acronyms

AS	Ankylosing Spondylitis
BNSSG	Bristol, North Somerset and South Gloucestershire
BRI	Bristol Royal Infirmary
BSR	British Society of Rheumatology
BHPR	British Health Professionals in Rheumatology
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CIA	Chronic Inflammatory Arthritis
DMARD	Disease-Modifying Antirheumatic Drugs
EULAR	The European Alliance of Associations for Rheumatology
GDPR	General Data Protection Regulation
GP	General Practitioner
HAQ	Health Assessment Questionnaire
IA	Inflammatory Arthritis
MRI	Magnetic Resonance Imaging
MSK	Musculoskeletal
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NSAIDs	Nonsteroidal Anti-Inflammatory Drug
OT	Occupational Therapist
PROM	Patient Reported Outcome Measure
PRP	Patient Research Partner
PsA	Psoriatic Arthritis
RA	Rheumatoid Arthritis
RCN	Royal College of Nursing
RCT	Randomised Controlled Trial
SLE	Systemic Lupus Erythematosus

List of outputs

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Chapter 1: Introduction to the thesis

This chapter introduces the thesis and provides background information, key concepts, justification for the PhD, aims and objectives as well as the research questions that address the objectives. The chapter also provides a summary of the mixed methods approach with an outline of methods used in this PhD. Lastly, this chapter introduces the researcher and the supervisory team.

The background for this PhD thesis is presented in the following section with an overview of RA, early RA, symptoms, disease impact and treatment strategy. Nurse-led care and recommendations for rheumatology nursing are explained, and gaps in knowledge are outlined.

1.1. Rheumatoid arthritis

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease which causes pain, swollen joints and risk of bone erosion (Aletaha and Smolen, 2018). The disease has a major impact on quality of life (Aletaha and Smolen, 2018; West and Jonsson, 2005) and people often need lifelong medical treatment and care. Patients can thus experience limitations in physical function, increased pain and fatigue, inability to maintain paid work or work instability, psychological distress, and limitations in participation in family, social, and leisure activities.

Guidelines for RA management changed dramatically over ten years ago. This included the British Society for Rheumatology and British Health Professionals in Rheumatology Guideline for the Management of Rheumatoid Arthritis (BSR/BHPR) for early RA (Luqmani *et al.*, 2006), BSR/BHPR guidelines for management of established RA (Luqmani *et al.*, 2009), the ‘treat-to-target’ recommendations by the European Alliance of Associations for Rheumatology (EULAR) (Smolen *et al.*, 2010) followed by the American College of Rheumatology (ACR) recommendations (Singh *et al.*, 2012). The ACR recommendations were updated in 2015 (Singh *et al.*, 2016), and the EULAR recommendations in 2016 (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, with the target being remission (Smolen *et al.*, 2020; Combe *et al.*, 2017), has been shown to have better clinical outcomes and better quality of life, and helps prevent further structural damage, functional disability and job loss (Smolen *et al.*, 2017; Combe *et al.*, 2015).

Recommendations for management of RA specify that composite measures should be used to monitor treatment response (Aletaha *et al.*, 2020; NICE, 2018; Combe *et al.*, 2017; Smolen *et al.*, 2010). The 28 joint disease activity score, which incorporates erythrocyte sedimentation rate (DAS28-ESR), is widely used as a measure of inflammatory disease activity in people with RA during clinical decision-making (McWilliams *et al.*, 2018). In the UK, DAS28-ESR is used to determine eligibility for biologic therapies (McWilliams *et al.*, 2018; NICE, 2018), and DAS28-ESR ≥3.2 can be used as a threshold for classifying active RA, and as a target for intensive treatment (NICE, 2018).

1.1.1. Early RA

Early RA has historically been considered as less than five years since diagnosis (Scott, 2007). By early-1990s it was described to be 24 months or less (Scott, 2007), with emphasis on the first 12 months (Emery and Salmon, 1995). It had proved challenging to recognise early RA as physicians often could not recognise it on clinical grounds alone (Scott, 2007). The main rationale for focusing on the need for prompt specialist involvement in early RA was that leaving patients with early RA either undiagnosed or untreated increased the risk of persisting inflammation and progressive joint damage (Scott, 2007). Therefore, inflammation in patients presenting with RA should be suppressed as early as possible (Scott, 2007; Emery and Salmon, 1995). In the extended report 'Very early RA' (Gremese *et al.*, 2013) the main message was to diagnose RA early and treat to target within 12 weeks from symptom onset. This approach was repeated in the updated EULAR recommendations in 2016 and 2019 for the management of RA (Smolen *et al.*, 2017, 2020) and early arthritis (Combe *et al.*, 2017). It constituted the clinical importance of early recognition of symptoms, referral to a rheumatologist and start of treat to target within 12 weeks from symptom onset (Combe *et al.*, 2017).

EULAR published recommendations for management of early arthritis in 2007 (Combe *et al.*, 2007), which were updated in 2016 based on evidence in the literature and on expert opinion (Combe *et al.*, 2017). A new element was the maximum delay of three months after the onset of symptoms before starting the first DMARD. The expert committee found that these three months were the ‘window of opportunity’ that should be considered to provide an optimal outcome in patients at risk (Combe *et al.*, 2017). Regarding the best definition for ‘early RA’, a duration of three months after the onset of symptoms was seen to be the longest allowable delay in prescribing the first DMARD, although it was acknowledged that this maximum delay was difficult to meet in clinical practice (Combe *et al.*, 2017). Most of the recent ‘early RA cohorts’ allowed a delay of six months from the onset of symptoms for inclusion (van Nies *et al.*, 2015; Mouterde *et al.*, 2011; Funovits *et al.*, 2010), which aligns with recent ACR guidelines of early RA being not more than six months post diagnosis (Singh *et al.*, 2016). Combe *et al.* (2017) concluded that a delay of more than one year from symptom onset must no longer be considered ‘early’.

However, a study from 2019 (Burgers, Raza and Mil, 2019) questioned an early ‘window of opportunity for RA treatment’ where the disease was more susceptible to DMARD treatment. They firstly conducted a literature review to establish if there was an agreement on the concept of the window of opportunity in terms of its time period and the outcomes it influenced. They then conducted a systematic review on the evidence of the benefit of early versus delayed treatment as provided by randomised controlled trials. They found that the concept of the window of opportunity had changed over time in regard to timing and outcome since it was first described 25 years ago. Thus, they found there is an ‘old definition’ pointing to the first two years after diagnosis, where there is an increased potential for disease-modifying treatment to prevent severe radiographic damage and disability. According to the authors, strong evidence supports this concept (Burgers, Raza and Mil, 2019). They concluded that a 'new definition', which presumes a therapeutic window in a pre-RA phase in which the biologic processes could be halted, and RA development prevented by very early treatment, was less well studied in trials and thus not supported by evidence (Burgers, Raza and Mil, 2019).

Due to the challenges in detecting and diagnosing RA and early RA, it is likely that nurses involved in rheumatology care see patients at varying stages of their disease. When exploring processes of nurse-led care in early RA it is important to take an inclusive approach to the definition of early RA. In this thesis early RA is defined as the first two years from diagnosis (Burgers, Raza and Mil, 2019; Luqmani *et al.*, 2006) as it encompasses all above mentioned definitions of early RA.

1.1.2. Recommendations for pharmacologic management of RA

According to the current EULAR recommendation for the management of RA with synthetic and biological disease-modifying antirheumatic drugs (Smolen *et al.*, 2020), it is widely accepted that clinical remission is the main therapeutic target for patients with RA. Low disease activity is seen as a best possible alternative, and a treat-to-target strategy should be applied when treating patients with RA (Smolen *et al.*, 2020). The recommendations concern the use of conventional synthetic (cs) DMARDs (methotrexate (MTX), leflunomide, sulfasalazine); glucocorticoids (GCs); biological (b) DMARDs (necrosis factor inhibitors (adalimumab, certolizumab pegol, etanercept, golimumab, infliximab), abatacept, rituximab, tocilizumab, sarilumab and biosimilar (bs) DMARDs) and targeted synthetic (ts) DMARDs (the Janus kinase (JAK) inhibitors tofacitinib, baricitinib, filgotinib, upadacitinib). They also provide guidance on monotherapy, combination therapy, treatment strategies (treat-to-target) and tapering if sustained clinical remission is achieved (Smolen *et al.*, 2020).

According to the EULAR recommendation, treatment should initially be started with MTX plus GCs. If there is insufficient response to this therapy within three to six months, stratification according to risk factors is recommended. This means that with poor prognostic factors (presence of autoantibodies, high disease activity, early erosions or failure of two csDMARDs), any bDMARD or JAK inhibitor should be added to the csDMARD. If this fails, any other bDMARD (from another or the same class) or tsDMARD is recommended. Finally, on sustained remission, DMARDs may be tapered, but not be stopped (Smolen *et al.*, 2020).

1.1.3. Recommendations for rheumatology nursing

In 2012, the European Alliance of Associations for Rheumatology (EULAR) published ten recommendations for the role of the nurse in the management of chronic inflammatory arthritis (CIA) (Eijk-Hustings *et al.*, 2012). The recommendations provided a basis for improvement and more standardised levels of professional nursing care in Europe, as access to rheumatology nurses and models of care varied across countries. The EULAR recommendations for the role of the rheumatology nurse have recently been updated with current evidence (Bech *et al.*, 2020). They specify three overarching principles:

1. Rheumatology nurses are part of a healthcare team

Rheumatology nurses work in close collaboration with the patient, family and significant others as appropriate, with the rheumatologist and if applicable a wider healthcare team, with a common focus on care and outcome (Bech *et al.*, 2020; Kilpatrick *et al.*, 2011).

2. Rheumatology nurses provide evidence-based care

Rheumatology nursing is based on the principles of evidence-based practice. Providing evidence-based care is broader than care based on protocols and guidelines. Evidence-based care integrates different sources of knowledge in practice: (i) research evidence, (ii) clinical nursing experience, (iii) patients' experiences, preferences and values and (iv) the local context (Bech *et al.*, 2020; Rycroft-Malone *et al.*, 2004; Sackett *et al.*, 1996).

3. Rheumatology nursing is based on shared decision-making with the patient

Patients' values and preferences are part of the comprehensive process of proper knowledge exchange and consensus on treatment decision (Bech *et al.*, 2020; Dy and Purnell, 2012; Makoul and Clayman, 2006).

However, the recommendations do not address the role of the nurse in early RA. There are thus no guidelines or recommendations for nurse-led care in early RA management, although patients with early RA attend rheumatology nurse-led clinics for RA management and support.

1.2. Nurse-led care

Nurse-led care was defined by Cullum *et al.* (2005) as a continuum, with nurses undertaking highly protocol driven focused tasks at one end and on the other end, nurses responding to diverse challenges in terms of clinical decision-making, such as first contact care and rehabilitation (Cullum, Spilsbury and Richardson, 2005).

In rheumatology, early attempts to describe the complexity of nurse-led care looked into day-to-day activities of clinical nurse specialists (Oliver and Leary, 2010, 2012). They identified five dimensions of clinical work: Physical, psychological, social, spiritual and referral. Tasks involved alleviating pain, assessment of symptoms (physical dimension), and dealing with psychological issues such as anxiety and distress (psychological dimension). There was evidence that an important part of rheumatology nursing was to conduct outpatient appointments, run telephone advice line support, do administrative work; have high levels of vigilance in relation to drug management, including blood monitoring, proactive management of potential drug-related side effects or poor disease control, and positive support for patients experiencing exacerbations of their condition (Oliver and Leary, 2010).

Clinical nurse specialists responsible for this model of care, practice at an extended role, assuming their own caseloads (Oliver and Leary, 2010, 2012). In the UK, rheumatology nurse-led clinics run alongside rheumatologists' clinics or are independent clinics working with support of the wider team (BSR and NRAS, 2019). The rheumatology nurse-led clinics started over three decades ago (Bird, 1983) and have been established as normal care in the UK (BSR and NRAS, 2019; NICE, 2018). Nursing interventions include assessment, monitoring the impact of disease, treatments, providing patient education, giving psychosocial support and referring appropriately to the multidisciplinary team (Oliver and Leary, 2010, 2012).

1.2.1. The effectiveness of nurse-led care in RA

The clinical effectiveness of nurse-led care in managing RA has been established in systematic reviews and in randomised controlled trials (RCTs). Currently there is evidence from six systematic reviews**,** and 11 RCTs conducted in France, Denmark, Norway, Sweden, Germany, the UK. and China.

The evidence from systematic reviews is summarised in the following section in chronological order from 2011 to 2022.

A systematic review (Ndosi *et al.*, 2011) was conducted to determine the effectiveness of nurse-led care in RA. The conclusion was that some outcomes favoured nurse-led care but there was insufficient evidence. More good quality RCTs of nurse-led care effectiveness were required (Ndosi *et al.*, 2011).

A systematic review (Eijk-Hustings *et al.*, 2012) was conducted to develop EULAR recommendations for the role of the nurse in the management of patients with CIA. The results were incorporated in the recommendations. The conclusion was that ten evidence-based and expert opinion-based recommendations for the role of the nurse in the management of CIA were developed.

A systematic review with meta-analysis (de Thurah *et al.*, 2017) was conducted to compare the efficacy of embedded nurse-led versus conventional physician-led follow-up on disease activity in patients with RA. The conclusion was that after one year no difference in disease activity, indicated by DAS-28, was found between embedded nurse-led follow-up compared with conventional physician-led follow-up, in patients with RA low disease activity or in remission.

A systematic review (Garner *et al.*, 2017) was conducted to assess the effect of nurse-led care for patients with RA using multiple dimensions of quality of care from the Alberta Quality of Care Matrix for Health. The conclusion was that nurse-led care was effective, acceptable, and safe as compared with other models. However, current evidence was insufficient to draw conclusions about its efficiency, accessibility, and appropriateness.

A systematic review (Bech *et al.*, 2020) was conducted to update EULAR recommendations for the role of the nurse in the management of patients with CIA. The results were incorporated in the updated recommendations like the previous recommendations from 2012 (Eijk-Hustings *et al.*, 2012).

The latest review is a systematic review with meta-analysis of RCTs (Sezgin and Bektas, 2021), conducted to investigate the effect of nurse-led care on fatigue in patients with RA. The findings indicated that nurse-led care played an important role in reducing fatigue in patients with RA.

In summary, the systematic reviews showed that rheumatology nurse-led care was effective, acceptable, and safe as compared with other models (Garner *et al.*, 2017).

The RCTs consistently supported effectiveness of nurse-led care in patients with RA. The evidence is overwhelming for patients with low disease activity (the majority of RCTs) and in the UK, this included patients with high disease activity. Where the economic evaluation was undertaken, nurse-led care was associated with low cost and increased patient satisfaction (Larsson *et al.*, 2015; Sørensen *et al.*, 2015; Ndosi *et al.*, 2014)

The Norwegian group (Koksvik *et al.*, 2013) aimed to study the effect of individual nursing consultations in patients treated with DMARDs in a rheumatology outpatient setting. The conclusion was that patients with CIA are likely to benefit from nurse consultations in terms of increased satisfaction with care compared with medical doctor (MD) consultations and without loss of efficacy in terms of clinical outcomes.

The first Danish RCT (Primdahl *et al.*, 2014), aimed to compare patient outcomes of three types of follow-ups for patients with RA low disease activity (planned rheumatologist consultations, shared care without planned consultations or planned nursing consultations). The conclusion was that it was safe to implement shared care and nursing consultations as alternatives to rheumatologist consultations for RA outpatients with low disease activity without deterioration in disease control. Furthermore, nursing consultations could enhance patients' self-efficacy, confidence and satisfaction.

The first Swedish RCT (Larsson *et al.*, 2014) aimed to compare and evaluate the treatment outcomes of a nurse-led rheumatology clinic and a rheumatologist-led clinic in patients with low disease activity or in remission who were undergoing biological therapy. The conclusion was that patients with stable CIA undergoing biological therapy could be monitored by a nurse-led rheumatology clinic without difference in outcome.

The RCT in the UK (Ndosi *et al.*, 2014) aimed to determine the clinical effectiveness and cost-effectiveness of nurse-led care for people with RA. There was robust evidence to support non-inferiority of nurse-led care in the management of RA. Furthermore, nurse-led care had higher ‘general satisfaction’ scores than rheumatologist led care in week 26 of the study. However, it was concluded that in terms of health policy firm conclusions on cost-effectiveness could not be drawn, given the variation in results between disease-specific and generic outcomes.

Another Swedish RCT (Larsson *et al.*, 2015) aimed to compare the costs of nurse-led care versus rheumatologist-led care in monitoring of patients with inflammatory arthritis undergoing biological therapy. The conclusion was that patients with low disease activity or in remission undergoing biological therapy could be monitored with a reduced resource use and at a lower annual cost by nurse-led care, with no difference in clinical outcomes. This could free resources for more intensive monitoring of patients early in the disease or patients with high disease activity.

Another Danish RCT (Sørensen *et al.*, 2015) aimed to compare the cost-effectiveness of three types of follow-up for outpatients with stable low-activity RA.

The conclusion was that shared care and nurse-led care seemed to cost less but provided broadly similar health outcomes compared with rheumatologist outpatient care. It was still uncertain whether nurse-led care and shared care are cost-effective in comparison with rheumatologist outpatient care.

An RCT in China (Wang *et al.*, 2018) aimed to evaluate the clinical effectiveness and cost-effectiveness of nurse-led care versus rheumatologist-led care in Chinese patients with RA. The preliminary finding suggested that RA patients managed by nurse-led care compared to rheumatologist-led care may have better clinical outcomes and more cost-effective care in China.

A multicentre RCT in Germany (Mai *et al.*, 2019) aimed to examine structured nursing consultation in rheumatology practices. The conclusion was that there was insufficient care of rheumatology patients in Germany, and that the study may be able to suggest improvements. Nurse-led care had the potential to provide more efficient and effective patient care. This included a more stringent implementation of the treat-to-target concept, which may lead to a higher percentage of patients reaching their treatment targets, thereby improving patient-related outcomes, such as quality of life, functional capacity, and participation. Nurse-led care may be highly cost-effective. The authors concluded that the findings from the project may form the basis for a sustainable implementation of nurse-led care in standard rheumatology care in Germany.

Another multicentre RCT (Hoeper *et al.*, 2021) in Germany aimed to compare the one-year treatment outcomes in patients with ACPA/RF-positive RA with rheumatologist-led care and nurse-led care using a non-inferiority design. The conclusion was that the study supported the non-inferiority of nurse-led care in managing treat-to-target (T2T) and follow-up care of patients with RA with moderate to high disease activity and poor prognostic factors in addition to rheumatologist-led care.

A single centre RCT (Kwok *et al.*, 2022) in Hong Kong aimed to determine the effectiveness of nurse-led consultations in patients with stable RA. Patients with low disease activity were randomised to either nurse-led consultations or rheumatologist follow-up visits for two years. The conclusion was that nurse-led consultations were not inferior to rheumatologist follow-up visits in patients with stable RA.

Lastly, a multicentre RCT from France (Beauvais *et al.*, 2022) aimed to evaluate the effect of nurse-led patient education on safety skills of patients with inflammatory arthritis treated with biologic disease-modifying antirheumatic drugs (bDMARDs). The conclusion was that educating patients was effective in promoting patient behaviours for preventing adverse events with bDMARDs and that education can be useful for patients starting a first bDMARD to help them self-manage safety issues.

Rheumatology nurse-led care is thus effective and safe and leads to higher patient satisfaction rates than in comparable services. However, available services and models of care, role titles and levels of experience for carrying out nurse-led care vary nationally (Ndosi *et al.*, 2017) and internationally (Bech *et al.*, 2020).

1.2.2. Evidence of rheumatology nurse-led care

While nurse-led care for people with RA has been shown to be effective (Bech *et al.*, 2020), processes of care in nurse-led clinics are not very well defined. Studies of nurse-led clinics have focused on different functions of the clinic such as patient education (Ndosi *et al.*, 2016) and supporting self-management (Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). However, only a few studies have studied aspects of care such as interaction styles (Vinall-Collier, Madill and Firth, 2016) and the holistic, person-centred approach to care (Bala, 2017; Bala *et al.*, 2012). These studies are from the UK, Denmark and Sweden.

Interviews with patients attending nurse-led consultations in Denmark (Primdahl, Wagner and Hørslev-Petersen, 2011) showed that patients valued the access, continuity and relationships developed with nurses. Patients felt they could talk to the nurses about anything, and that nurses took the time if they had problems and cared for them as people. They were confident that their arthritis was being ‘checked’. The nurse-led care approach seemed to have contributed to an increase in patients’ self-efficacy (Primdahl, Wagner and Hørslev-Petersen, 2011).

In the UK, a study of clinic interactions in nurse-led clinics (Vinall-Collier, Madill and Firth, 2016) revealed the value patients placed on continuity of care offered by these clinics. The relationship developed between patients and the nurses fostered familiarity, not only with their particular medical history but also their individual personal circumstances. This encouraged patient participation (Vinall-Collier, Madill and Firth, 2016). However, the high workload of the nurse specialists has recently been shown to hinder the progress of this work (BSR and NRAS, 2019).

In Sweden, a qualitative study of nurse-led clinics for biologic therapy (Larsson *et al.*, 2012) found that nurse-led clinics added value to patient care. The encounter with the nurse led to a sense of security due to the nurses' competence, accessibility, and familiarity, which encouraged patient participation. They found that nurses and rheumatologists complemented each other as they approached patients from different perspectives.

Another Swedish qualitative study (Bala *et al.*, 2012) suggested that nurse-led clinics provided a social environment and professional approach, which contributed to a positive experience of care. The care was described as 'person-centred' as it was based on the individual's unique experience of his/her disease and needs. Later studies by the same research team - Bala *et al*, (Bala *et al.*, 2018a, 2018b; Bala, 2017) developed a framework to conceptualise outpatient person-centred care, comprising five domains: 1) social environment, 2) personalisation, 3) shared decision-making, 4) empowerment, and 5) communication. This framework incorporated all the aspects of nurse-led care described above in previous studies. The framework was developed into an instrument (PCCoc/rheum) (Bala *et al.*, 2018b) intended to evaluate nurse-led rheumatology clinics, providing a measure of person-centeredness (Bala *et al.*, 2018b). However, the full questionnaire used in the instrument is currently only available in Swedish (Bala, 2017).

1.2.3. Nurse-led care in early RA

Patients with early RA are monitored at rheumatology nurse-led clinics which run alongside rheumatologists' clinics (BSR and NRAS, 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; West and Jonsson, 2005; Rupp *et al.*, 2004).

The implementation of treat-to-target regimes in early RA requires close monitoring and support (Smolen *et al.*, 2020; NICE, 2018). Patients' care needs include support in treatment in order to control disease activity, as well as social, emotional and psychological support (NICE, 2018). However, there is limited evidence on how rheumatology nurse-led care meets these needs. The recently updated European recommendations for the role of the nurse in CIA (Bech *et al.*, 2020) 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. Consequently, the role of the nurse in early RA and the related processes of care in nurse-led clinics are not well defined. Models of nurse-led care vary across countries based on different healthcare systems, legal frameworks and training (Bech *et al.*, 2020). This is important particularly in this new era of early diagnosis and 'very early' start of treatment with intensive therapy as recommended in the treat-to-target strategy (Smolen *et al.*, 2020; Combe *et al.*, 2017).

Nurse-led care has been established as normal RA care in the UK, and many patients with early RA see a rheumatology nurse specialist for RA management (BSR and NRAS, 2019). Current guidelines from the National Institute of Clinical Excellence (NICE, 2018) advocate that patients with RA should have access to a clinical nurse specialist for RA management and support. However, processes of care in the UK vary from centre to centre (BSR and NRAS, 2019; Ndosi *et al.*, 2017), and there are currently no guidelines for early RA nurse-led care.

As nurse-led care is characterised by a holistic approach to care, taking account of patients' physical, psychological, social and spiritual needs (Ndosi *et al.*, 2011) it has the potential to empower people with RA to manage their disease (Arvidsson *et al.*, 2006). Previous studies in established RA have shown that nurse-led care is associated with increased self-efficacy in patients (Ndosi *et al.*, 2016; Primdahl, Wagner and Hørslev-Petersen, 2011). This may be a result of patient education

(Ndosi *et al.*, 2016), the supportive relationship with the nurses (Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011) or the person-centred character of these clinics (Bala *et al.*, 2012). However, it is not clear how well rheumatology nurse-led clinics meet the needs of patients in early RA, especially with the implementation of treat-to-target regimes (Smolen *et al.*, 2020; Combe *et al.*, 2017), which require monitoring and support in the nurse-led clinics (BSR and NRAS, 2019).

1.3. The knowledge gap

The current treat-to-target treatment approach in early RA requires early detection and early start of treatment with close monitoring and support of patients (Smolen *et al.*, 2020; Combe *et al.*, 2017). Patients at this stage of the disease are in distress, experience symptoms such as pain and fatigue, and start new treatment regimes, while adjusting to the disease. Rheumatology nurse specialists are increasingly involved in the management of RA. EULAR guidelines for rheumatology nursing recommend that patients with RA have access to a rheumatology nurse. However, there is no clear definition of the role of the nurse in early RA. Processes of care are not well described, and it is not known how well early RA nurse-led care meets the needs of patients with early RA.

1.4. Summary of aims and objectives

This PhD study aims to provide new knowledge in understanding what comprises nurse-led care in early RA and how needs of patients in early RA are met by nurse-led care. This will help to design a nursing model that has the potential to meet patients' care needs and thus the potential to optimise patient outcomes.

The objectives are:

1) To develop an understanding of rheumatology nurse-led care from the perspective of people with early RA using a systematic review of qualitative studies with thematic synthesis.
2) To understand from the perspective of rheumatology clinical nurse specialists, what comprises nurse-led care in early RA, using semi-structured interviews with thematic analysis.
3) To assess how patients' needs are met in early RA nurse-led care, and to understand patients' perceptions of a provisional model of early RA nurse-led care derived from the systematic review and the interview study, using a cross-sectional online survey.
4) To propose a refined early RA nurse-led care model that seeks to address holistic care needs of patients with early RA.

1.5. The overall outcome

The intended original contribution to knowledge of this PhD is to provide new understanding of what comprises nurse-led care in early RA, and how care needs of patients in early RA are met by early RA nurse-led care.

The research is intended to propose a model of early RA nurse-led care that seeks to meet patients' holistic care needs and has the potential to optimise patient outcomes.

1.6. Methodology

1.6.1. Mixed method

A mixed methods approach was chosen to address the objectives of this thesis as this approach is flexible and allows the mixing of methods with the aim to develop a model of care.

A mixed method approach in health research is appealing, as it implies both a method and a methodology for research studies, they purposely bring together qualitative and quantitative research to understand a research issue (McClean *et* *al.*, 2019). Mixed method uses both qualitative and quantitative research paradigms mixing these at different stages of the research depending on the design (McClean *et al.*, 2019; Creswell and Clark, 2011; Dures *et al.*, 2011; Creswell, 2003).

Qualitative research is a term used to describe research methods that seek to explore and understand individuals' experience, lifeworld and the collective social meanings that underpin that lifeworld (McClean *et al.*, 2019), following a constructivist understanding of the social world (McClean *et al.*, 2019). It usually takes an interpretive stance which aims to explore complex human and social phenomena through consideration of multiple viewpoints, context, and meanings (McClean *et al.*, 2019). Key strengths of using qualitative research are that it can generate in-depth and rich data, and that it is appropriate for situations where a detailed understanding about a phenomenon is sought (McClean *et al.*, 2019). Events are thus explored within a specific socio-cultural context (McClean *et al.*, 2019). The limitations are that qualitative research can face criticism for producing 'unreliable' findings as for example different findings might be observed on a different day, or if research is conducted with different people (McClean *et al.*, 2019). As findings are not directly generalisable, they may have a limited impact at public health policy, practice and implementation levels (McClean *et al.*, 2019).

Quantitative research traditionally follows positivist philosophy with an underlying belief that reality can be measured and observed objectively (McClean *et al.*, 2019). Quantitative research has the strength that large sample sizes increase opportunities for producing generalisable findings, and if statistical methods are used appropriately, they are considered reliable (McClean *et al.*, 2019). Quantitative research can thus be used to generate systematic and standardised comparisons (McClean *et al.*, 2019). However, limitations are that findings may not explain the full complexity of human experience or perceptions, as seeking to identify 'what' (quantitative research) will not always cover 'why', 'how' or 'for whom' (qualitative research), and they may give a false impression of homogeneity in a sample (McClean *et al.*, 2019).

Mixed methods research seeks to better understand a research problem that could not be expected to be fully understood from using either a qualitative or a quantitative approach alone (McClean *et al.*, 2019). A problem which needs a mixed method can, according to Creswell and Clark (2007), exist when qualitative research can provide an adequate exploration of a problem, but when such an exploration is not enough, and quantitative research is needed to further understand the problem (Creswell and Clark, 2007). The situation when this occurs is when qualitative research initially can best explore and identify variables, constructs, taxonomies and theories to test as well as aid in the identification of items and scales to develop a quantitative instrument (Creswell and Clark, 2007).

Mixed method research is thus increasingly recognised for its potential to overcome some of the limitations associated with quantitative and qualitative research (McClean *et al.*, 2019; Kaur, 2016; Padgett, 2012). The mixed method can be seen as a third philosophical paradigm choice, which often will provide the most informative, complete, balanced and useful research results (Dures *et al.*, 2011; Johnson and Onwuegbuzie, 2004).

However, it is debated what constitutes a mixed method approach (Dures *et al.*, 2011; Tashakkori and Creswell, 2007). Defining characteristics include: a) quantitative and qualitative methods within the same research project; b) a research design that clearly specifies the sequencing and priority given to the quantitative and qualitative elements of data collection and analysis; c) an explicit account of the manner in which the quantitative and the qualitative aspects of the research relate to each other; d) and pragmatism as the philosophical underpinning for the research (Dures *et al.*, 2011; Denscombe, 2008). The mixed methods approach combines elements of qualitative research asking *what* and *how* in order to explore, gain insights and understand underlying issues, while quantitative elements ask how many and how strong in order to measure, predict and correlate (Dures *et al.*, 2011). The shared qualitative and quantitative aims are thus to identify and to look at relationships, and to examine links between the phenomena under investigation (Dures *et al.*, 2011).

The weight of the mixed method design can either be on the collection and analysis of quantitative or qualitative data depending on the research problem to be addressed (Creswell and Clark, 2007). The mixed methods approach is a flexible approach, which enables the researcher to be responsive to a range of issues (Dures *et al.*, 2011). However, it is seen as important that the approach is used thoughtfully and appropriately (Dures *et al.*, 2011), and working within this third paradigm in a thoughtful way requires a theoretical rationale and description of the process (Dures *et al.*, 2011).

Creswell (2003) describes six different mixed method strategies, with the sequential exploratory strategy having many features similar to the sequential explanatory strategy, meaning it is a straightforward approach. It is conducted in two phases, with the priority generally given to the first phase (Creswell, 2003). This method is characterised by an initial qualitative phase of data collection and analysis, which is followed by a phase of quantitative data collection and analysis. The priority is thus given to the qualitative aspect of the study (Creswell, 2003). The findings of the two phases are then integrated during the interpretation phase, and the purpose of this strategy is to use quantitative data and results to assist in the interpretation of the qualitative findings (Creswell, 2003).

The sequential exploratory strategy approach was deemed appropriate for this thesis, as the phenomenon, early RA nurse-led care, could be explored with qualitative methods, and findings from one study could inform the following study and expand further on the findings with the aim to develop items of a model of care, which could be complemented by quantitative methods (Creswell and Clark, 2007). The weight was thus on the qualitative methods with the collection and analysis of qualitative data. Each study informed the following study, and the interpretation of the overall findings were assisted by collection and analysis of quantitative data (Creswell and Clark, 2011).

A key feature in mixed methods is the description of how the mixing or integration and quantitative elements were achieved (Halcomb, 2019; Zhang and Creswell, 2013). Zhang and Creswell identified three distinct procedures for mixing data in health service (Halcomb, 2019; Zhang and Creswell, 2013). The first procedure, integration, refers to the approach where qualitative and quantitative data are collected concurrently and analysed separately for then to be integrated in the interpretation phase. The second procedure, connection, involves one approach being built upon the findings of the other approach. The third procedure, embedding, involves one type of date being embedded within the other (Halcomb, 2019). For this PhD, the mixing of methods involved one approach being built upon the findings of the other approach (Halcomb, 2019), and the synthesis of findings was thus the 'connection' between studies. With the weight on the qualitative part of the thesis (Creswell, 2003), the quantitative part assisted in the overall interpretation of the qualitative findings (Creswell, 2003).

1.6.2. Outline of individual studies and design

The individual studies are outlined below.

Study 1: The patient perspective of nurse-led care in early rheumatoid arthritis: A systematic review of qualitative studies with thematic synthesis.

Study 2: Understanding nurse-led care in early RA: Interview study with rheumatology nurse specialists.

Study 3: The patient perspective of early RA nurse-led care and satisfaction with care in early RA: A cross sectional survey.

The methods used in these studies will be described in detail in the chapters reporting each study. Study 1 is reported in Chapter two, Study 2 in Chapter three and Chapter four, and Study 3 is reported in Chapter five. A refinement of a model of early RA nurse-led care by synthesis of evidence is reported in Chapter six, with discussion and overall conclusion in Chapter seven.

1.6.3. The impact of the COVID-19 pandemic

This section provides a summary of implications for the research of the outbreak of the COVID-19 pandemic in 2020. The first study, the systematic review of qualitative studies (Chapter two), was not affected by the COVID-19 pandemic as it was a systematic review with no need for personal contact. However, the following studies were affected by the COVID-19 pandemic and adjustments had to be applied to the research to answer the research questions in a safe and feasible way.

Due to COVID-19 restrictions, face-to-face contacts in research were prohibited. To get the perspectives of nurse specialists, interviews had been planned as face-to-face or telephone options, depending on the nurses' preferences. Due to COVID-restrictions, face-to-face contact was not possible, and the planned interviews with nurses were changed to telephone interview (Chapter three and Chapter four). Data collection and analysis were conducted during the first COVID-19 lockdown in 2020.

Originally, it had been planned to get the patient perspective on nurse-led care with a combination of observation of clinics with follow up interviews, and survey methods. However, this was changed to survey methods only (Chapter five). Collection and analysis of survey data were conducted while COVID restrictions were still in place at hospitals in the winter of 2021-2022.

1.7. The researcher

1.7.1. Background of the researcher

The researcher is a PhD student in rheumatology nursing. She has extensive clinical experience of rheumatology as for several years she worked as a rheumatology nurse, clinical nurse specialist and research nurse at university hospitals in Copenhagen, Denmark. Very early in her nursing career she experienced hospitalisation for many months with Guillain-Barré Syndrome, an acute immune condition which left her paralysed and in need of rehabilitation in a rheumatology ward. This experience introduced her to rheumatology and provided her with deep insights into what it is like being a patient at different stages of disease.

Having recovered, the researcher worked as a nurse at various types of wards, and eventually started her career in rheumatology nursing at the same ward where she had once been a patient. This offered valuable insights into what it is like providing nursing care to rheumatology patients and gave her the rich opportunity to reflect on her profession. As a clinical nurse specialist at outpatient clinics in Copenhagen, the researcher met numerous patients who generously introduced her to their lives with RA. The friendship with a former patient provided her with insights in what it was like living with the disease and being a patient in the health care system. Conversations revealed that despite access to a modern healthcare system, patients experienced that quality of care could vary, and at times seem unsatisfactory. Kindness, understanding and the feeling of being listened to as a patient could thus be lacking despite the best intentions from healthcare staff.

The researcher's interest in improving rheumatology care led to research into the patient perspective of treatment and care, and she took up nursing studies at Aarhus University in Denmark. Her master's thesis was a phenomenological interview study with five participating patients, exploring how patients experienced living with RA and receiving treatment and care in a rheumatology outpatient clinic. The conclusion was that living with RA was life changing and challenging and that people living with the disease may have unmet care needs in the management of RA and psycho-social support (Sweeney, 2017). The researcher's findings suggested that nurses could strengthen and develop the impact of rheumatology nursing by taking on this task (Sweeney, 2017).

The researcher decided to continue the research journey and embarked on this present PhD programme at University of the West of England. She has an altruistic outlook on life, and a holistic approach to care. Her field of interest is the implementation of the patient perspective in clinical practice and the delivery of optimal care based on best practice and the patients' expressed needs and preferences. The researcher has led research which tested and implemented an outpatient system for patients with RA based on an on-demand, follow-up, Direct Access System (Sweeney *et al.*, 2018). The system was originally pioneered at the Academic Rheumatology Unit and the Rheumatology Department at Bristol Royal Infirmary (Hewlett *et al.*, 2005). The researcher is now an honorary research nurse at the Rheumatology Department, and a member of the Academic Rheumatology team at Bristol Royal Infirmary, Bristol, UK.

1.7.2. Epistemological position

The researcher's perspectives inform research, as do ontology and epistemology, what we know and how we can know it (Braun and Clarke, 2013). It is therefore important and a strength in research to clarify the researcher's position as it helps the reader to understand the context for the researcher's position and how it may have shaped and impacted the research (Braun and Clarke, 2013; Meyrick, 2006).

For this research, the researcher chose to take a pragmatic approach. A researcher who is a pragmatist understands truth and reality to be whatever is appropriate for the study needs and research questions (Jones, 2019; Dures *et al.*, 2011). Using this approach does not reject epistemologies, but it suggests that it is more valuable to consider appropriate methods to generate useful data than being limited to a single methodological viewpoint (Jones, 2019; Dures *et al.*, 2011). The approach is thus appropriate for mixed method research (Morgan, 2007), which was used for this PhD. A pragmatic researcher position can be helpful in mixed methods research, as it can provide the flexibility required to approach 'real world' research questions with methods that are appropriate (Jones, 2019; Creswell and Clark, 2007; Johnson and Onwuegbuzie, 2004; Creswell, 2003).

1.7.3. The supervisory team and the patient research partner

The supervisory team comprised senior nurse researchers of rheumatology and pain, a rheumatologist, a psychologist, and a patient research partner. This meant that the group had extensive professional and personal knowledge and experience regarding the research area and methodology. At all stages of the research, the patient research partner was involved in the planning and development of the PhD programme. The patient research partner provided in-depth knowledge and insights into what it is like living with the different stages of the disease and of being a patient and was furthermore a valued academic support as a very experienced research partner.

1.8. People or patients

The choice of referring to 'people' with RA as 'patients' with RA was considered, as 'patient' can emphasise the condition instead of the identity of the person when looking into views and care issues (Crocker and Smith, 2019; Jones, 2019). The preferred reference should therefore be ‘people’ with RA as used in the title of this PhD thesis. However, the term ‘patients’ will be used for brevity and consistency when presenting and discussing issues relating to rheumatology nurse-led care. The Mirriam-Webster Dictionary defines ‘patient’ as an individual awaiting or under medical care and treatment and the recipient of any of various personal services (Merriam-Webster, 2021), which indeed includes the care aspect of early RA. The researcher understands and acknowledges that being a patient is only part of a person’s identity.

1.9. Thesis structure

This thesis is structured into seven chapters to address the proposed objectives. Chapter one provides the background for the PhD research, the knowledge gap, aims and objectives as well as a presentation of the researcher and the supervisory team. Chapter two reports a systematic review of qualitative studies, reviewing literature which explores the patient perspective of early RA nurse-led care. The following two chapters report an interview study with rheumatology nurse specialists to get an understanding of the nurse perspective of early RA nurse-led care. Chapter three provides the background and methods for the interview study, Chapter four reports the findings, the discussion and conclusion of the study. Chapter five reports a survey with patients in early RA to get an understanding of the patient perspective of early RA nurse-led care as well as the patient perspective of a provisional model of early RA nurse-led care derived from the interview study. Chapter six provides a synthesis of evidence and presents a model of care which has the potential to meet patients’ holistic care needs in early RA. Finally, Chapter seven provides an overall discussion and conclusion of the PhD with recommendations for further research, as well as implications for practice.

Chapter 2: Nurse-led care from the perspective of people with early rheumatoid arthritis

This chapter reports a systematic review of qualitative studies, which was conducted to address the first objective of the PhD. Background for the study, aims and rationale and methods are presented, followed by findings, discussion, and conclusion. The following section introduces the study with rationale, aims and choice of methods.

2.1. Rationale for this study

Guidelines for RA management changed dramatically ten years ago with the implementation of the treat-to-target treatment strategy (Smolen *et al.*, 2010). They recommend early detection of RA, and early start of intensive treatment with a combination of disease modifying anti-rheumatic drugs (DMARDs) and tight monitoring of disease activity until the state remission or low disease activity is achieved (Smolen *et al.*, 2020; Combe *et al.*, 2017). Current treatment guidelines in the UK (NICE, 2018) recommend that patients with RA should have access to a clinical nurse specialist for RA management and support. However, processes of care vary nationally (BSR and NRAS, 2019; Ndosi *et al.*, 2017), and internationally, based on different healthcare systems, legal frameworks and training (Bech *et al.*, 2020). Although nurse-led care has become normal in care in the UK (BSR and NRAS, 2019), it is not known how well nurse-led care meets the need of patients with early RA.

2.2. Aims

The aim of this systematic review of qualitative studies was to develop an understanding of rheumatology nurse-led care from the perspective of patients with early RA.

2.2.1. Research question

The research question for this review was: What experiences and expectations do patients with early RA have of rheumatology nurse-led care?

2.3. Methods

2.3.1. Design

This chapter reports a systematic review of qualitative literature, with a thematic synthesis (Sweeney *et al.*, 2020b, 2020a). The 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 brought 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 (Sweeney *et al.*, 2019).

The reporting of this systematic review of qualitative studies followed appropriate elements of Preferred Reporting Items for Systematic Reviews and Meta-Analyses, PRISMA (Liberati *et al.*, 2009).

2.3.2. Eligibility criteria

A scoping search conducted during the protocol development indicated that qualitative studies in early RA were few; a disease duration restriction was therefore 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 a 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.

2.3.3. 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 Table 1.

Table 1. Databases searched 2010 to 2019

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

2.3.4. 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 2.

Table 2. The search strategy March 2019 (Search 2010 to March 2019)

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)

2.3.5. Study selection

2.3.5.1. Screening for eligibility

The researcher 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 researcher 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 a second reviewer (a research colleague from Rheumatology Research, BRI) 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 polyarthritis, including RA. Where there were doubts or conflicting opinions, a third reviewer from the supervisory team was invited, and the issues were discussed until agreement was reached.

2.3.5.2. 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 and 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 and Lewin, 2011; Thomas and Harden, 2008). The researcher extracted all data, which was checked by the second reviewer. Any discrepancies were discussed until consensus was reached (Thomas and Harden, 2008).

2.4.5.3. Quality assessment of studies included in the study

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 (Porrit, Gomersall and Lockwood, 2014; Hannes, Lockwood and Pearson, 2010). 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.

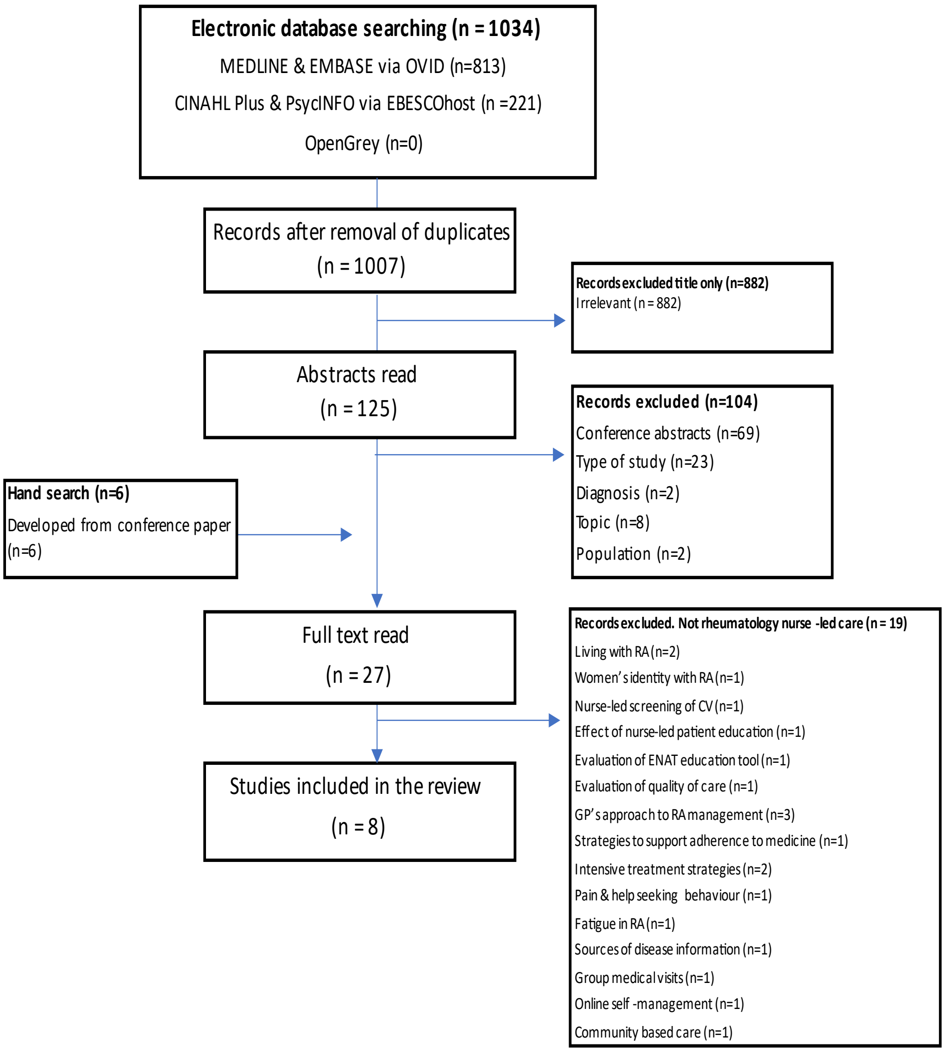
2.3.6. Data synthesis

A thematic synthesis was used according to Thomas and Harden’s framework (Thomas and 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 and Harden, 2008). Tables were created to manage coding and themes. The researcher carried out the thematic synthesis, and the process and results were discussed with the second reviewer. The findings were finally reviewed by the supervisory team, and the quality of the data extraction and synthesis were assessed according to Noyes *et al.* (2018) prior to the publication of the full paper (Sweeney *et al.*, 2020b). A summary of the synthesis assessment process is provided in Appendix A.

2.4. 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.

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



2.4.1. Characteristics of the included studies

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

Primdahl *et al.* (2011) in Denmark conducted six focus groups 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 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 (van Manen, 2016).

Arends *et al.* (2017) in the Netherlands conducted a mixed method study to evaluate a goal management intervention for participants with polyarthritis 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 3.

Table 3. 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	Polyarthritis (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.

2.4.2. 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 (Sjo and Bergsten, 2018; Bala *et al.*, 2012, 2017; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011) 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) (Sjo and Bergsten, 2018; Arends *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Bala *et al.*, 2012; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011), 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 4.

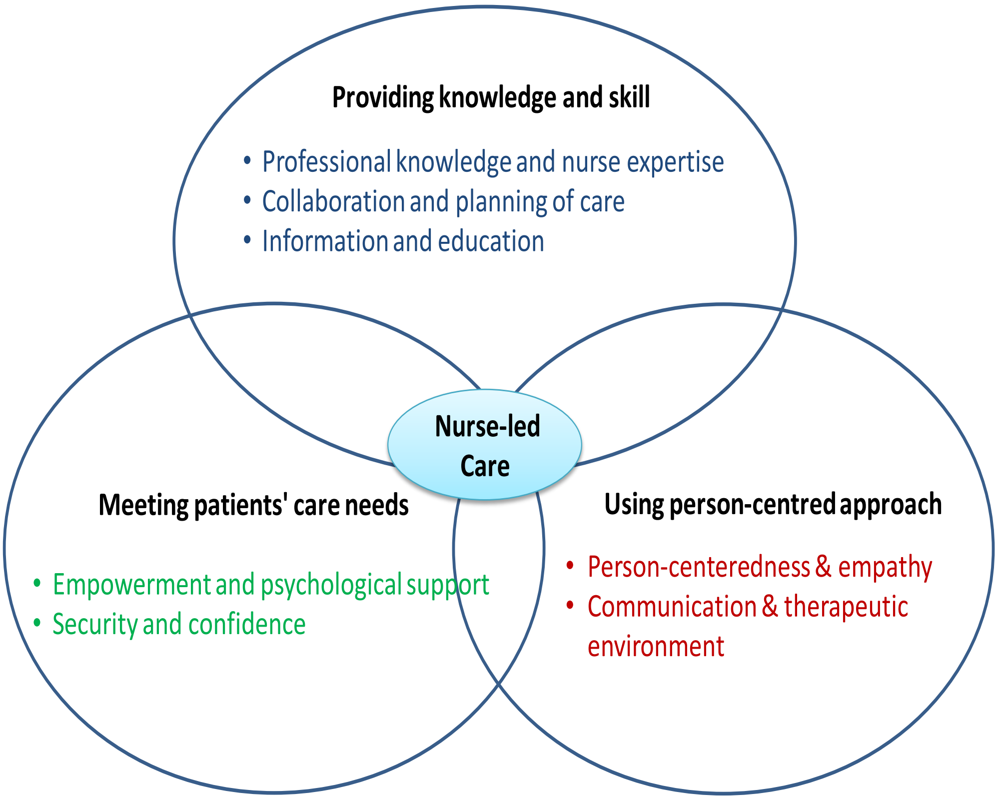
Table 4. Summary of JBI Assessment

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

2.4.3. 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 Appendix B.

Figure 2. Identified themes and sub-themes



The following section of the chapter will present the identified themes and sub-themes, underpinned with illustrative quotations.

2.5. 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.

2.5.1. 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 (Sjo and Bergsten, 2018; Bala *et al.*, 2012, 2017; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012). 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 (Sjo and Bergsten, 2018; Primdahl, Wagner and Hørslev-Petersen, 2011). 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 and Bergsten, 2018).

2.5.2. 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 (Sjo and Bergsten, 2018; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011)**.** 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 (Sjo and Bergsten, 2018; van Eijk-Hustings *et al.*, 2013; Primdahl, Wagner and Hørslev-Petersen, 2011), 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).

2.5.3. 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 and 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 and keep mobile (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.

2.6. 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.

2.6.1. 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 (Sjo and Bergsten, 2018; Arends *et al.*, 2017; Bala *et al.*, 2012, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). Positive experiences of the nurse-patient encounter were related to the nurses' ability to have a holistic and empathetic approach, being sensitive, and showing interest and involvement in the individual patients' circumstances (Sjo and Bergsten, 2018; Arends *et al.*, 2017; Bala *et al.*, 2012, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). 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 (van Eijk-Hustings *et al.*, 2013; Bala *et al.*, 2012). 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).

2.6.2. 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 and 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 (Sjo and Bergsten, 2018; Bala *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Primdahl, Wagner and Hørslev-Petersen, 2011).

> *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 (Sjo and Bergsten, 2018; Bala *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013).

2.7. 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.

2.7.1. 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 (Sjo and Bergsten, 2018; Arends *et al.*, 2017; Bala *et al.*, 2012, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012). The unpredictability of the disease meant, that patients could experience flares, pain and feeling down and depressed (Ryan *et al.*, 2013; Larsson *et al.*, 2012). 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 (Ryan *et al.*, 2013; Larsson *et al.*, 2012). 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 and 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 and 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).

2.7.2. 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 (Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Bala *et al.*, 2012; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). 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 (Sjo and Bergsten, 2018; Bala *et al.*, 2012, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). 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).

2.8. Discussion

This review aimed to explore 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 empathetic 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.*, 2020) 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.*, 2020). Education is thus important in order to undertake and maintain extended roles in rheumatology nursing.

A repeated search was carried out by the researcher to update the literature search for this study from January 2019 to January 2022. Summaries of the process are provided in Appendices C, D, E, and F.

The identified paper (Pedraz-Marcos *et al.*, 2020) looked at the experience of living with rheumatoid arthritis, as interviews were conducted in Spain with 19 patients with over one year of disease duration and analysed using thematic analysis. However, the patient perspective on rheumatology nursing was limited to one quotation (first order) from one participant who had been at a consultation with a nurse.

> *The work of Teresa (nurse) is essential, she clarifies things for you, listens, teaches you . . . (EM8, patient)* (Pedraz-Marcos *et al.,* 2020).

According to the study (Pedraz-Marcos *et al.*, 2020), the role of the nurse was still limited in rheumatology and focused primarily on providing information and training on biological therapies despite the EULAR recommendations (Bech *et al.*, 2020; Pedraz-Marcos *et al.*, 2020). The development of nurse specialists and advanced practice nurses in Spain were thus seen as an important step in helping people to self-manage chronic disease such as RA (Pedraz-Marcos *et al.*, 2020). These findings confirm the variations between countries as reported in the updated recommendations for rheumatology nursing, and the need for developing the role of the nurse to optimise patient outcomes (Bech *et al.*, 2020). In contrast, rheumatology nursing has a prominent role in the UK, with nurse-led care being established as normalised care in RA management (BSR and NRAS, 2019).

However, a recent UK nation-wide survey of rheumatology clinical nurse specialists carried out by the British Society for Rheumatology (BSR and 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 in the UK is reported to be under high demand and in need of more specialist nurses to meet patients care needs (BSR and 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.

The findings highlighted the importance of the person-centred and empathetic 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 and could suggest that access and continuous contact to a rheumatology nurse could help improve treatment outcomes in RA. A National Early Inflammatory Arthritis Audit (HQIP, 2016) supported the importance of nurse specialists in early RA care. It found that higher numbers of nurse specialists were associated with patients better achieving agreed targets for treatment at their time of follow-up (HQIP, 2016). It was also found that there was a strong correlation between nurse staffing levels and compliance with treatment initiation within six week (HQIP, 2016). In the audit this was seen as likely reflecting the fact that the delivery of treat to target care through shared decision-making primarily will be through nurse-led clinics (HQIP, 2016).

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-centred 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 *et al.*, 2018b, 2018a), 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, Madill and Firth, 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 (Sjo and Bergsten, 2018; Ryan *et al.*, 2013). 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. However, only four identified studies included patients with early RA, and the remit of the review was widened to include all stages of the disease trajectory, as reported in the original studies. The evidence was therefore limited in informing nurse-led care in early RA and more research which specifically addressed early RA nurse-led care was warranted. Thus, a qualitative study with rheumatology nurses who see patients in early RA would begin to address this knowledge gap of what is known about nurse-led care in early RA.

2.8.1. Strengths of this study

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.

2.8.2. Limitations

This review has some limitations: First, the researcher 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 co-reviewers to minimise errors and maximise the credibility of the findings. Second, only four studies (Sjo and Bergsten, 2018; Arends *et al.*, 2017; van Eijk-Hustings *et al.*, 2013; Bala *et al.*, 2012) included participants with up to two 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 (Arends *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012), clearly labelled quotes of patients with RA (Arends *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; Larsson *et al.*, 2012), or the vast majority of patients had RA (Arends *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; 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 (Arends *et al.*, 2017; Ryan *et al.*, 2013; van Eijk-Hustings *et al.*, 2013; 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.

2.9. Conclusion

Patients with RA were supportive of rheumatology nurse-led care, and the findings outlined key ingredients of nurse-led care that were important to patients with RA. Patients thus valued the provision of professional expertise and the use of a person-centred approach, which gave them a sense of security and confidence and meet their holistic care needs. However, the evidence was limited in informing nurse-led care in early RA, and more qualitative studies of nurse-led care in early RA are thus needed to address the knowledge gap in this population.

2.10. Relevance to clinical practice

This review presented patients' perspectives of nurse-led care and is therefore highly relevant to informing clinical practice. However, it also highlighted an important gap in literature, that nurse-led care in early RA is not well understood and warrants further research. 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 person-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.

2.11. Relevance to further research

While the findings of this study were interesting and provided secondary data from the patients and practitioners’ perspectives, the dearth of data in early RA meant that more research was required. The themes identified in the systematic review were taken forward to the next qualitative study and used to develop an interview guide to be used in the qualitative study with specialist nurses. This meant that the interview study would contain questions addressing the topics of *Providing knowledge and skill*, *Using a person-centred approach*, and *Meeting patients’ care needs,* amongst other topics.

Chapter 3: Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: Background and methods

This chapter addresses the second objective of the PhD. It presents a qualitative interview study with clinical nurse specialists. The chapter covers rationale for the study, design and methods. The results, discussion and conclusion of the study are presented in Chapter four.

3.1. Rationale for this study

Although nurse-led care for people with RA has been shown to be effective, processes of care in nurse-led clinics are not very well defined. It is not clear how well rheumatology nurse-led care meets the needs of patients in early RA, especially with the implementation of treat-to-target regimes, which require monitoring and support in the nurse-led clinics. Despite nurses' increasing extended role in RA care and the emphasis on early detection and early start of treatment in RA, there are no current recommendations or guidelines to help define nurse-led care in early RA.

The systematic review of qualitative studies in Chapter two found that nurse-led care for people with RA was characterised by the provision of rheumatology nursing expertise and meeting patients' care needs using a person-centred approach. Whilst the review found that patients valued rheumatology nurse-led care, and patients' holistic care needs were being met, only a few studies included participants with early RA. There was thus a dearth of literature on nurse-led care in early RA, and more research was needed to understand what comprised early RA nurse-led care and how patients' needs were being met in early disease.

3.1.1. Research question

The research question for this study was: What comprises nurse-led care in early RA from the perspective of rheumatology clinical nurse specialists?

3.2. Aim

This study aimed to understand from the perspective of rheumatology clinical nurse specialists what comprises nurse-led care in early RA.

3.3. Methods

3.3.1. Design

The research question was of a qualitative nature and required the use of qualitative methods. The design was thus a qualitative interview study, which could provide qualitative in-dept data of individual people's views and perspectives. This phase of the research involved qualitative semi-structured telephone interviews with rheumatology nurse specialists in England, analysed using inductive thematic analysis according to Braun and Clarke's framework (Braun and Clarke, 2013).

3.4. Data collection

3.4.1. Interview as method of data collection

Qualitative Interviewing has evolved as a means of getting close to individuals or groups to understand, interpret and represent their perspectives and experiences (McClean *et al.*, 2019). Interviewing can involve any number of people, depending on the purpose of the research, and it can be described as being on a continuum between structured and un-structured with semi-structured being the most common approach (McClean *et al.*, 2019). Semi-structured interviews maintain focus around a research problem by using an interview guide but allow the researcher to digress or investigate further (McClean *et al.*, 2019). The interview is dynamic as it responds and adapts to the narrative that emerges from the individual or the group (McClean *et al.*, 2019). The researcher has the agenda, but the key objective is to facilitate communication and seek to obtain rich, meaningful accounts that can help to inform the researcher's understanding (McClean *et al.*, 2019).

Conducting one-to one interview involves the researcher striving to facilitate and generate a conversation based on trust and empathy in a process where the researcher aims to give unconditional positive regard to the interview (McClean *et al.*, 2019). The purpose of the interview is to achieve a productive relationship that can generate a rich, detailed description (McClean *et al.*, 2019). While survey interviewing could be described as a method, a qualitative research interview is closer to a craft (Brinkmann and Kvale, 2015). The researcher thus needs personal skills and respect to practice qualitative research, which cannot be reduced to methodological rules.

For this current study, one-to-one semi-structured interviews were chosen to provide in-depth, rich data to get an understanding of nurse specialists' views on their clinical practice of nurse-led care in early RA. Focus groups were considered, as this method could provide rich data and generate ideas through the interaction (Bowling, 2014; Braun and Clarke, 2013). However, with focus groups there could be issues of conforming to majority views or being dominated by one or two strong voices (Braun and Clarke, 2013), and focus groups can be logistically challenging, for example with participants who are geographically dispersed or very busy people (Braun and Clarke, 2013). One-to-one interview was chosen as the focus was on in-depth views of the individual nurses (Braun and Clarke, 2013). One-to-one interviews allowed the nurses to speak freely without colleagues listening ears, which could limit their willingness to share their thoughts and views (Braun and Clarke, 2013). One-to-one interview was also a pragmatic approach, which allowed interviews to be flexible around the individual participants (Braun and Clarke, 2013).

3.4.2. Telephone interview

Telephone interviews can provide in-depth data about the research question, and at the same time it allows the opportunity to talk to people who are geographically distant from the researcher (Braun and Clarke, 2013; Block and Erskine, 2012).

It was important for this study to obtain in-depth, rich data, focusing on clinical nurse specialists' knowledge and experience. This type of data can be communicated verbally by telephone interview just as well as by face-to-face interview (Block and Erskine, 2012).

Participants were based across England and were professionals with limited time for engaging in research, they might find it challenging to participate in face-to-face interviews. Telephone interview was therefore deemed appropriate in this study.

This study was conducted immediately after the outbreak of the COVID-19 pandemic (Summer 2020). Telephone interview was therefore an ideal medium for conducting safe research while complying with COVID-19 restrictions. It could be argued that Zoom or Teams video calls could have provided face-to-face interview conditions. However, as these interviews were conducted at the beginning of the COVID-19 pandemic, technical solutions for video calls were not in place yet, and nurses generally communicated via telephone, both with patients and colleagues.

3.4.3. Drawbacks of telephone interviews

Using telephone interview has some limitations, as interviewer and interviewee can only communicate verbally and the communication medium itself could influence the conversation and thus provide either less or more in-depth data (Block and Erskine, 2012). Not being able to see each other could present a challenge for the interviewer when seeking to build up a good interview environment with trust and an engaging, equal and familiar atmosphere, which is essential for a good quality interview (Braun and Clarke, 2013; Brinkmann, 2013; Block and Erskine, 2012). However, telephone interviews also have benefits, as they can be convenient and empowering for participants, accessible and more anonymous, potentially ideal for sensitive topics and relatively resource-lite (Braun and Clarke, 2013; Block and Erskine, 2012).

To reduce potential drawbacks of telephone interviews, the researcher concentrated on listening, paying attention to language, tone of voice, pauses, laugh, mood change and sought to follow these. The researcher used encouraging short acclamations, repeated some part of the interviewee’s response, asked for clarification and assured that the provided information was important and valuable. This showed participants that the interviewer listened, paid attention to their response and found their thoughts, ideas and accounts of their clinical practice interesting, important and valuable contributions to the study. This helped create a very positive, open and equally balanced interview situation, where participants spoke most of the time, only guided slightly by the interviewer.

3.4.4. The skill of conducting interviews

The skill of conducting interviews is important for data collection (Brinkmann and Kvale, 2015). According to Brinkmann and Kvale (2015), interviewing is a craft, and practice and reflection can help the researcher to learn and to improve the skills involved in interviewing (Brinkmann and Kvale, 2015). It is key for the interviewer to show interest in participants and the subjects discussed (Brinkmann and Kvale, 2015). A professional and effectively conducted interview will thus enable the collection of better data than a poorly prepared interview where neither questions nor technique work properly. To make participants feel acknowledged and respected, the interviewer thus has to be well prepared, with a good understanding of how the event comes across to participants (Braun and Clarke, 2013).

For this study, the careful preparation and review of the interview guide as well as conducting a pilot-interview helped to minimise these issues. Furthermore, before each interview the researcher looked through the interview-guide, as well as notes from earlier interviews. The researcher checked the audio-recorder, the telephone number and the phone line and made sure that everything was in place in good time before the interview. It was important to the researcher that she knew that she was well prepared for the interviews and could concentrate on participants, reflect and respond to the answers she would receive during the interview, without being distracted by technical challenges or lack of follow-up questions. It was also important to come across to the nurse specialists as being personally interested in their views, showing them that their time and effort in participating was worthwhile, both professionally and personally (Braun and Clarke, 2013).

3.4.5. The role of the researcher

Participants knew from the study information that the interviewer was a researcher in rheumatology nursing. The researcher did not hide her professional background as a rheumatology clinical nurse specialist but was able to use her knowledge and experience to ask meaningful follow up questions. As the researcher was not originally from the UK, she could also ask clarifying questions about the health system and the nurses’ clinical practice. The power balance in the interview was considered (Braun and Clarke, 2013), and deemed equal based on professional background, experience and interacting style.

3.4.6. The COVID-19 pandemic

The COVID-19 pandemic broke out in spring 2020 followed by national lockdown and restrictions prohibiting all face-to-face contact. The COVID-19 pandemic was thus at its height at the time of data collection (Summer 2020). As this study had been planned pre-pandemic as both face-to-face and telephone interview depending on participant preferences, it was easily changed to telephone only, and it could proceed as planned in accordance with COVID restrictions. It was thus possible to obtain ethics approval of the study from the UWE ethics committee.

3.4.7. Interview guide

An interview guide for semi-structured interviews was designed, following Braun and Clark (Braun and Clarke, 2013) and Burke and Miller (Burke and Miller, 2001). The interview guide was developed to ensure consistency in the interviews and that the collected data were relevant to the research question. However, as the interview guide was semi-structured, it also allowed for other topics to be discussed according to the individual participants' wishes and according to the development of the individual interviews.

The interview guide was developed by the researcher and discussed with the supervisory team, including the patient research partner, to check if the questions were relevant, appropriate and understandable for participants and could provide data which could help answering the research question. The interview guide was based on the objectives of the study and the findings of the systematic review (Chapter two) which explored patients’ perspectives of nurse-led care in early RA and identified themes that characterised nurse-led care from the perspective of people with RA. Themes identified in the systematic review provided areas of interest for the inquiry, and the structure of the interview guide built on the identified themes.

The systematic review themes were: *(i) Providing knowledge and skill*, *(ii) Using a person-centred approach*, and *(iii) Meeting patients' care needs.* Examples of the interview questions from the last theme are: *What would you describe as good care in early RA? How would you know if patients' needs have been met? (Probe questions: What are challenges in early RA care? What works/What does not work?).* The full interview guide is presented in Appendix G.

Participants were asked to describe their normal clinical practice. Interview questions were neutral, non-directive and open ended, allowing participants to talk freely (Burke and Miller, 2001).

The interviewer aimed to create a respectful, friendly, non-threatening and equal atmosphere during the interview. This aspect of the interview method is important for a successful interview (Brinkmann, 2013). It is thus important that participants feel acknowledged and comfortable with participating and talking about views and perceptions (Burke and Miller, 2001) in order to obtain varied and in-depth data (Brinkmann, 2013).

It was agreed with supervisors to test the interview guide in a pilot interview prior to the start of interview study to allow for adjustments.

3.4.8. Pilot interview

A pilot interview was carried out before the study interviews to test the interviewer's interviewing style as this study was part of a PhD learning process. The pilot interview also tested the appropriateness of the interview guide, and the operational use of telephone and audio-recorder during interviews (Burke and Miller, 2001). A university senior lecturer with a rheumatology nurse specialist background agreed to assist as participant and a PhD supervisor and highly experienced qualitative researcher listened in and gave feedback on the pilot interview. The feedback was positive: i) The interview style had enabled a good interaction for providing data: ii) the questions from the interview guide followed by prompt questions provided in-depth data that could answer the research questions: iii) and the telephone and audio-recording technology worked well. Nothing was changed as a result of the pilot interview, and the study interviews could thus commence. The interview guide was reviewed between interviews (Braun and Clarke, 2013), and follow up questions and areas of interest to the research question were added as interviews were conducted.

3.4.9. Considerations regarding sample size and data saturation

Qualitative research involves the selection of a data sample which is then analysed. Important issues of data sampling are: How much data are needed, how to select the sample and how to recruit participants. Data saturation is a concept that developed from grounded theory (Braun and Clarke, 2013). Researchers debate and question the use of the term ‘data saturation’ in qualitative research. Data saturation means stopping data collection when new information is no longer identified but only repetitions occur (Wray, Markovic and Manderson, 2007). The concept has been considered ‘gold standard’ in qualitative research (Saunders *et al.*, 2018). However, others have argued that true saturation is impossible to achieve because of the uniqueness of human experience offering endless themes (Wray, Markovic and Manderson, 2007). If each life is seen as unique, then no data are truly saturated and there are always new things to explore (Wray, Markovic and Manderson, 2007). Braun and Clarke go even further and state, that data saturation is never valid and never a useful concept (Braun and Clarke, 2021). They thus encourage researchers ‘to dwell with uncertainty’ and to recognise that meaning is generated through interpretation of data (Braun and Clarke, 2021). Meaning is not excavated from data, and judgements about ‘how many’ data items and when to stop data collection are therefore inescapably situated and subjective and cannot be determined (wholly) in advance of analysis (Braun and Clarke, 2021).

As the researcher intended to conduct inductive thematic analysis according to Braun and Clarke (2013), the researcher followed Braun and Clarke (2021) in their approach to saturation. The researcher thus saw the process of identifying meaning and themes in data as a subjective interaction between the researcher and data and acknowledged that data saturation is not valid or a useful concept (Braun and Clarke, 2021).

However, Braun and Clarke (2013) do offer guidance of how many participants to recruit when using interviews as a method for qualitative data collection. They state that sample size will be affected by what the researcher wants to know, the purpose of the inquiry, what is at stake, what will be useful, what will have credibility, and what can be done with available time and resources (Braun and Clarke, 2013). They thus highlight, that it is important to have enough data to tell a rich story, but not too much so it prevents deep, and complex engagement with the data in the time available (Braun and Clarke, 2013; Onwuegbuzie and Leech, 2005). Braun and Clarke (2013) mention, that a sample size of 15 to 30 participants tends to be common in research that aims to identify patterns across data (Braun and Clarke, 2013; Terry and Braun, 2011; Gough and Conner, 2006).

Brinkmann and Kvale (2015) agree that the answer to how many is to interview as many participants as necessary to find out what we need to know, and the number of participants depend on the purpose of the interview (Brinkmann and Kvale, 2015). In common interview studies the number of interviews thus tend to be 15 plus or minus 10 (Brinkmann and Kvale, 2015). According to Brinkman (2013) fewer interviews that are thoroughly analysed are preferable to many interviews that are only superficially explored (Brinkmann, 2013). The aim is not statistical representativeness (although it can be, e.g., in mixed methods studies), but instead the chance to look in detail at how selected people experience the world (Brinkmann and Kvale, 2015). Interview studies thus tend to have around 15 participants, which according to Brinkmann (2013) is a number that makes possible a practical handling of the data. The aim of sampling is thus the chance to look in detail at how selected people experience the world (Brinkmann, 2013).

For this study, it was sought to recruit as many participants as possible to provide varied and rich data. A sample size between 10 and 30 was deemed likely to provide data that could answer the research question. However, it was acknowledged, that it could be necessary to recruit more participants depending on data and its richness.

3.4.10. Participant selection

A purposive sampling strategy (Bowling, 2014) was used combined with snowballing (Bowling, 2014) to obtain data. The purposive sampling strategy was used with the aim of generating insight and in-depth understanding of the topic of interest (Bowling, 2014; Patton, 2002). Snowballing was also used, as participants were encouraged to mention the study to their colleagues.

The sample included nurse specialists that run early RA nurse-led clinics, at different types of rheumatology centres in different parts of England. Scotland, Wales and Northern Ireland were not included due to administrative differences between the countries healthcare systems (Nicholson and Shuttleworth, 2020). However, as considerable variations in the delivery of care had been shown in surveys with participants mainly from England (BSR and NRAS, 2019; Ndosi *et al.*, 2017), an interview study with nurse specialists from different geographical areas and types of clinics in England was considered appropriate to get an understanding of rheumatology nurse-led care from the perspective of nurse specialists.

Inclusion criteria: Participants included were clinical nurse specialists, nurse practitioners or rheumatology nurses, who ran nurse-led clinics for people with early RA in England.

Exclusion criteria: Excluded were nurses who did not run nurse-led care for people with early RA.

Participants were recruited through professional networks outside of the NHS. Invitation adverts were published online at the Royal College of Nursing (RCN) Rheumatology Nursing Forum and RCN Advanced Practitioner Forum, professional groups for nurse specialists on Facebook and Twitter platforms.

3.5. Ethical considerations

A research protocol was developed, and ethical approval was granted by the University of the West of England (UWE) Research Ethical Committee (FREC), UWE REC REF No: HAS.20.03.143. The final ethics approval of the study is provided in Appendix H.

No further ethics applications were required as the research was conducted outside NHS trusts through professional networks of the Royal College of Nurses Rheumatology Nursing Forum and using participants' own time. The ethics approval included the approval of participant information as provided in the Participant Information Sheet (Appendix I), information about data security as provided in the Privacy Notice (Appendix J), and a prepared informed participant consent form as provided in the Participant Consent Form (Appendix K).

All participants provided oral and written informed consent, as they prior to the interviews returned the signed participant consent form, and prior to the interview orally repeated their consent to participate in the research and to the interview to be audio-recorded.

3.6. Study processes

3.6.1. Participant information

The invitation adverts published online included a short presentation of the study and the researcher with contact details. Potential participants who responded to the invitation adverts were sent an email by the researcher with the Participant Information Sheet (Appendix I), a Participant Consent Form (Appendix K) and the Participant Privacy Notice (Appendix J) and contact details for the researcher who they could contact if they wished to discuss the study. Potential participants could also request paper copies of the Participant Information Sheet, Consent Form and Privacy Notice. These would be sent out with a reply-paid envelope included.

Potential participants were informed that the project was part of a PhD in Rheumatology nursing in early RA and that the interviewer was a PhD student in rheumatology nursing. It was highlighted that the nurses' experience and views of nurse-led care for people with early RA were valuable for this study and that they would be asked about these things. Potential participants were informed that the researcher wanted to ask about participants' professional roles and how long participants had been working in rheumatology. All the information that the researcher received from participants would be kept confidential. The researcher would anonymise the telephone interview transcripts by removing the names of people and places. Research material would be kept in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements.

Participants were informed that they could withdraw from the study without giving any reason up until their anonymised data were analysed. If participants withdrew before analysis of data, all their data (audio, transcripts, any personal data) would be securely destroyed. After data analysis participants would not be able to withdraw, as the quotes would have been anonymised and it would not be possible to trace them back to an individual participant.

3.6.2. Arranging telephone interviews

Participants contacted the researcher, and telephone interviews were arranged. Potential participants who had shown interest in the study and asked for the information pack but did not contact the researcher were contacted once to inquire if they wanted to participate or needed more information.

Interviews were organised and scheduled by the researcher to accommodate participants for time and convenience. A schedule for interviews was followed, and new appointments were re-scheduled in the event that they should be cancelled (Burke and Miller, 2001). The interviews were scheduled to last approximately 30 minutes.

3.6.3. Conducting interviews

At the beginning of the interview participants were asked if they were still interested in taking part in the interview, and if they were still happy for the interview to be audio-recorded.

Participants were then asked about their experience and background, how they would define nurse-led care in early RA if possible, and they were asked questions about aspects of care according to the interview-guide (Appendix G).

3.7. Analysis

Methods of analysis were considered. The following section provides a summary of thematic analysis and a justification for using this analysis method in this study.

3.7.1. Thematic analysis

Thematic analysis is seen as a flexible method for data analysis without prescribing methods for data collection, theoretical positions, epistemological or ontological frameworks (Braun and Clarke, 2013). It can thus be used to analyse almost any kind of data, and themes can be identified in a data-driven way or 'bottom up' on the basis of what is in the data (Braun and Clarke, 2013). This is relatively unique for qualitative analytic methods compared to for example Grounded Theory and Phenomenology (Braun and Clarke, 2013).

A weakness is that because of the focus on patterns across the data set, it cannot provide any sense of the continuity and contradictions within individual accounts, and the 'voices' of individual participants can get lost (Braun and Clarke, 2013). However, for the aim of this study, which focused on identifying themes of nurse-led care from a wide range of nurse specialist backgrounds and views, the approach was deemed appropriate. Different varieties of thematic analysis exist: Inductive thematic analysis, theoretical thematic analysis, experiential thematic analysis, constructionist thematic analysis and Interpretative phenomenological analysis (IPA).

For this study, inductive thematic analysis was used, as the focus was to understand nurse specialists' perspective of rheumatology nurse-led care to identify themes and patterns of meaning that could contribute to the development of a new theory of early RA nurse-led care.

Thematic analysis enabled the identification of themes and patterns of meaning across the data set in relation to the research question (Braun and Clarke, 2013). The approach consists of the following steps: Reading and familiarisation, coding - complete across the entire data set, searching for themes, reviewing themes, defining and naming themes, writing – finalising analysis (Braun and Clarke, 2013). In Braun and Clarkes's new book (Braun and Clarke, 2022) inductive thematic analysis is now called reflexive thematic analysis. The authors have commented that this change was to highlight the reflexive nature of thematic analysis, which was already implied in inductive thematic analysis, but had needed to be underlined (Braun and Clarke, 2022). As Braun and Clarke's earlier book (2013) was used for this study, the term 'inductive thematic analysis' will be used, as this was accurate when the researcher was doing the analysis – and for the references cited in this chapter. The following section provides an overview of the process of thematic analysis.

3.7.1.1. Transcription

According to Braun and Clarke, transcription and preparation of the transcripts can be seen as part of the analysis, as the process involves getting to know the data (Braun and Clarke, 2013). For this study, the audio-recordings of interviews were transcribed verbatim by a UWE approved, General Data Protection Regulation (GDPR) compliant transcription service (Essential Secretary) which has a confidentiality agreement with the University of the West of England for data processing. The audio-recordings were of good quality, which was confirmed in writing on the transcription by the Essential Secretary Service.

3.7.1.2. Anonymisation

The researcher anonymized the interviews. Each recorded interview was downloaded onto a secure folder in UWE OneDrive, labelled with an allocated ID code (CNS01 to CNS16) and deleted from the recording device. A list of participants with allocated ID codes linking them to the audio-recordings was stored in a separate folder within the secure UWE OneDrive server. This list of participants codes with identifiers (professional title, professional experience and region) was deleted at the end of the study.

The researcher then uploaded the audio-recordings in a secure system directly to the professional transcription service. The completed transcriptions were delivered using a secure code and downloaded directly to a separate folder in the secure UWE OneDrive server.

3.7.1.3. Checking transcripts for accuracy

The researcher checked the transcripts for accuracy against the audio-recordings. This process involved listening through the audio-recordings multiple times while comparing with the transcripts. After checking for accuracy, the transcripts were then anonymised, with any identifying information (e.g. names and NHS trusts) being removed. The researcher also considered continuously what information might potentially make participants identifiable, such as occupation, not only as isolated information but as a cumulative effect (Braun and Clarke, 2013). Geographical data were replaced with NHS regions for place, and names of people were changed to xx. Following the accuracy checks and anonymisation, the audio recordings were deleted from the secure server. Each participant was linked to the interview recordings by an allocated number which was kept on a list of participants codes in a separate folder within the secure UWE server. This list of participants codes with identifiers (professional titles, experience, and region) was deleted at the end of the study.

3.7.1.4. Reading and familiarisation

The process of familiarising herself with the data involved reading and re-reading the transcripts and writing first notes using the comment feature in word software. The researcher had developed the interview guide with the Director of Studies, and had conducted all interviews, and therefore the researcher had a good understanding of the data. However, thorough familiarisation with the entire data set meant that this process generated comments and notes for individual transcripts and across several transcripts with summarising comments as more interviews were conducted and transcribed.

The researcher made a copy of the anonymised transcripts and used Word with the comment feature to read through the transcript and noticing what the data were about, commenting in the margin following Braun and Clarke (2013). The comment function was used to create text, that could be used as first codes. Keywords in the text were highlighted which helped to get an overview of data. This was, according to Braun and Clarke (2013), the first step of looking at the transcripts as data, and a first step in the reduction process, when the researcher starts to put into words what participants have described, as well as topics, issues and views discussed.

3.7.1.5. Coding - complete across the entire data set

Coding provides the building blocks for analysis (Braun and Clarke, 2013) and is an essential phase in the analysis process. Coding is seen by Braun and Clarke (2013) as a process of identifying aspects of the data that relate to the research question where the main approaches are 'selective coding' and 'complete coding'.

Selective coding involves the identification of instances of the phenomenon of interest and selecting these out (Braun and Clarke, 2013). According to Braun and Clarke (2013) this process implies some level of pre-analysis to decide what counts as instance of interest, and where it starts and finishes. It also requires pre-existing theoretical and analytical knowledge to provide the ability to identify the analytical concepts of interest (Braun and Clarke, 2013). Complete coding is a different process, where instead of looking for particular instances of the phenomenon of interest, the aim is to identify anything and everything of interest or relevance to answering the research question within the entire data set (Braun and Clarke, 2013). According to Braun and Clarke (2013) this means that all data that are relevant to the research question are coded, and it is only later in the analytic process that the researcher becomes more selective. The latter approach of coding was thus deemed most fitting for this study, as everything relevant for the research question could be coded, with a more selective approach only applied later in the analysis phase (Braun and Clarke, 2013).

According to Braun and Clarke, the coding process is not an exclusive process with only one way of coding, as they state that any data extract can and should be coded in as many ways as fits the purpose (Braun and Clarke, 2013). Codes can be data-derived or semantic codes, reflecting the semantic content, or researcher-derived or latent codes, reflecting more conceptual or theoretical interpretations of the data (Braun and Clarke, 2013).

Complete coding was carried out using semantic coding, which is usual for new researchers (Braun and Clarke, 2013). Afterwards, the researcher went through the data looking for latent codes relating to frameworks and assumptions (Braun and Clarke, 2013). The researcher began with the first data item, systematically working through the whole item looking for data that could potentially address the research question (Braun and Clarke, 2013). Most codes were line by line coding, staying very close to the original wording to avoid interpretation of the original data. Later in the analysis process more researcher derived codes were added to label identified meaning patterns.

Codes thus identified and provided a label for a feature of the data that was potentially relevant for answering the research question, with the 'code' understood as a word or brief phase that captured the essence of why the particular piece of data might be useful (Braun and Clarke, 2013). Following Braun and Clarke (2018), codes were created, so they could stand alone and give meaning, when data were taken away (*Thematic analysis - an introduction*., 2018).

Themes are according to Braun and Clarke (2013) developed from the codes, and Braun and Clarke recommend creating as many codes as you like (Braun and Clarke, 2013). They also advise to start from one end of the data set and work the whole way through in the same way, with detailed coding over the whole data set, adding and rearranging as you go along (Braun and Clarke, 2013). These procedures were followed and provided a multitude of codes across the data set, which the researcher compared to data and to other developed codes during the analysis.

3.7.1.6. Searching for themes

According to Braun and Clarke (2006, 2013), a theme should capture something important about the data in relation to the research question, and represent some level of patterned response or meaning within the data set. Whereas a good code will capture one idea, a theme has a central organising concept but will contain lots of different ideas or aspects relating to the central organising concepts (Braun and Clarke, 2013). The initial themes are according to Braun and Clarke (2013) provisional and candidate themes as they will be revised and refined through the developing analysis. Transcripts were compiled in one Word file. This made it possible to navigate across transcripts using the search function, using key words, codes and initial candidate themes. It also made it possible to search the compiled document for illustrative quotes. Codes and initial candidate themes were added in the comment sections of the Word file. Also handwritten notes were developed with diagrams of candidate themes and potential relationship between them. All codes and initial candidate themes, handwritten and digital, were compared continuously with the data set to get an understanding of patterns of meaning across the data set.

3.7.1.7. Reviewing themes

Tables were developed with candidate themes identified from codes across the data set with a separate Word document for each candidate theme. Codes could be used for more than one theme. The themes were not numbered according to importance, but only for clarity. All candidate themes were reviewed by the first author and the provisional themes, subthemes and relationship between them were mapped in diagrams to support the development of themes.

Reviewing and revising candidate themes involved going back to the coded and collated data to make sure that each candidate theme worked in relation to the other candidate themes (Braun and Clarke, 2013). Each candidate theme should thus be coherent, work together and relate to the research question (Braun and Clarke, 2013). Each theme was considered on its own and in relation to other themes (Braun and Clarke, 2013).

The next step of revision was to go back to the whole data set to read and re-read all the data items to ensure that the themes captured the meaning of the data set (Braun and Clarke, 2013).

PhD supervisors who were also co-investigators reviewed a subset of the transcripts independently. The interpretations were compared, and differences discussed to ensure the most suitable interpretation were found. The patient research partner who was a member of the supervisory team reviewed and commented on summaries of the process, and candidate themes were discussed at joint supervisor meetings and confirmed for relevance and meaningfulness.

According to Braun and Clarke (2013), the researcher can keep reviewing, looking for the perfect ‘fit’ (Braun and Clarke, 2013). As themes continue to take shape in the next phase of the analysis, Braun and Clarke therefore recommend moving on when the researcher does not want to make substantial changes anymore (Braun and Clarke, 2013). This phase ends with a set of distinctive, coherent themes and a sense of how they fit together as well as the overall story they tell about the data (Braun and Clarke, 2013). At this stage of the analysis, the researcher therefore moved on to defining and naming themes.

3.7.1.8. Defining and naming themes

This phase of the analysis involved defining and naming themes as well as writing. To help process of defining and naming themes and to get an overview of themes, subthemes, codes and data extracts, the researcher created tables with themes and subthemes and selected codes and quotes for the narrative, using highlighted codes and quotes from the more detailed preliminary table of candidate themes. The researcher also created diagrams with preliminary identified themes to understand how they were connected and related to each other. Diagrams were first developed as handwritten drafts, then eventually developed as Microsoft PowerPoint figures which could be shared with the supervisory team for review.

Braun and Clarke (2013) advise that in the final text narrative, each theme should be developed and presented in its own right, and in relation to the research question and in relation to the other themes so the analysis is interconnected and presented in a logical way (Braun and Clarke, 2013). Through writing the thesis the researcher engaged in continued reflections of the patterns of meaning that she had identified, themes and considerations of how these should be organised in order to ‘tell the story’ in a logical and convincing way, at the same time as being loyal to data. The themes were commented on, discussed and confirmed by the full supervisory team.

3.7.1.9. Writing – finalising analysis

According to Braun and Clarke (2013) you cannot really do qualitative analysis without writing it, as qualitative analysis uses words to tell the story about data (Braun and Clarke, 2013). Writing is thus the process through which the analysis develops into its final form (Braun and Clarke, 2013). This analysis then involved selecting the extracts that the researcher would use to illustrate the different facets of each theme (Braun and Clarke, 2013). Then writing a narrative around these extracts which told the reader the story of each theme as a narrative that would persuade the reader of the plausibility of the argument (Braun and Clarke, 2013). In this part of the analysis, the narrative, Braun and Clarke highlight the importance of actually analysing data, as it has not just to paraphrase data, but to tell what is interesting about the data and particular data extracts, and why that is (Braun and Clarke, 2013). They also encourage the researcher to reflect on data, to offer an interpretation of data and even integrate literature into the analysis to go beyond just summarising the content of the data (Braun and Clarke, 2013).

As the researcher in this study had an active role in the interaction with data and the analysis process (Braun and Clarke, 2013), the researcher decided that it was appropriate to follow this approach. The researcher thus sought not only to summarise the content of the data, but to reflect on data, to relate data and developed themes to the research question and reflect on implications for clinical practice (Braun and Clarke, 2013).

3.7.1.10. Reporting of the study

The reporting of this interview study followed appropriate elements of The Consolidated Criteria for Reporting Qualitative Studies (COREQ), a checklist with 32 items (Booth *et al.*, 2014; Tong, Sainsbury and Craig, 2007). COREQ covers the reporting of studies using interviews and focus groups, and it is the only reporting guidance for qualitative research which has received other than isolated endorsement (Booth *et al.*, 2014). This checklist can help the researcher to report important aspects of the research team, the study methods and context of the study, findings, analysis, and interpretations (Tong, Sainsbury and Craig, 2007). The COREQ checklist was thus used to ensure that sufficient detail on methods and data analysis, and the relationship between the analysis and the findings in the research was reported, so that the readers can assess the rigor of the analysis and the credibility of the findings (Booth *et al.*, 2014).

Chapter 4: Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: Results, discussion, and conclusion

This chapter reports the results, discussion, and conclusions of the interview study with rheumatology nurse specialists. This study aimed to develop an understanding of what comprises nurse-led care in early RA from the perspective of rheumatology nurse specialists.

4.1. Results

Telephone interviews were conducted in summer 2020 by the researcher, and the interviews lasted between 30 to 60 minutes. This section provides a summary of participants, and presents the themes and subthemes, which were identified from interviews with rheumatology nurse specialists using inductive thematic analysis (Braun and Clarke, 2013).

4.1.1. Participants

Sixteen rheumatology nurse specialists who ran nurse-led clinics in England were interviewed. The majority of participants worked at Hospital Rheumatology Departments across England, fourteen nurses in all. Two participants worked in community settings. The nurse specialists were based in the NHS regions: Yorkshire, North East, South West, South East, East and London. Thirteen participants were rheumatology nurse specialists, two participants were rheumatology consultant nurses, and one participant was a nurse practitioner. The nurse specialists' professional backgrounds varied in length of rheumatology experience, from new clinical nurse specialists to highly experienced consultant nurses. Participants had rheumatology experience from one year to over 25 years with roles on a continuum from newly appointed nurse specialist to roles with extended care and management responsibilities. Some participants had other professional experience from training and previous employment, such as training in counselling (one) and connective tissue diseases (one). Two participants had master's degrees (MSc), and some participants had acquired further academic qualifications, such as modules in rheumatology nursing (one), prescription (five), and intra-articular injection technique (one). Five nurses were non-medical prescribers, and eleven nurses were non-prescribers.

Due to the risk of breaching anonymity, characteristics of the individual participants will not be provided in detail, such as years of experience, detailed work responsibilities and geographical area. However, an overview of participants with interview number, role in clinic, years of rheumatology experience and type of Trust employment is provided in Table 5.

Table 5. Summary of participants

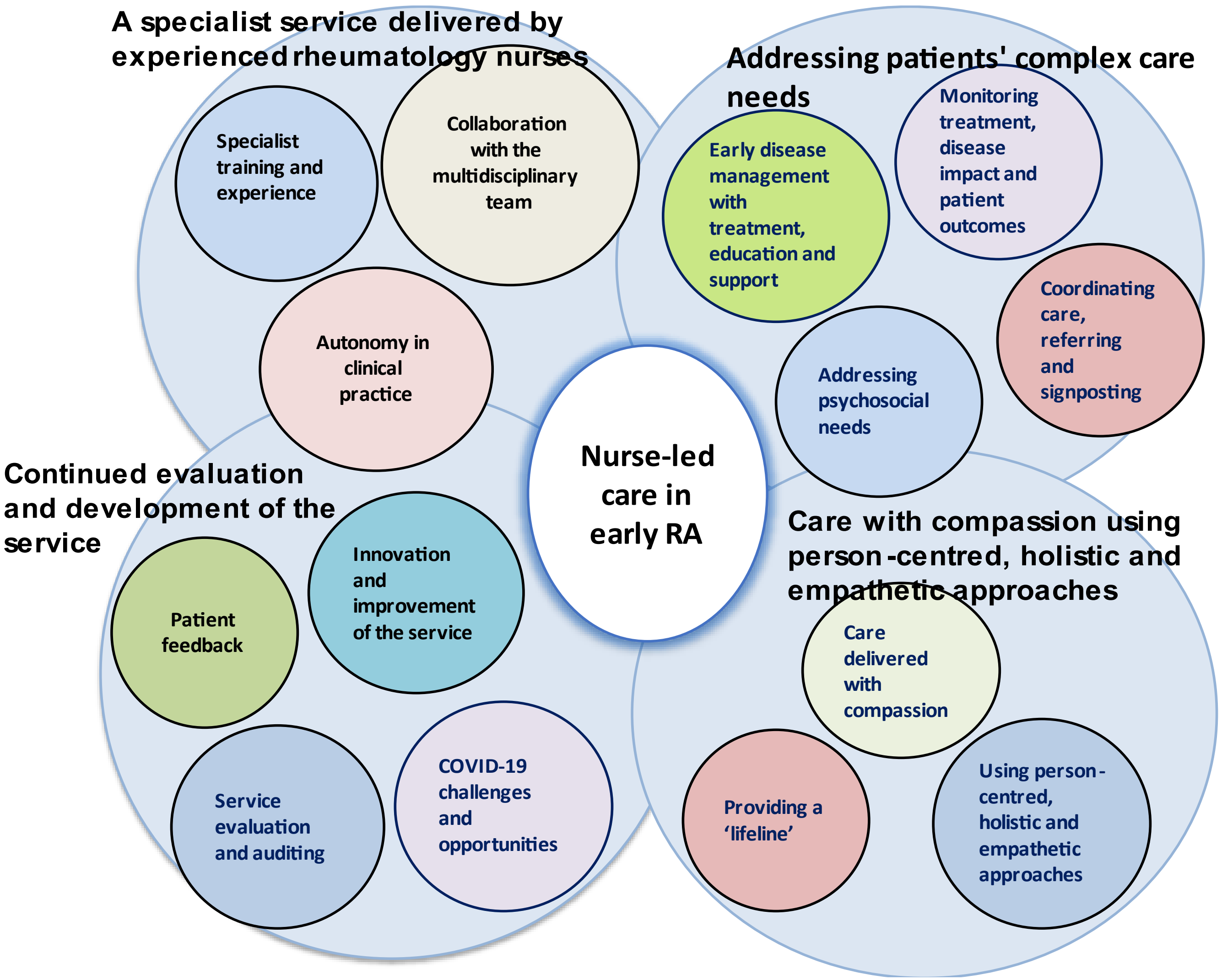
Participant	Role in clinic	Rheumatology experience	Employment
CNS01	Rheumatology nurse specialist	13 years	Hospital Trust
CNS02	Rheumatology nurse specialist	28 years	Hospital Trust
CNS03	Rheumatology consultant nurse	Over 25 years	Community Trust
CNS04	Rheumatology nurse specialist	15 years	Hospital Trust
CNS05	Nurse practitioner	25 years	Primary Care
CNS06	Rheumatology nurse specialist	24 years	Hospital Trust
CNS07	Rheumatology nurse specialist	6 to 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 to 7 years	Hospital Trust
CNS15	Rheumatology consultant nurse	Over 25 years	Hospital Trust
CNS16	Rheumatology nurse specialist	4 to 5 years	Hospital Trust

4.1.2. Themes

Four themes with subthemes were identified which characterised nurse-led care in early RA from the perspective of rheumatology nurse specialists.
The themes were: 1) 'A specialist service delivered by experienced rheumatology nurses'; 2) 'Addressing patients' complex care needs'; 3) 'Care with compassion using person-centred, holistic and empathetic approaches'; and 4) 'Continued evaluation and development of the service'.

The themes were connected and had some overlap between them. They were supported by subthemes and showed the concept of complexity of care. All themes and subthemes contributed to the characterisation of early RA nurse-led care. A summary of themes and subthemes is provided in Figure 3. A table of themes, subthemes and illustrative quotations is provided in Appendix L.

Figure 3. Themes and subthemes characterising early RA nurse-led care



In the following section each theme with supporting subthemes will be presented in detail, underpinned by participant quotations.

4.2. A specialist service delivered by experienced rheumatology nurses

The first theme captures the nature of the service as the provision of a specialist rheumatology service. Organised under this theme are subthemes that describe aspects of the nurse specialists' knowledge and skill acquired through extensive training, work experience and academic study. The theme also captures the autonomy of the rheumatology nurse while collaborating with the multidisciplinary team.

4.2.1. Specialist training and experience

Participants described nurse-led care as a specialised rheumatology practice requiring extensive knowledge, skill, and experience to plan and deliver care in rheumatology for the rheumatology patients. The specialist nature of rheumatology nurse-led care was highlighted, and the importance of the service in the delivery of specialist disease management to vast numbers of patients with complex care needs.

> *When I first started, I had no idea how massive or how specialised [nurse-led] rheumatology is […] Basically what we do is, we keep them all out of hospital, because we treat them, and I think this is another thing why people don't understand, because they think outpatients, they think we just take the notes to the doctors, and they see the patients, but it's not like that at all [...] We have I think, about 14.500 patients in [nurse-led] rheumatology (CNS16).*

Participants reported that they used their knowledge, experience, and skills to plan and deliver care for the rheumatology patients, applying their specialist knowledge within day-to-day service delivery, and cooperating with the multidisciplinary team and the patients.

> *And it's to know, know and to have the experience and knowledge is absolutely critical (CNS04).*

> *Working sort of independently, but equally very much alongside the rest of the rheumatology team, in delivering care (CNS02).*

Participants described having extensive clinical experience in rheumatology, the musculoskeletal field, surgery, and medicine. Participants thus expressed being proud of their experience, knowledge and ability to help people in need.

> *I think we're hugely important in the whole of the rheumatology experience. I think we play a major part. We are their support, we're their educator, you know we're sort of like, almost like we're the corner man (CNS04).*

Participants were involved in management of rheumatology departments, lead of nursing teams, the nurse-led services, biologic medication teams, rheumatology day care and advice lines. Some participants reported that they had extended their practice by pursuing new skill sets which they could apply in their clinical practice. Examples were prescribing, ultrasound scanning, counselling and shared care decision making.

> *I'm a nurse prescriber so I can prescribe for patients. So that's, really crucial actually to my role now. It's made a big difference to my practice (CNS08).*

Participants reported that they had acquired extensive nurse training before taking on their roles in early RA care. Some had supplemented their nurse training with master's degrees in clinical science, had nurse practitioner degrees with rheumatology modules or had undertaken university courses in prescribing. It was reported that before participants started running their own consultations at nurse-led clinics, they had received extensive in-house training.

> *So the first few months I spent in Rheumatology, I had an induction which involved, which I was able to sit in, on clinics run by my colleagues, the other Rheumatology Nurse Practitioners and also, Consultants, Registrars clinics, and then sort of gradually I built up and obviously I did a lot of sort of personal*

> *study, you know, sort of developing my knowledge, and then I started off in running an Education clinic (CNS13).*

Participants were encouraged by their management to keep their knowledge up to date, and some had access to study days and educational evening meetings. However, education was mainly provided by medical companies and by attending conferences. Access to conferences was seen as beneficial and could 're-vitalise' the nurses. However, lack of funding and time away from work seemed to limit access to these learning opportunities.

4.2.2. Autonomy in clinical practice

The participating nurse specialists reported that they worked with a high degree of autonomy. Depending on the organisation of the workplace, their experience and role in the clinic, they would independently run education clinics, clinics for escalation of medication according to guidelines, follow-up and review clinics as well as providing support via the telephone advice line.

> *We run our clinics independently (CNS14).*
>
> *We have patients who don't see a doctor for years and years […] (CNS10).*

Participants who were prescribers could make treatment decisions, discuss with the rheumatologist and then initiate treatment. However, also participants who were non-prescribers had autonomy, as treatment protocols allowed them to adjust medication as long as criteria in the protocol were met. One participant described how Patient Group Directories (PGDs) allowed nurses to administer steroids according to a strict protocol.

> *Depo Medrol we have a PGD which allows us to give rescue PGD Depo Medrol (CNS04).*

The participant explained that any prescription or adjustment of medication followed protocols and guidelines, and the participant conferred with the rheumatologist and her colleagues as appropriate to secure safe and effective treatment. Participants also reported that patients in early RA were treated with medication that could have severe side effects and could cause health hazards if they were not prescribed, administered and monitored with care. According to participants, they managed patients' medication in early RA, where high dose DMARDs were introduced and escalated according to protocols. Therefore, the close collaboration between rheumatologists and nurse specialists was especially important.

> *I know I've got the backing of a really good medical team and I've got a good team that I work with. So I feel safe in my practice (CNS08).*

Participants agreed that their autonomy had proved especially important when the COVID-19 pandemic disrupted the service. According to participants, they had thus been able to continue treatment and patient support despite disruption to the service with change from face-to-face consultations to telephone consultations conducted from home.

4.2.3. Collaboration with the multidisciplinary team

Participants reported that they worked closely together 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. The collaboration with colleagues in the nursing team was seen as important for the professional development as a nurse specialist, and it built confidence in participants' individual clinical practice.

> *I was in and out of the clinics all the time, asking the other girls for advice, but that's how you learn and I think, I think the patients respect you for that […] (CNS13).*

Data indicated that the nursing team was associated with feelings of confidence and pride of being a member of a knowledgeable and highly supportive team. This strong feeling of support from the nursing team was reported to provide good care for patients and helped managing challenges in clinical practice as lack of staff, time and work pressure.

> *I've worked in a lot of areas, and personally I think the patients do get a really good service in rheumatology from the nurses. And I think a lot of that is down to the team (CNS08).*

Participants reported that they had good work relations with other members of the multidisciplinary team such as physiotherapists and occupational therapists (Ots). According to participants working at hospital departments, early RA care was generally organised as nurse-led care in collaboration with rheumatologists and the wider multidisciplinary team. The support from the multidisciplinary team was seen as important.

> *[Nurse-led care is:] Working sort of independently, but equally, very much alongside, the rest of the rheumatology team, in delivering care (CNS02).*
>
> *I think knowing that you've got a Multidisciplinary team is really helpful (CNS09).*

Participants described that they worked 'in tandem' and 'hand in glove' with the rheumatologist and the medical team. They dealt with medication and intensive monitoring of treatment response, so the backing of the medical team was seen as important for feeling safe in participants' clinical practice. As patients in early RA start treatment early with a multitude of medications and close monitoring, participants saw the collaboration with the consultants and the medical team as very important. The close collaboration meant that the medical team could trust that the nurses would seek advice and confer whenever there were any problems or issues regarding patients that needed to be discussed.

> *I'm working, you know as a lone individual in clinic. But in the early rheumatoid arthritis side of things there's always a medical person around. So we're running*

> *in tandem really, so we can bounce things around, and you know we can collaborate, I guess (CNS07).*

4.3. Addressing patients' complex care needs

The second theme captures the complex nature of early RA nurse-led care, with subthemes describing aspects of care that are used to address patient's care needs. Subthemes thus describe aspects of early RA care as early disease management which includes starting treatment and keeping in treatment, education, and support. Further aspects of care such as monitoring treatment, disease impact and patient outcomes, as well as addressing psychosocial needs, and coordinating care with referrals and signposting are presented.

4.3.1. Early disease management with treatment, education, and support

Participants reported that they were involved in RA management from early disease.

> *I do see patients as early inflammatory arthritis, and have done the pathway clinics (CNS02).*
>
> *We look after the patients from diagnosis (CNS04).*

Care was characterised by evidence-based RA management as it followed current international recommendations and national guidelines with early detection, start of treatment and following a treat-to-target approach.

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

The aims of patient care were to: start treatment, keep in treatment, educate, and support. Participants agreed on the importance of getting patients into treatment as soon as possible. A participant from primary care, who was responsible for initial assessment of patients with suspected RA, and referral to specialist review, described how she sought to shorten any delays for early RA detection and start of treatment.

She would thus sort blood tests and x-ray in advance, so the rheumatologist at the rheumatology department could see the results and make quick treatment decisions. Participants at the hospital nurse-led clinics would seek to book the first nurse consultation for start of treatment as soon as possible after diagnosis.

> *So when patients are newly diagnosed, within a week of diagnosis, they'll get, … an appointment with a specialist nurse, and that appointment will be for about an hour, and it'll go through all the medications, that we want them to start, and that will depend on whether we're having them in to sort of a moderate pathway, or a more, comprehensive, pathway, depending on their … their actual type of disease, and how bad their disease is (CNS02).*

Interview data showed that keeping patients in treatment was an important aspect of early RA care as patients could meet obstacles that made them drop out of treatment, with risk of damage to the joints. Participants saw it as essential to educate and support patients especially at the early stage of disease. They used their knowledge about the disease, its impact and treatment as well as their knowledge about the healthcare system and patients' everyday lives to help patients to adjust to the disease, to manage their symptoms and seek support when they needed it.

> *Good care is to help with our knowledge, knowledge of the condition, to help them to be the best that they can be, with that condition and for them to have strategies for setbacks (CNS06).*

Participants reported that RA pathways and protocols secured a structured patient journey with a plan for the categorisation of patients at the beginning made by the doctor that diagnosed them.

> *So there's a plan for, the, you know, the categorisation of patients at the beginning is made by the doctor that diagnoses them and then they go on one of two pathways which is then, a pathway involving different degrees of*

> *medication, and depending on their disease activity obviously it's treat to target (CNS08).*

Participants reported that education of patients was an essential part of their role and that they provided timely and balanced education from the first meeting with the patients. It was thus reported that participants introduced patients to csDMARD treatment at the first consultation with the nurse after diagnosis. Participants explained that the time of diagnosis could be stressful and difficult for the patients, and additionally many patients feared starting treatment with csDMARDs, especially with Methotrexate. According to participants, some clinics planned a gap of one to four weeks between diagnosis and the first nurse consultation with education and start of treatment to let the patient process the news. Other clinics had same-day or next-day nurse consultations and concentrated on the most essential information needed for safety reasons, and more information would be added on the following visits.

> *There's such a huge amount of information. We designed a top ten in order to just give them the top ten salient points and also the same for the arthritis, for their diagnosis of RA (CNS04).*

Awareness of the psychological impact of getting a new diagnosis as well as timely information at the patients' own pace were emphasised as important for a successful outcome and a positive patient experience. Participants reported that using clear and trustworthy communication was essential when interacting with patients in early RA. It was seen as important to provide information about the medication and why it was given, as well as the expected benefits of the treatment, together with reassurance of support and advice when the patient needed it.

According to participants they informed patients about the disease, the medication, side effects, precautions with medication and lifestyle, monitoring of blood, and later introduced the patients to self-injection if it was needed. Further information was given at later consultations and by follow up telephone consultations. It was seen as important to let the patients know that their concerns were taken seriously and that they were part of the decision-making. Sometimes the patients needed more time to consider what they wanted or needed to have more conversations with the nurse about what to expect. The participants would support patients in whatever decision they made and inform them that they were welcome to come back.

Participants reported that they saw patients with early RA at frequent visits after they had started treatment with csDMARDs.

> *We see them a lot at the beginning […] (CNS13).*

Most participants referred to these clinics as escalation clinics. According to the participants, the csDMARDs were increased at these clinics according to the NICE guidelines (NICE, 2018) to get disease control as soon as possible. The participants reported that they saw patients with stable RA at follow-up clinics and conducted annual review clinics for patients who had completed the early one-year RA pathway. Participants reported that they also conducted annual review clinics for patients who had completed the early RA pathway. These clinics could be face-to-face consultations or be carried out in annual telephone clinics.

> *The annual review will basically look at medication, side effects, bloods, cardiovascular risks, and if we able to start deescalating, so start reducing their medication (CNS16).*

Some participants reported that they conducted Direct Access Clinics. These Direct Access Clinics were follow-up for patients with stable disease who did not have scheduled visits but could request a visit according to need. If patients had not been seen and had not requested a medical review before then, they had follow-up visit every two years.

> *I also, run my own clinics, for direct access review patients, so patients that are on the direct access system, and haven't been seen for two years, who … and*

> *haven't requested a medical review before then, actually come up to see me, and I review them, from my perspective (CNS02).*

According to participants these reviews every two years were conducted by very experienced nurse specialists. Patients would be invited to contact the clinic between the reviews to request a visit when they needed it.

Some participants were specialised in treatment with biologic medication and conducted clinics for patients who did not reach disease control with csDMARDs within six months from diagnosis and were elicitable for biologic treatment. They were thus responsible for screening and follow up.

> *I do see patients that are newly diagnosed and talk about disease modifying therapies […] So currently I run three nurse-led clinics a week, primarily seeing patients that are on biologic therapy […] So screening them to start therapy, assessing their response to therapy and then switching therapy if they, if they're failing to respond to treatment (CNS08).*

4.3.2. Monitoring treatment, disease impact and patient outcomes

According to participants, 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, wellbeing and keeping in work.

> *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).*

Observation of the patients' movements as well as physical examination of the joints were seen as important for these assessments.

> *First of all, you, you literally look at the patient when they walk through the door, how they've walked through the door [chuckling], number one, that's always my key (CNS12).*

Participants reported that they assessed disease activity and response to treatment using blood tests for inflammation markers and x-ray for joint erosion. Participants emphasised the importance of contacting patients if results indicated that adjustments had to be made to the medical treatment because of irregular blood tests or signs of progression of the disease. This reassured the patients that they were well looked after and that they could trust that the nurse would contact them if needed.

Participants reported that they used clinical measurements to assess disease activity and impact of the disease. The DAS28 (NICE, 2018; Fransen and van Riel, 2009) was an important measure when considering disease activity, treatment response and options for further treatment.

> *We would do the DAS28 at every appointment and certainly, you know the regularity of it over ... because in the escalation clinic they're seen six weekly until stability (CNS04).*

It was mentioned that feet were not included in the DAS28, only hands, which was a problem if patients had symptoms but then did not fit into the requirements for bDMARD. However, it was reported that participants had used patients' hands instead to help patients to get access to treatment despite these limitations.

Some participants reported that they used the Health Assessment Questionnaire (HAQ) (Maska, Anderson and Michaud, 2011; Bruce and Fries, 2003; Fries *et al.*, 1980) for assessment of the patients' functional status and quality of life in RA. However, some had used it a few times to get an overall status of the patient's self-assessed functional status and quality of life but did not use it on a regular basis, while others had stopped using HAQ, either because it had been deemed outdated by their rheumatology departments or because it took up too much time for the patients to fill in without being used for treatment decisions. Instead, the participants discussed functional status in conversation with the patient.

> *We used to use HAQ, but they've stopped using it now, I think the consensus was from the department that it was quite outdated (CNS09).*

Participants reported that they used the Visual Assessment Scale for pain assessment (VAS-Pain). The VAS-Pain scale was described as a 0-to-10-point scale with 10 as the highest level of pain. According to participants, the VAS-Pain scale could not be used to describe the experienced pain in detail, but it could provide some understanding of the patient's experienced pain, and follow-up questions could then be applied.

> *We do the, the Visual Analogue Scale, for looking at their sort of pain (CNS11).*

According to participants, the Visual Assessment Scale Global (VAS-global) was used to assess the overall impact of the disease. However, participants emphasised that it was necessary to look at different factors to get 'the whole picture' of the impact of the disease and the effect of the treatment.

> *The blood test doesn't tell us the whole picture. It's actually the patient, the patient will tell us and we have the ... we review each appointment that they come to during the escalation period and we look back at the DAS, we'll do another DAS and another global assessment and VAS and we look at that. And we compare it to the previous visit. So looking at the efficacy of treatment, the response and how they feel. Have they improved? (CNS04).*

Participants explained that it was about looking at how the disease was affecting the patients, and the scores could give the nurse an idea about how the patient was feeling and to see if there were any changes from one appointment to another.

Participants agreed that fatigue played a major part in the patient's overall experience of the disease. Participants reported that they would have a conversation with the patient and ask questions about the patient's experience, of daily impact and of what the patient did to limit the impact of fatigue.

> *And also a big thing with fatigue, understanding that the fatigue is part of the condition, and that there's not something else seriously wrong, because quite a few people will think there must be something else like cancer or something. So at least you could understand you know, that that's part of it (CNS06).*

The conversation about fatigue was reported to start at the first consultation with the nurse specialists and followed up at later consultations. According to data, the use of validated fatigue measures was limited.

Participants in this study agreed that also anxiety and depression were common issues in RA. Participants would thus talk to the patient about anxiety as part of the conversation to explore the degree of impact on everyday life, and especially to explore if the patient could be in danger.

Participants also monitored and addressed co-morbidities and lifestyle, including high-blood pressure and diabetes.

> *We're also looking after their other co-morbidities […] So a lot of people have other things going on, maybe heart problems, and so on. So we have to take that all into account (CNS05).*

Participants reported that they addressed lifestyle issues as smoking, weight and exercise at follow up consultations.

> *[…] We have to talk about smoking, and try and get them to stop smoking. We have to talk about weight, we have to talk about exercise […] We often will talk about work and whether they're in work and coping and whether they want to be in work and what support they might be able to get if they want to be in work (CNS10).*

Some participants reported that their clinics had protocols for nurse clinics with suggested areas of interest and questions to ask the patient to assess disease activity and impact of the disease, others asked their own questions to get an understanding of the patient's current situation and issues that needed addressing.

> *I tend to like just to have a chat with people, and you know as we say […] take a view on it (Laughs) […] just put everything in together, just, do the assessment, their wellbeing, their physical wellbeing, how they're coping with it, if there's any problems (CNS05).*

4.3.3. Coordinating care, referring and signposting

According to participants, they were responsible for the planning of early RA care. Participants thus coordinated care, referred to other health professionals and signposted patients to relevant services and charities.

> *We're pretty good at referring straightaway in the early arthritis, for Physio and OT [occupational therapy] I think that's really helpful for them as well to have that extra sort of support as well (CNS12).*

Referral options could be suggested in developed RA pathways, or the participants could discuss with the patient a course of action according to the patients' needs. Referrals could be 'out of the house' to health care professionals outside the nurse-led clinic. One participant reported that pain-psychologists were connected to the clinic.

> *We've also got pain psychology within our service […] (CNS03).*

One participant reported having a good collaboration with the occupational therapists regarding fatigue management.

> *With fatigue management, we do often refer to Occupational Therapy, because our Occupational Therapy Service do a really good, body of work on fatigue management […] (CNS14).*

It was reported that the participants signposted their patients to charities for support. Some charities were thus reported to have advice lines and patient support groups which offered psychological support.

> *They [patients with early RA] also need psychological support, they need information of other sources of support, so, we always give out information about third sector. So, NRAS, Versus Arthritis, um, and other charities (CNS03).*

Some of the participants had developed patient information about for example fatigue management and information about helpful resources online for depression and low mood, another participant had collected a library of information for rheumatology which she shared with her patients. One participant reported that she had developed a leaflet with information about the best websites for accurate information.

> *And you know, that we listen to them, we don't dismiss anything […] and they know how to contact you, you know, leaflets, knowing, which are the correct, the best websites to go onto, you know, there's a lot on the internet that's scary and not accurate. But knowing the correct sources to go to that are most up to date, and useful information (CNS06).*

However, participants agreed that access to psychological expertise was warranted as psychological issues were so massive in early RA. A few participants reported that they had access to pain psychologists, to Cognitive Behavioural Therapy (CBT) and fatigue management conducted by trained occupational therapists or nurses. However, these were exceptions.

> *We don't have access to any kind of counselling services, apart from the Occupational Therapist. OT, they do CBT, so we can refer them in for that service (CNS14).*

> *Mental Health and sort of CBT access […] it's, I think it's an area that's lacking, and it's something that we could really do with anyway (CNS11).*

It was reported that participants would appreciate support from psychologists, either as direct input with individual patients or as support for nurse specialists with advice and supervision.

> *It would be really … well we know it would be really helpful for a number of our patients, to be able to have some sort of … whether that's sort of, input directly from a psychologist, with an individual patient, or whether that would be support for us, from a psychologist, you know, that they can give us tips and help, and suggestions on … on consultations with patients, who are particularly struggling (CNS02).*

According to the participants, rheumatology departments monitored the first three months of treatment until the patients were stable with disease control. Shared care agreements with the patients' general practitioners (GPs) meant that patients were then monitored and got their cDMARD prescriptions via their GP surgery. However, a participant explained that if changes to medication were needed, patients came back to the rheumatology department, which then prescribed medication and followed the patient until the patient was stable again and could continue with monitoring and prescription of DMARD at their GP surgery.

> *We only monitor them until they're stable. And then our shared care agreement is that we monitor for … until they're six weeks stable on their new medication. But if you remember, like at the beginning, we're adding new things so you know, we're constantly extending that period to another six weeks, another six weeks, sort of thing (CNS16).*

It was reported that especially the handover between GP and hospital could be challenging as GPs worked differently, and prescriptions had to be double checked as well as booked blood tests to secure the safety of the patients.

> *Probably the biggest thing for us is when, when to take over the care of the patient, as in taking over prescribing their treatment, and doing the routine blood monitoring [...] (CNS14).*

The participants thus reported that they spent a fair amount of time on checking up on their patients and checking with GPs and other health partners. Furthermore, the varied clinical contacts were reported to cause some confusion amongst patients.

4.3.4. Addressing psychosocial needs

Participants reported that it could be very challenging for patients to be diagnosed with RA, and it was important to address the psychological side of the disease from the start. Participants were asked about psychological support to patients. In most cases, participants provided the psychological support, but acknowledged that they were not experts. Participants thus provided psychological support from experience with patients and knowledge of the disease.

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

> *You are there as a listening board absorbing it all […] My approach as well is we can't go backwards we have to go forwards (CNS15).*

According to participants, patients with early RA experienced shock, fear, anger, grief and denial while feeling unwell with pain and fatigue. To get a life-changing diagnosis could feel overwhelming. Starting intensive medical treatment with risk of side effects, being afraid of needles, being a patient depending on help, worried about work, family responsibilities or increasing physical disability could add to the distress.

> *It can be quite an enormous shock for some patients. They've obviously been feeling poorly anyway. So that's one side of it which they're having to cope with They're then faced with this diagnosis of a long term life changing chronic illness They also have the fear of all the medication (CNS13).*

According to participants, these concerns and worries would be present at the first consultations with the nurse and could interfere with the patient's ability to take in information, start treatment and eventually stay in treatment.

> *So the early arthritis patients we recognise the incredible fear and distress and anger and all of those things in the very early days and of course the impact that that can have on their decision to, accept treatment, accept diagnosis (CNS04).*

Participants explained that early RA with everything being new was very different from established RA where disease control had been achieved, where patients knew more about their disease, and over time had gained confidence and trust with the nurses and the rheumatology team. A participant reported that the psychosocial aspect of care was where she especially felt that she could contribute to care, and she used counselling skills from earlier employment in her clinical practice.

> *Something I try and do and I'm very conscious about doing is perhaps areas we traditionally have done very well at as nurses, not just in rheumatology. So care around the psychological and the social side of things and the impact they have on a patient's experience of the illness and how they manage and can be encouraged to self-care. So that kind of side of things I think there's much more of a, erm, independent, kind of a nurse led approach (CNS07).*

It was reported that RA and its treatment could have a major impact on patients' life decisions. Patients could thus suddenly have to postpone starting a family because of the risk of harming an unborn child with the medication. Participants reported that these conversations could be sensitive and emotional. According to participants they would inform about the facts, offer support, and suggest that patients considered and had a conversation with their partner. It could be necessary to offer alternative treatment, postpone start of treatment, or postpone the pregnancy.

> *It can be very emotional, very emotional, especially you know, if patients you know, we've had a couple of patients who have, maybe put off starting a family until slightly later in life and then this has developed and they were at that point where they were just about to start and then we're telling them, oh no well you can't […] (CNS14).*

Changes of lifestyle such as avoiding pregnancy and limiting alcohol intake because of the medical treatment could also be challenging for patients with worries about social life. Participants emphasised that they sought to encourage patients by telling them that with a good [treatment] outcome, RA should not stop them from living a normal life.

> *So, because patients do get some quite bizarre things into their minds that they think they can't do this anymore because they've got rheumatoid arthritis. And actually, it's about talking to them to say that really, it shouldn't be stopping them doing anything if, in a good, if you had a good outcome, it shouldn't stop them doing anything. They should lead a, lead a totally normal life (CNS01).*

This was consistent with recent research where a normal life despite RA (Elst *et al*., 2020b), and mastering a new life situation which entailed coping with RA and not being restricted by it (Landgren *et al.*, 2020) were found to be the main patient preferred outcomes in early RA.

It was reported that an essential aspect of early RA care was to establish a relationship with patients right from the initial meeting between nurse and patient. The building of this relationship was seen as crucial for effective successful care, as a working and special relationship would encourage patients to get in touch with the nurse if they experienced symptoms, side effects problems with medication or had worries in general so these problems could be addressed, and solutions found. This relationship ensured that patients could trust that the nurse would listen and take any concerns seriously, and the nurse could trust that patients would call if experiencing anything unusual, and thereby secure a safe and effective treatment.

> *What works is being responsive to someone, and trying to build a relationship and therefore a dialogue where people can ... you know building trust I guess where people can tell you what's going on and how they feel and what they want and what they don't want (CNS07).*

Participants emphasised the importance of the close relationship and reported that they assured patients that patients were not alone, but they were in it together from start and throughout the journey.

> *It is a long-term journey, we are going to be there with the patients…It's a partnership and we're doing it together (CNS14).*

It was evident from interview data, that communication was important to create trust and a working relationship. Participants thus emphasised the importance of using communication skills, being calm, kind, listening, and appreciate the patients' feelings, while providing reassurance and encouragement.

> *I think it's you know, being calm, being kind, listening to them, appreciating their feelings, and not sort of, undermining how they're feeling about anything. Trying to you know, find out what it is you know, what's the thing that's worrying them most perhaps? […] Even if it's reassuring them, and saying look, you know, your joint count is much better, you know [...] just trying to keep them positive and er, and listened to and respected I think (CNS06).*

Participants reported that they would make sure, that patients were informed about the recommended treatment plans, that it was expected that they would get better and that they would get support all the way as necessary. Participants explained that education and a person-centred approach played an important part in easing the patients' distress and help them to adapt.

> *There's an education facet to how people work through loss and adapt*
> *But I think, you know my belief, or my knowledge base is if you're to be effective at that you've got to be very patient or person centred (CNS07).*

According to participants, education from the start, psychological support from the nurse and access to the advice line were used to get the patients onboard, so they felt informed and confident to start treatment. Important was also giving patients control at a time when they could feel an overwhelming loss of control.

> *[…] A lot of it is psychological, you know, helping people to come to terms with it, to understand it, to educate people, um, to reassure them and to explain the options. And also to give them control I think […] (CNS06).*

Control could be a matter of limiting information to the most necessary at the beginning, so patients had time and capacity to take it onboard. It could be a matter of giving patients the opportunity to ask questions and invite them to call the nurse if they had any worries; it could also be a matter of giving patients strategies for setbacks and supporting and guiding patients to self-management. One participant thus advised patients to prepare an emergency box, so they knew what to do if they had a flare and could not contact the nurse. This box could contain pain killers and remedies that the patient knew had worked before.

> *Managing pain, managing flares, yes so they're advised to have a flare box in their house, that they keep things that they find, are useful for them when they're having the flare up, and that could be things like plain Paracetamol, Ibuprofen, it can be gels and rubs that they find useful, heat packs, things like that, so that they can go and, and grab that flare pack and they know, they're always going to have something there, whenever the flare attacks (CNS14).*

Participants reported that they also provided patients with leaflets of information about pain, fatigue, and information about how to cope with these, with much of the written material being developed by the nurses themselves based on their experience of patient needs. Participants also stressed the importance of using the telephone advice line and encouraging patients to contact them whenever they needed advice or support. Participants would thus make sure that patients had a contact number to the telephone advice line from the first appointment with the consultant rheumatologist at the clinic.

According to participants, practical help could be necessary, when just too many issues at the same time could make it difficult for patients to cope. Examples were helping patients to fill in forms for benefits and providing leaflets so patients could be prepared for meetings with their employer.

> *I've helped to sort out forms for benefits, I've talked them through how to do things like that, you know, giving them obviously … there's obviously the, I want to work you know, the leaflets for employers and employees (CNS06).*

Participants stressed the importance of giving patients a platform for discussion and asking questions, as well as talking to patients and really listening to understand what was important for them to achieve.

> *It's talking about them, to them about, you know, what they want to achieve from things. And sometimes it's quite surprising what patients, what patients want to achieve rather than what you want to achieve, can be very, very different. I mean obviously, we're very medical-minded, even the nurses, we're very medical-minded is that we want to, get their disease under control... whereas sometimes, it's important to the patient that, just that they can do their knitting or … they can hold their grandchild and things like that (CNS01).*

Participants saw it as important for patients’ mental health and ability to cope with the changes the disease would make in their lives, that they had somebody to talk to who knew them and their disease well, somebody they could ask questions and who would listen and understand.

> *I generally try to get to the bottom of it. If it’s something that’s very RA–related, like pain or fatigue or something, then we’ll talk about the specifics of managing that (CNS10).*

According to participants, being there as patients’ main contact and support secured some certainty for patients at a challenging time.

> *So often these days, you just can’t speak to anyone. All they want to do is speak to someone a lot of the time, even if it’s not rheumatology related (CNS16).*

4.4. 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 empathetic 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.

4.4.1. Care delivered with compassion

Interviewing participants, one thing stood out: despite different experiences and backgrounds, participants spoke as with one voice about the patients’ experiences in early RA. Participants felt that they understood the patients, their shock, fear, anger and despair. They had compassion with the patients and wanted to help the best they could. One participant said: ‘I could feel her [the patient’s] pain because she can’t have a baby’(CNS15). Another participant recounted a meeting with a young challenging patient that came across as quite aggressive and difficult to help. The participant interpreted this as due to anger and pain and felt upset by it.

> *I feel really upset that this poor ... you know she's a young woman, her life ahead of her, she's got a disease which is really badly controlled and she's frightened and she's angry about this and maybe other things (CNS07).*

A participant reported how she used to do her best to help patients who needed support.

> *I always pulled out all the stops to sort everything out for them, if it was housing or stair lifts you know, but they know that you would do your best for them, you know. So yeah, very good relationship (CNS06).*

The use of the phrase 'pulling out all stops' was echoed by another participant using the expression 'go the extra mile'.

> *We all go the extra mile for the patients, and try to put them first. And they really appreciate that. So yeah, we've got good, we've got really good relationships with […] with the patients (CNS10).*

One participant said: *'It is a partnership and we're doing it together' (CNS14).* Another participant stated: '*The Nurses are there for the patients and they know that' (CNS04).* These expressions underlined participants' commitment, their compassion for patients, their understanding of patients' situation and feelings of distress, and their intention to help to the utmost of their capability. Participants explained how they helped their patients to navigate the healthcare system, leading and guiding them at a time when everything was new, and patients did not have energy or capacity to take in new things. The participants' attitude to care were similar to compassion as defined by Strauss *et al.* (2016), who found compassion crucial in health care but difficult to define and measure, leading to the development of a definition from a systematic review (Strauss *et al.*, 2016). Furthermore, participants expressed joy and gratitude for their work and the relationship with patients, using words such as ‘privileged’, ‘glad’ and ‘lucky’ about meeting and working with patients in RA.

> *I feel quite privileged as well in a way because I feel very you know, lucky and glad that I can meet people in this way, and hopefully and you know, I’ve been with people and around people, one of the big reasons I do my job, but I do, because I love being around people and talking to people […] You try and be sort of have that professionalism there, but you know, I also just hope that it is sort of a trusting relationship and that they feel that they can, can you know, feel that they feel supported (CNS11).*

4.4.2. Using person-centred, holistic and empathetic approaches

Participants described how they used person-centred, holistic, and empathetic approaches to address patient needs in early RA. According to participants they were very sensitive to the patients’ psychological state at consultations in clinic or on the telephone at the same time as they tried to help them start or stay in treatment to ease their symptoms. Describing their clinical practice, participants thus came across as being highly skilled in meeting patients at the different stages of their disease and centring the care on their immediate holistic needs.

Participants reported it was important to look at the whole person, as care was holistic, and everything was connected.

> *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 used expressions such as ‘being a listening ear’(CNS13) and a ‘listening board’ (CNS15) for the patient to highlight the importance of actually listening to patients.

> *They have to have a voice and we have to listen (CNS13).*

Participants reported that they would make sure to ask patients what was important for them to achieve. 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.

> *It is about talking to them. It's talking about them, to them about, you know, what they want to achieve from things [...] We can get all their disease under control and if they still can't do their knitting or, pick up their grandchild up or something like that, then that's … it's what important to the patient I think is the most important aspect of all our care (CNS01).*

According to participants they were keen to follow the guidance of early start of treatment to get disease control as quick as possible to limit damage of the joints, and to help patients back to a normal life or as close as possible to life before the disease. However, it was also important that patients understood why they were treated.

> *We spend a lot of time in the early days from the education appointment to explain that actually it is vitally important that they start treatment, but equally it's vitally important that they understand why and what's happening to them (CNS04).*

Interview data suggested that participants used person-centred and empathetic approaches to lead patients in the direction of disease control. They educated patients, helped them to manage the disease and provided strategies for regaining control when patients could experience lack of control with pain and distress. Participants were aware that patients needed the right information at the right time, and that the nurses had to be led by the speed at which patients were able to take in information.

Good care was thus seen as treating all patients as individuals and looking after the whole person when tailoring their care.

> *The nurse' belief or knowledge base is, if you're to be effective you've got to be very patient or person centred (CNS07).*

> *So I'm a firm believer, and I've instilled it into my team, that all of our patients must be seen as individuals. Their needs are not going to be, erm, the same as the next patient that you see who may have all the support in the world and not need anything from you whatsoever (CNS04).*

The use of combined patient-centred, holistic and empathetic approaches seemed to be beneficial for patients. Using these approaches, participants managed to establish working relationships with patients built on trust and collaboration, and helped patients to get disease control and adapt to the disease.

4.4.3. Providing a 'lifeline'

Participants reported that they were the patients' primary contact at the rheumatology clinics, the first port of call.

> *Especially with our Early, Rheumatoid Arthritis patients, we, we are literally the first port of call really for that patient (CNS12).*

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. Patients could thus contact the nurse specialists through the nurse-led telephone adviceline to get appointments if they had RA related issues.

> *After the initial diagnosis, obviously they come back and they see a doctor at various times, but the initial port of call is always the nurse … the nurses, whether that's through routine appointments, or whether they are contacting*

> *us via our nurse led helpline, if they're having issues with their side effects from their drugs, or if they're struggling with anything in particular, whether they want to ask more questions and things like that (CNS02).*

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

> *The advice line has been a lifeline to them, to be able to speak to someone, to be able to get a response quickly to their questions, they feel very well supported, they know that they can always call us* (*CNS16).*

According to participants, the telephone advice line was always very busy and an essential part of the service. It was run by experienced nurse specialists, as they needed to know the specialty very well to offer advice and support. New nurse specialists were supervised by more experienced colleagues and would confer with members of the nursing team or rheumatologists for advice.

Access to the telephone advice line was important if the patients needed follow-up information and support in case of worries and pain. Access to the advice helpline was seen as crucial as prompt advice and reassurance could limit distress and solve problems, so the patient felt heard and encouraged to stay in treatment. According to participants, many patients called the telephone advice lines due to side effects to the medication and worrying if the medication worked at all.

> *That's probably one of the biggest ones, side effects of medication, they don't think it's working, because there's so much to take in, when they've been newly*

> *diagnosed and started on quite intensive medication, they don't really, they don't always take everything in and a lot of it you know, after three weeks, the patient will call and say it's not working, it's not working, so it's reassurance, saying, no it is, you just need to give it a bit more time, do we need to be looking at your pain management, to help you just get through those next couple of weeks? Do we need to be looking at a short course of steroids? You know, what exactly are the issues you're having? And just providing support, so they know they're not on their own with it (CNS14).*

Participant explained that patients knew from start of disease that they could call the nurses if they needed support, if they experienced setbacks with flare or whenever they encountered difficulties regarding their disease and get the support they needed. Participants therefore saw the telephone advice line as essential for giving patients reassurance, confidence, and control in their lives.

4.5. Continued evaluation and development of the service

The fourth theme captures the aspect of 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 challenges and opportunities caused by the pandemic are described.

4.5.1. Patient feedback

According to participants, it was seen as important to ask patients what they expected from the consultation with the nurse specialist. Patients were for example invited to write down questions prior to the consultations, so the nurses knew what they would like to discuss and could check with the patients if their expectations had been met.

> *...It's really important to ask them initially what they expect to have from the consultation (CNS02).*

> *We have an agenda setting process, whereby patients can write notes before their appointment. So we know what they're expecting to talk about (CNS03).*

Participants reported, that at the end of the consultation the nurse would then ask the patients if they got answers to their questions and if their expectations had been met. According to a participant, her clinic had developed a focus form 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 they could circle those or ask something else where it said 'other'. The patients were asked to circle or mention three top three priorities and focus on these. According to the participant, the clinic put intimate relationships on the form, because The British Society for Rheumatology (BSR) had found that this topic was not talked about enough with patients, and people then started circling it. However, the participant confessed that it was a difficult topic to address, as it could feel awkward to talk about these issues. As a solution, her clinic had developed a leaflet with key information, which was handed out, and patients were then invited to ask questions.

> *Often we're the only people that they [the patients] feel they can talk to, but we don't ever bring it up [intimate relationship]. So we did put that on there as something that they could talk about. And then when (Laughs), when people started circling it, everyone was like, "Oh God, why did you put that on there?" (Laughter). Everyone was really awkward about it […] We've got some leaflets now. (Laughs) […] We try our best, and some of us are better than others. And we're very much like, you know, we're always kind of like, "Okay, open body language, you know, turn and face the patient, let them talk about it." (Laughs). But it's not our favourite topic to talk about (CNS10).*

Although the issue was addressed at this clinic it was reported that it could feel challenging to take the conversation. Similar barriers to addressing the topic were identified in research on practice and barriers to the management of sexual issues in rheumatology (Helland *et al.*, 2013), where few health professionals addressed the issue.

However, it was found that the majority of participants in the study requested more education, which was associated with fewer barriers for addressing sexual issues (Helland *et al.*, 2013). Recent research (Flurey, 2022; Bay *et al.*, 2020) has shown that there is a need, which is rarely addressed in rheumatology. It is thus possible, that patients might need access to specialists to be able to get answers to their questions and be able to talk freely to somebody who is used to have this type of conversation.

Participants reported that the individual clinics were reviewed regularly. Patients were asked for feedback about their experience of appointments with the nurse specialists, about the rheumatology service and about changes to the service. According to participants they generally had very positive feedback from the patients. It was thus reported that some clinics sent out questionnaires to get the patient view on for example their appointments with the specialists.

> *[…] We do, and we have had various questionnaires at various points, you know, that we send out to all, that the patients complete, that get sent out to them, or in clinic and that sort of thing, that have asked them about perhaps they're, you know, for their appointments with the specialist nurse and that sort of stuff. So sort of, which has been, you know, completely anonymous sort of stuff […] and we've always had really good feedback in general from those as well (CNS02).*

It was reported that especially the simple things such as the caring approach and the attitude patients were met by when in contact with the nurses and other staff members at the clinics were important. It was thus the whole patient experience of the contact with the healthcare system that mattered in the patients' satisfaction with care, from the first meeting with the receptionist, to the nurses, the doctors and the nurse specialists. A friendly, warm and welcoming approach with healthcare staff and working towards the same goal were seen as essential to contribute to a positive patient experience.

According to participants, complaints could be varied, such as about the physicality of the department and waiting times. However, mostly complaints would not be about the care the patients had received but be experiences of something that had happened or gone wrong, which often had to do with communication. These complaints would be used to understand what had happened and how it could have been done in a different way.

> *Well complaints can be really varied from the physicality of the department if they were kept waiting to be seen. Mainly I would say they're not about the care they've received from us, thank goodness. Occasionally we've had patients where they've maybe had to make a complaint about their experience, and often it's, you know, when things happen something very simple has happened, gone wrong, it's usually about communication (CNS08).*

4.5.2. Service evaluation and auditing

Participants reported that the individual clinics and the service 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.

> *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).*

> *Good care in early RA? That you get their disease out, under control, and that the patient is able to lead a virtually near normal life, in honesty, because you can see that, that we're able to keep them in work, particularly if they're young, that we're able to keep them in work, we're able to keep them well, and um, you know, I would consider that to be a good outcome (CNS01).*

According to participants, it could be seen from the patients' facial expression when they felt better. Patients would also send letters and messages to let the nurse know that they were well and improving. Participants reported that also if patients did not feel well and experienced no progress, they would still feel confident to contact the nurse to tell how they were doing and acknowledge that they knew that the nurse was doing her best to help them.

> *So I think it's just the look on their faces when they come through the door, and they're so happy. You know, or when they send you, send a little letter or a message or something […] And then also obviously if it's not been successful, but they still know they can talk to you, you have that rapport as well, where they can come in and say look it hasn't been so good, but you know. I know you're trying your best, sort of thing (CNS06).*

According to a participant, knowing if patients' needs had been met was a matter of simply asking them.

> *So it is about, you know, asking the patients how they're doing, is there anything that they're finding that they can't do, and is, you know, to talk about that, why can't they do it, and do it like that (CNS01).*

Another way of knowing this was to look at their case from diagnosis until remission. The team would look at how pain had been managed from the patient perspective, how education had worked, and then learn from the patients. Additionally, all cases were audited annually.

> *I think again a measure of their needs in terms of their ... from diagnosis to treat to target, to remission, is to actually see those patients and look at them. And look through their pathway, through the six months and if you're ... if their needs have been met in terms of their pain, their understanding, their education...and you can see that and learn from the patients. But patients will*

> *tell us really. But the audit, we audit all of our clinics annually and regularly after each visit we ask for feedback (CNS04).*

According to participants, regular audits were conducted to get patient feedback about the current service or changes to the service. Participants informed, that the nursing team sent out questionnaires and explained to patients that it was their service and therefore their opinion was important.

> *We regularly audit all of the clinics that we do and we ask for patient feedback, we send out questionnaires, we explain to them why we're doing it. This is their service and they need to tell us where ... you know what we did well and what we didn't do well (CNS04).*

Participants reported that they used feedback cards with boxes for response as well as questionnaires to get feedback from patients. The use of feedback and suggestions from patients had helped understand the patient experience of the service and how it could be improved. Additionally, the use of questionnaires for patient feedback was reported to have helped to develop the biologic service and the young adult service in some clinics. It was reported that patient feedback both positive and negative was reviewed at governance meetings to understand if there were areas that could be improved.

> *We have governance meetings, where we then look at the complaints, the compliments and the complaints, and look at … you know are there areas of the service that could be improved, and then try and address those (CNS08).*

According to participants, patient partners were involved and provided feedback too. It was thus reported that some rheumatology departments had a Patient Advisory Group which was a group of patients who met regularly. These patient partners attended international conferences, and they would be asked for advice on for example leaflets for patients and changes to the service.

> *We are really lucky in that we…we have a very close, we even have the Patient Advisory Group who meet regularly […] They're a group of patients who are, obviously they're always going to be the more motivated, more opinionated, group of patients. But they meet regularly and they, I mean, some of them attend conferences and things all over the world […] We ask them for advice on things like, for example, the leaflet. I've written quite a lot of leaflets…and I always ask them for feedback on whether it's clear […] When we're looking at redesigning services, we get their feedback on all of that (CNS10).*

4.5.3. COVID-19 challenges and opportunities

This subtheme describes the challenges of major disruptions to the service caused by the COVID-19 pandemic, and its role as catalyst for innovation and change.

Participants described the impact of the COVID-19 pandemic had on the delivery of care, the challenges they faced, and the solutions they came up with to provide care despite circumstances. According to participants, the COVID-19 pandemic caused major disruptions to the services as most face-to-face clinics were prohibited and emergency measures introduced to care for patients. Participants reported that nurse specialists were deployed to hospital wards to provide care during the escalating hospitalisation of COVID patients. This meant that only a few nurse specialists were left to take care of the rheumatology patients at the outpatient clinics as they managed telephone advice lines working from home.

> *You know, like the same with everywhere we were redeployed to the wards, all we could do was manage really the advice line, and now we were relocated offsite as well (CNS04).*

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.

According to participants they had addressed the challenges of taking care of the patients despite not being able to see them face-to-face in varied ways within the individual clinics' practice framework. Participants reported that the telephone advice line thus became the main link between patients and nurses. The telephone advice lines were thus essential for patients who needed reassurance, medical and psychological support or had questions. Face-to-face consultations were changed to telephone consultations, and only limited face-to-face appointments were available at the rheumatology outpatient clinics for patients who could not be managed via telephone. As observation and physical examination were essential aspects of clinical assessment, these changes of the service caused significant challenges in early RA management.

> *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).*

> *We have basically been running video clinics and telephone clinics, so we've still been running consultations, but remotely, basically. We do have what we call boiling hot clinics, which we've had, about three a week, at the moment, and they are face to face clinics, for patients who we feel that actually really do need a face-to-face appointment and can't be managed remotely at all (CNS02).*

Participants reported that challenges also had provided opportunities to implement new processes of care and technical solutions. Participants thus described how the adaptation of the service had happened over a couple of weeks, whereas earlier any change to the service would have taken months to develop and implement.

> *What this has done, Covid has done is as actually pushed these things so much quicker, you know, to be able to sort of literally within a matter of a couple of weeks, have the ability to do telephone or video consultations, because we've had to, has been unbelievable really (CNS02).*

According to participants, transformation of the outpatient service had been on its way, and the COVID pandemic had thus become a catalyst for making these already necessary changes to the service.

4.5.4. Innovation and improvement of the service

In the process of adapting to the COVID-19 pandemic, it was reported that the emphasis on telephone consultations had led to innovations with potential to improve the service. According to participants, nurse specialists had developed new ways of running the outpatient clinics, so patients could receive education, start treatment, escalate treatment and get monitored despite lockdown restrictions on face-to-face consultations.

> *We have been seeing new patients and in fact, we're starting patients on the pathway, even pathway patients, which is quite odd, because you know, if you'd said this a few months ago, you can you know, do … see a patient or conduct a consultation for a newly diagnosed patient, over the telephone, you'd be thinking, no, you can't do that properly (CNS02).*

Participants thus reported that they had developed telephone consultations combined with video tutorials or written material posted to the patients in advance. Nurse specialists scheduled a telephone consultation before and after to ensure that information had been received and understood, and to give the patient an opportunity to ask questions.

Some participants reported that they had developed telephone consultations with protocols for the individual types of consultations, such as education clinics, escalation, follow-up and review. A participant reported that her team used telephone consultations to start treatment with DMARDs assisted by video, which the patient watched, followed by education and information on the telephone.

> *With Covid we're doing it [education appointment] over the telephone, and we're getting them to watch the video before we have the appointment with them, running through everything. And they can either do the injection while we're on the phone or choose to do it after they've had their telephone call and then we've arranged to ring them back to find out if they were okay and if they managed it alright (CNS04).*

Data indicated that the use of telephone consultations required strong communication skills. Participants thus reported how they relied on what the patients told them to assess symptoms, side effects and issues related to their disease.

> *I do have to rely on them telling me what's going on, because I can't see it at the moment (CNS14).*

According to participants, they asked questions, listened carefully to the patients, and helped them to describe their observations and experiences by designing questions for assessment of joints, pain, fatigue and activity. Participants also reported teaching patients the names of the joints, so they could describe which joints were tender and swollen on the phone. According to a participant, 'the man with the hand', an illustration from the DAS28 scoring system with a drawing of a person with the 28 joints and very big hands, allowed detailed scoring and documentation of the individual joints.

> *I would have the, we always call it the man with the hand […] it is a really good leaning tool to talk about because patients are saying oh why is my feet not …they're the worst and so we explain all of that. And again then they understand that, so they understand that when they do ring up, if they ring up and say oh my feet are …but I know now, so I know that's not in the man with the hands (CNS04).*

It was reported that a disadvantage of telephone clinics was the lack of access to observation and touch, which were essential aspects of clinical assessment. Participants reported that access to video consultations could help. However, it would not solve the lack of physical examination to assess the joints.

> *And there certainly are barriers you know, it's not as easy, we can't do, things like we would be doing, a disease activity score and joint count and things like that, if we have that patient face to face to us, so as well as them reporting how they're feeling with their arthritis, we would get you know a, and actual clinical physical indication of exactly what's going on, by doing a joint count (CNS02).*

It was emphasised by participants that the digital supported consultations did not fit everybody. Some patients had to be seen in person, and individual solutions had to be found depending on their specific problems. Not all patients had access to wi-fi or the internet. This could be due to geographical area or economical means. It was also emphasised, that many elderly people might not have a SMART phone, maybe not even a mobile phone and could rely on older technology or have limited computer skills depending on age and IT-literacy.

> *We still see a significant number of patients who wouldn't even know what a Smartphone was, you know, who have a mobile that might be 20 years old. So it's, it's very different and this is, you know I think, it's vital to recognise the absolute unique and individuality of each of our patients (CNS04).*

However, it was thought that video-consultations could become more common in the future, which could provide an alternative to telephone and face-to-face consultations.

Participants reported that the introduction of telephone clinics with their own schedule had improved the service regarding access, planning and documentation. According to participants, the booking was managed digitally by a call service at the clinic, and patients who called the clinic were allocated a timeslot where the nurse would contact them. Patients then knew when to be around the telephone, and the nurse had the allocated time to answer questions and deal with the patient's issues. The visits were visible in the service as they had their own day schedule, and they were documented online, using innovative standardised templates for telephone consultations.

> *Now what we've done is changed it so that it is a more, it's an appointment based system, so they phone, and the answer phone either cuts in, or the admin assistant answers the phone. She books them a time slot, within an hour, you know, within … so if she phones them at 10, she might say oh, you'll get a call back between 12 and 1 [...] So in effect it's like another sort of two … two clinics really (CNS16).*

It was reported that the change from face-to-face to telephone consultations also had led to changes of prescription procedures. Digital solutions were now used for prescription of medication, as prescription requests and prescriptions were managed by email.

> *The whole sort of process of Education has changed now, so we've educated over the phone. Once the Education has been done over the phone and we, we've done blood work and stuff and the patient is good to go, we'll then email the Consultant and say, could you do the prescription, that's working really well, they're doing that really quickly. You know, so there's no real delay in the patient starting treatment. So it's pretty good I think on the whole (CNS13).*

Prescriptions were forwarded digitally from the consultant or nurse prescriber to the pharmacy and documented in digital records which were accessible for relevant health care professionals. Procedures were thus streamlined and improved, as well as being documented.

> *At the beginning, the first step when they're diagnosed and treatment is started, we then will get the prescription and everything is on electronic now which is much better […] that's raised electronically so that's absolutely fine and*

> *throughout the escalation pathway we send an email, it's prescribed electronically and it's sent out. The patients receive it at home, within a day or two (CNS04).*

Participants suggested that the use of self-assessment apps could limit the need for face-to-face consultations in the future. However, currently there were no guidelines or recommendations in this area.

> *I think the thought at the moment is that, there's no, The British Society for Rheumatology hasn't specifically said that this is the best app to use for this, or this is the best self assessment technique or whatever (CNS02).*

It was reported that clinics were piloting schemes using Microsoft Teams for group education and self-management. However, guidelines and recommendations were also needed in these areas. A participant suggested that especially in early RA, the use of video could be useful in future educational groups, as for example Zoom could offer privacy, while also attending a group session.

> *I think with early RA, I mean, some people may be more comfortable going into a Zoom group and saying 'hi', than actually walking into a room and baring all. You know, there's a safety behind the screen where you can, you know, give as much as you want to, and leave the rest behind (CNS03).*

Another participant thought that telephone clinics worked well and was something that would probably be taken forward and implemented more widely after the current COVIE-19 pandemic, especially for follow-up and education clinics.

> *I think that the telephone clinics work very, very well […] And I think this is something we will take forward and we will do a lot more of our, especially our follow ups and, and our Educations over the telephone, that seems to work really, really well, for Escalation, we may need to introduce some kind of face to face or video calls, or something like that. So we can visibly assess joints, but certainly a lot of the work that we do, we've realised we can actually do over*

> *the telephone and we don't need to be brining patients into hospital all the time (CNS14).*

Participants agreed that clinical practices developed for telephone consultations and use of digital solutions would stay after the COVID-19 pandemic. According to participants the introduction of remote care could be good for patients, as long as they had access to consultations and support according to needs and preferences.

> *I think things have changed […] And I don't' think they will go back to exactly as they were […] I think as long as we've got the ability to do both, I think absolutely remoter things could work really well for people […] But equally there will always be, particularly with something like rheumatoid arthritis, you physically need to be able to examine people, you know, you need to be able to see people, but you know having a mixture of the two is I think, you know,* is definitely a way forward *(CNS02).*

4.6. Discussion

This interview study with rheumatology clinical nurse specialists identified four themes with supporting subthemes characterising nurse-led care in early RA. The themes captured the specialised nature of early RA nurse-led care, which was delivered with compassion using person-centred, holistic and empathetic approaches to address patients' complex care needs in early RA, with continued evaluation and improvement of the service. The COVID-19 had caused disruption of the service, but had also been a catalyst for change, which streamlined and improved the service. The four themes provided a provisional model of early RA nurse-led care.

4.6.1. Rheumatology nurses provide specialist early RA management

The process of analysing data revealed that the specialist nature of rheumatology nurse-led care was important in participants' understanding of their clinical practice. Participants highlighted how they built their specialised clinical practice on professional, academic and personal experience, and obtained further rheumatology knowledge and experience while working in a learning environment.

They were taught and supported by colleagues from across the multidisciplinary team. Participants aired some frustrations of not feeling acknowledged as specialists. Examples given were that they could be deployed to work in the wards, while nobody could assist them in the rheumatology clinic. This was experienced at times with lack of staff, as for example during the current COVID-19 pandemic.

The vulnerable, and at times unacknowledged role of rheumatology nurse specialists was addressed in research that outlined dimensions of rheumatology nurse specialists in the UK (Oliver and Leary, 2010, 2012). By documenting nurse specialist workload during a year, it was shown that rheumatology nurse specialists had an important role in providing care in rheumatology which reduced the workload for rheumatologists. Nurse specialists were thus found to address physical needs which required specialist knowledge and specialist assessment (Oliver and Leary, 2010, 2012). They secured safe medical treatment as they monitored and checked medication and side effects, and addressed psychological, social and spiritual needs as well as managed referrals and pathways (Oliver and Leary, 2010, 2012).

This study provided evidence that nurse specialists indeed had this important role in early RA management, and evidence also showed that nurse specialists had met challenges of supporting their patients when they were deployed to hospital wards due to lack of nursing staff as for example during the COVID-19 pandemic. The importance of the role of rheumatology nurse specialists for start of early treatment, monitoring and adherence to treatment and thereby improving the likelihood for positive patient outcomes was highlighted by a national audit on rheumatology care (HQIP, 2016), the report on rheumatology nurse specialists from 2019 (BSR and NRAS, 2019), and supported by the EULAR recommendations for the role of the nurse in CIA (Bech *et al.*, 2020). The competency framework for rheumatology nurses in the UK (RCN, 2020) which is currently being implemented in rheumatology also acknowledges the highly complex role of the rheumatology nurse. It is focused on knowledge and skill in RA management and will help secure professional clinical standards and inform training and education.

4.6.2. Compassion is essential in early RA care

This study identified ‘compassion’ as another important aspect of early RA nurse-led care. Participants’ views and motivations were similar across the data set. Participants expressed that they acknowledged the patients’ experiences and expressed their wish and will to help. Participants stated that the patients could rely on them and knew this.

However, participants did not use the term ‘compassion’ but described their thoughts, views, and practices which together corresponded with ‘compassion’ as described by Strauss *et al.* (2016). According to their paper (2016), compassion in care and the importance and the effect on patient outcomes are increasingly acknowledged but not well understood, and there is no acknowledged definition or measure (Strauss *et al.*, 2016). However, 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 (Strauss *et al.*, 2016).

Similarly, kindness has been found to be important for positive patient experiences in cancer care (Berry *et al.*, 2017). Personal stories of patients, families and clinicians have illustrated the impact of simple acts of generosity and kindness such as the human touch can make a profound difference (Berry *et al.*, 2017). Kindness 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 the interview data and the identified themes. Kindness, support, being understood and led – sometimes carried—on the way at the beginning of disease could be essential. The importance of these aspects of early RA nurse-led care were discussed with the supervisory team and endorsed by the patient research partner.

4.6.3. Person-centred care

This study found that rheumatology nurse specialists use person-centred, holistic and empathetic approaches to address patients' complex care needs. These approaches included the nurses' attitude and relationship with the individual patient. The concept *person-centred care* is used in the competency framework for rheumatology nurses (RCN, 2020) as an instruction of how to deliver care, but no definition of what person-centred care means or what it involves is provided.

According to a recent systematic review (Byrne, Baldwin and Harvey, 2020) the concept of person-centred care is well known to nurses, yet ill-defined and operationalised into practice (Byrne, Baldwin and Harvey, 2020). The authors suggested that person-centred care potentially is hindered by its apparent rhetorical nature, and further investigation of how person-centred care is valued and operationalised through its measurement and reported outcomes is needed (Byrne, Baldwin and Harvey, 2020). Their investigation of the literature found many definitions of person-centred care, but no one universally accepted and used definition (Byrne, Baldwin and Harvey, 2020). Therefore, they stated that person-centred care remained conceptional in nature, leading to disparity between how it is interpreted and operationalised within the healthcare system and within nursing service (Byrne, Baldwin and Harvey, 2020).

In Sweden research was conducted to conceptualise person-centred care in rheumatology nursing and to develop a tool to measure patients' perception of levels of person-centredness of rheumatology nursing (Bala *et al.*, 2012, 2018b, 2018a; Bala, 2017). Bala *et al.* (2018a, 2018b) developed a framework for person-centred care that focused on five domains: Social environment, personalisation, shared decision-making, empowerment and communication with questions relating to each domain. These domains resembled dimensions of care identified in this interview study, and the tool could have been used to assess levels of person-centred care in early RA nurse-led clinics in a following study. However, the first author was contacted about permission to use the tool for this PhD and informed that the original Swedish version of the tool was under further development, and currently no validated English version existed. Other measures were thus considered. The review 'Helping Measure Person-centred care' (De Silva, 2014) provided a review of evidence about commonly used approaches and tools used to help measure person-centred care. According to the review (2014), person-centred care could be explored in many ways, for example using patient satisfaction with care (2014).

4.6.4. Rheumatology nurse-led care as a trend

This interview study (Chapter three and Chapter four) suggested that the organisation of rheumatology care varied, and that the nurse specialists' professional experience, as well as their access to training and further education could vary. This was consistent with literature (Bech *et al.*, 2020; BSR and NRAS, 2019; Ndosi *et al.*, 2017). Participants reported that they managed patients from the start of disease throughout the RA journey with treatment, monitoring, education, and support, with responsibility for up to 14-15000 patients at a clinic. It was emphasised that early RA management was evidence-based and followed the treat-to-target strategy, which required close intensive pharmacological treatment and close monitoring of treatment response. It was also emphasised that early RA nurse-led care was practised within the context of the multidisciplinary team, and with an especially close collaboration with rheumatologists regarding the medical aspects of care in early RA management.

Despite variations, nurse-led clinics run by rheumatology nurse specialists seem to be on the rise in the UK (BSR and NRAS, 2019), and the current guidelines for rheumatology care (NICE, 2018) do not reflect this development. According to the report 'Specialist nursing in rheumatology: State of Play' (BSR and NRAS, 2019), nurses are increasingly taking on extended roles in rheumatology care due to pressure on the health service, leading to nurse-led clinics also becoming under pressure with rising number of patients (BSR and NRAS, 2019). It was found in this study, that access to education and training could be limited regarding availability, time and funding. This was consistent with findings in the report, ‘Specialist nursing in rheumatology: State of Play’ (BSR and NRAS, 2019). Although the RCN competency framework (RCN, 2020) could help standardise requirements for competency in different nursing roles, nurse specialists would need to have access to adequate training and education to keep up with the requirements for early RA care.

4.6.5. Need for psychological support

This study found that the psychological aspects of care in early RA were important to address. These findings were consistent with literature on the psychological effects of living with rheumatoid arthritis (Ryan, 2014). However, the study also found that nurse specialists often were the only providers of psychological support without access to specialist referral or supervision. Only a few participants in the study had access to for example pain psychologists, CBT, or fatigue interventions. Participants agreed that psychological issues needed to be addressed to get good patient outcomes. They were of the impression that they managed to support the patients well, but agreed that they were not specialists, and that specialist support was warranted. These findings were in line with the findings from the systematic review of qualitative studies (Chapter two). Patients in the systematic review were found to value the empowerment and psychological support provided by nurses. It was also found that patients could need increased psychological support when experiencing pain and flares (Sjo and Bergsten, 2018; Ryan *et al.*, 2013). A British study reported that the connection between pain and feeling depressed was emphasised by patients (Ryan *et al.*, 2013), as they compared their needs to those of patients with cancer.

The NICE guideline for depression in long-term chronic conditions (NICE, 2009) supports the provision of psychological support by nurses and other trained health professionals. However, according to the guideline, a four – stepped model of care is recommended (NICE, 2009). In the four-stepped care model, the least intrusive, most effective intervention should be provided first. If the patient does not benefit from the intervention, or does not want an intervention, the patient should be offered an appropriate intervention from the next step. According to this model (NICE, 2009), nurses and healthcare professionals with appropriate experience and training can provide psychological support at the two first steps of the model, whereas the next two steps involve medication and therefore specialist interventions.

Recent research on the psychological needs of patients with RA (Dures *et al.*, 2016) found that the demand for psychological support was high in inflammatory arthritis, which includes RA, but only a few patients were asked about social and emotional issues. According to Dures *et al.* (2016), the patients with inflammatory arthritis 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. Furthermore, the patients were found to prefer support from rheumatology clinicians and in particular from the rheumatology nurses (Dures *et al.*, 2016). These findings suggest that nurses with appropriate training and experience could provide adequate psychological support in early RA, and that the patients value this service. This area needs to be further explored to develop and improve the service. Additionally, issues about sex and intimate relationship were found to be challenging for nurses to address, which is consistent with recent research (Flurey, 2022). These aspects of care may need addressing with access to education and specialist referral to meet patient needs.

4.6.6. Need for guidelines in remote nursing

As it was found in this study, the COVID-19 pandemic had caused sudden needs for innovation to provide care for people with RA. The pandemic prompted the immediate implementation of remote care within the first weeks of the national lockdown in summer 2020. Participants reported that they had managed to set up telephone helplines and telephone consultations to take care of the day-to-day care of present patients, but eventually also to take care of new patients as the service adjusted to the need for continued remote care. Some clinics had developed standards for telephone clinics with protocols for the different types of clinics with the nurse specialists, which had helped standardise the consultations.

However, the lack of face-to-face contact had been challenging when assessing patients' joints and the overall impact of the disease, as observation and physical examination were not possible. Although the patients with severe symptoms, as well as new patients in the clinic were seen face-to-face by rheumatologists and a few nurse specialists in the rheumatology department, most patients were 'seen' via telephone by the nurses, and in video-clinics with rheumatologists.

The development of new clinical practices for prescription and education of new medications and start of new patients in the clinics had thus required creative and innovative solutions. The use of telephone, video, IT platforms for booking of tests and appointments, digital file systems for documentation and communication, and email correspondence between health professionals were thus expanded and systematically implemented in day-to-day clinical practice. However, it was found that different procedures were used by different nurses at different clinics to assess the patient via telephone, and that there were no guidelines in place for these assessments.

The need for assessment of patients via telephone and video led to research in remote RA monitoring. A study conducted by Ndosi *et al.* (2021) aimed to determine the agreement between remote treatment decisions based on patient self-assessment questionnaire assessed blindly by a health professional and treatment decisions based on routine outpatient monitoring appointments. The study found that remote RA monitoring using patient self-assessment and outcome measures was feasible with fair agreement on treatment decisions. However, further work was required on understanding the importance of adding blood test monitoring to remote decision-making (Ndosi, Kingsbury and Conaghan, 2021).

Participants in this study reported that although it had been a challenging time for patients and health care professionals, the overall impression was that the patients had received support to maintain disease control, safety, and to get support when needed. Participants had used their communication skills to assess patients via telephone consultations and had used their educational skills to teach patients how to assess their joints and report their symptoms. They had also used telephone consultations in combination with video links on the internet as well as written information with follow-up telephone consultations. However, the challenges of assessing the patients without access to observation and physical examination had not been solved. Solutions had either been to see the patients in few face-to-face consultations or to use telephone with limited accuracy of the assessments. A positive development had been the improvement of communication and documentation within hospital departments and between health care partners and healthcare sectors. The use of digital solutions had thus streamlined practices, as messaging between health care professionals, bookings and prescriptions were delivered online. However, the different clinics had developed different solutions to deal with the same issues, and participants highlighted the need for guidelines in remote care.

A recent paper (de Thurah *et al.*, 2022) addressed the need for guidelines in remote care and tele-health and identified areas where telehealth could improve quality of care and increase healthcare access. The aim was to develop EULAR points to consider for the development, prioritisation and implementation of telehealth for people with rheumatic and musculoskeletal diseases. A broad scoping review of current research was conducted to develop statements which were presented to a task force for consensus. This process resulted in the development of four overarching principles and nine points of consideration. It was agreed that the use of telehealth should be tailored to patients' needs and preferences; the healthcare team should have adequate equipment and training and have telecommunication skills; telehealth could be used in screening for rheumatic and musculoskeletal diseases as preassessment in the referral process, for disease monitoring and regulation of medication dosages and in some non-pharmacological interventions; and people with rheumatic and musculoskeletal diseases should be offered training in using telehealth, and barriers should be resolved whenever possible. The taskforce suggested areas for further research which included RCTs, longitudinal studies, evaluation of preassessment methods, cost-effectiveness, factors associated with digital health literacy for both patients and healthcare professionals, barriers and solutions to implementation, use of artificial intelligence, as well as patient safety and data security. It is believed that the suggested research will help develop new EULAR guidelines which nurse specialists in this reported interview study had lacked when they rapidly had to transform the service as a response to the COVID-19 pandemic. The paper (de Thurah *et al.*, 2022) is important for early RA, as data from the interview study indicated that use of telephone consultations and digital solutions were expected to stay after the COVID-19 pandemic.

4.6.7. What is special about early RA nurse-led care?

The findings of this study suggest that early RA nurse-led care has the potential to meet patient needs. Participants reported that patients in early RA had complex care needs, as everything was new, including the diagnosis itself, being ill, in pain, in need of treatment and not knowing what would happen in the future. As the patients adjusted to the disease and gained disease control, they would also adjust to a life with the disease. The study findings suggested that the nurse specialists through their clinical practice treated, monitored, educated, and supported the patients. These aspects of nurse-led care were also found by Garner *et al.* (2017), and according to their study, patients were highly satisfied with nurse-led care. This seemed to be related to education, empathy, continuity, and accessibility (Garner *et al.*, 2017).

In this study, an essential part of early RA nurse-led care was the establishing of the relationship between the patient and the nurse, which ensured that patients would contact the nurse if they had any symptoms or questions that needed to be addressed. This relationship helped patients to stay in treatment and helped secure patient outcomes that allowed them to control the disease. The findings suggested that early RA nurse-led care is sensitive to the needs of patients in early RA, where the patients may struggle with pain, fatigue, fear, and distress, and face multiple challenges in their everyday lives due to the impact of RA. The rheumatology nurse-led care thus seemed to offer an all-in-one model of early RA care providing patient access to a service that catered for their holistic care needs.

Minnock *et al.* (2018) looked at the ‘added value’ and the ‘art of nursing’ influence on patient outcomes with the challenge of capturing both the easily identifiable quantitative outcomes and the unspecified, qualitative aspects of nursing care. They identified, and reported, a set of multidimensional outcome measures that were sensitive to nursing interventions in rheumatology specifically, ranging from outcome measures such as disease activity, clinical effects, pain, to fatigue, patient satisfaction, confidence in care received, mental health status, and quality of life (Minnock *et al.*, 2018). The findings of this study suggest that rheumatology nurse specialists use a range of outcome measures and interventions to address and meet patients’ care needs. It was reported that patients seemed to have their care needs met in early RA nurse-led care. However, the findings reflected the nurse perspective, and not the patients’ perspective. To get an understanding of the patient perspective of early RA nurse-led care, further research is needed to address the patient perspective of early RA nurse-led care.

4.6.8. Towards a provisional model of early RA nurse-led care

This interview study with thematic analysis provided themes of early RA nurse-led care which described and explained aspects of early RA nurse-led care from the perspective of rheumatology nurse specialists. According to the findings, rheumatology nurse specialists provide early RA specialist care delivered with compassion, using holistic, person-centred and empathetic approaches. This study suggested a strong link between psychosocial and medical needs in relation to outcomes in early RA, and the findings suggested that patients in early RA benefitted from the combination of the nurse specialists’ approaches to care. This study identified themes of aspects of early RA care from the nurse perspective and provided new knowledge about how early RA nurse-led care works. Finally, this study provided a provisional model of early RA care based on the identified themes characterising early RA nurse-led care.

However, the study was from the nurse perspective. It is not known how well early RA nurse-led care meets patient needs in early RA from the patient perspective, and it is not known if patients agree with the provisional model of early RA care developed from interviews with rheumatology nurse specialists. More research is needed to get an understanding of the patient perspective of early RA nurse-led care.

4.6.9. Strengths of this study

This study has several key strengths. First, the thematic analysis according to Braun and Clarke's approach (2013) allowed the identification of themes across the entire data. Themes were derived from data in a bottom-up approach, with the development of themes describing and charactering nurse-led care in early RA. The thematic analysis approach according to Braun and Clarke (2013) provided a stepped and flexible guide for the analysis of data which ensured that each step of the analysis was addressed and reflected upon.

The interview method provided in-depth and rich data, and telephone interviews accommodated the participation of rheumatology nurses from across England which helped obtain varied data. The semi-structured interview method using an interview-guide during interviews ensured that topics of interest derived from a prior conducted systematic review of qualitative studies were addressed, albeit allowing for prompt questions and other topics to be discussed. Using her communication skills, the researcher established an interview environment which accommodated an appreciative, clear, and professional dialogue with the participants who openly and willingly shared their views, which helped provide varied and rich data. Telephone-interview might have offered some privacy, encouraging to a more intimate and open conversation than face-to-face or focus group interviews might have provided.

To ensure that data relevant to the research would be collected and to provide consistency in the interviews, an interview guide was developed. The interview guide was informed by findings of an earlier systematic review of qualitative studies (Chapter two), conducted by the researcher, which identified themes characterising early RA nurse-led care in early RA from the patient perspective. The interview guide was initially drafted by the researcher and then discussed and agreed with the supervisory team prior to the interviews were conducted. The interview guide and the interview skills of the researcher were tested in a pilot interview session with an experienced qualitative researcher from the supervisory team listening in and commenting to ensure a professional and effective collection of data. It is possible that an interview guide with other questions, and another interviewer with other interview skills would have provided different data.

It is acknowledged in thematic analysis according to Braun and Clarke (2013), that the researchers' interpretation of data is an important part of the research process, but the researcher's reflections need to be recognised and documented. Each stage of the research process was thus checked by one or more of the supervisors to minimise errors and maximise the credibility of the findings. The research process was continuously discussed with the Director of Studies and the supervisory team, and a subset of transcripts of interviews were reviewed by members of the supervisory team to check and comment on candidate themes and the research process. The patient research partner was a member of the supervisor team and discussed and commented on the development of themes for relevance and meaning in early RA care.

4.6.10. Limitations

This interview study has some limitations. Only sixteen nurse specialists participated in the study. However, the interviews provided rich and varied data as participants answered the questions from the interview-guide, prompt questions as well as added new topics into the conversation which brought depth and with to the interviews. It is possible that other and more participants would have brought more varied data.

Only participants in England were recruited. It is possible that participants from other parts of the United Kingdom, or from other parts of the World could have different perceptions of nurse-led care and thus could have provided different data. However, participants from England alone provided rich and varied data within a similar organisation of healthcare, and more research in a wider geographical area could be warranted.

Choosing to take part in this study may reflect an interest in research, and the participant sample may therefore not include the voices of less research active, less research interested or less motivated nurse specialists as well as the quieter voices. Clinical care may be better in in research active Trusts, and the clinical practice reported by participants that chose to take part in the study may thus reflect high clinical standards. Each individual account was valuable in provide insights into early RA nurse-led care clinical practise to begin establishing key elements of good clinical practise. For a broader investigation, more research using for example survey methods could be conducted, which may be more attractive to nurse specialists who are not usually engaged in research.

Participants who chose to participate were female. Two male nurse specialists showed interest in the study, but eventually did not participate. However, the limited number of male nurses may reflect that the majority of nurse specialists are female. It is possible that male participants or participants' who define themselves as binary or transgender could have provided different data. The invitation to participate was open to any nurse specialist who was eligible according to the study criteria, and an effort was made to include as many participants as possible to get varied data. More research which includes a wider range of participants with different genders is thus needed to get more varied data. Ethnicity was not addressed, and during the interviews no references were made to ethnicity by any of the participants, neither their own nor their patients. It is possible that addressing ethnic aspects in early RA care could have provided different and more nuanced data, and more research is thus needed.

The COVID-19 pandemic caused disruption with the first national lockdown in March 2020. In person research was prohibited and could not get ethics approval at the University of the West of England. This caused adjustment of the research protocol, so interviews were conducted via telephone only, and not with an option of face-to-face interview depending on participant preferences. Later as practices for Zoom meetings were developed, face-face interviews on Zoom could possibly have been carried out. At the time of the interviews, telephone was the only option for interviewing the nurse specialists as video options were not yet available in the clinics. However, using telephone interview 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. The disadvantage of not being able to observe participant's nonverbal communication was minimised by using communication skills and establishing a friendly interview environment which provided in-depth and varied data. It is possible that face-to-face interview in person or on Zoom could have provided more and different data.

4.7. Conclusion

This interview study identified themes and subthemes that described early RA nurse-led care as a specialist care delivered with compassion, addressing patients complex care needs using person-centred, holistic, and empathetic approaches with continued development and improvement of the service. COVID-19 challenges and opportunities were identified as a separate theme as the COVID-19 pandemic had caused disruption in the service, but eventually had contributed to innovation and improvements as a catalyst for change. As psycho-social issues were found to play a major role in early RA care and could have an impact 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. This study provided the nurse perspective of what comprises early RA nurse-led care identified as themes and subthemes, which provided model of early RA nurse-led care. More research of nurse-led care in early RA is needed to understand how early RA nurse-led care meets the needs of patients, and to get the patient perspective of the identified themes characterising early RA nurse-led care.

4.8. Relevance to clinical practice

This interview study with rheumatology nurse specialists presents the nurse perspective of what comprises early RA nurse-led care, and it 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 thus 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 person-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.

Chapter 5: The patient perspective of early RA nurse-led care and satisfaction with care in early RA: A cross-sectional survey

The previous qualitative interview study identified themes characterising early RA nurse-led care from the rheumatology nurse perspective. Therefore, it was important to build on these findings to understand the patient perspective of early RA nurse-led care. This chapter reports study three addressing the third objective of the PhD.

5.1. Rationale for this study

The nurse specialists interviewed in Study 2, the interview study (Chapter three and Chapter four), had in-depth insights into their own clinical practice as well as their perception of patients’ needs in early RA. However, they could not speak on behalf of the patients. It was therefore not known if patients' needs were met in early RA nurse-led care, and it was not known if patients with early RA would confirm the provisional model of early RA nurse-led care developed from the nursing perspective. Research was needed to determine the extent to which care needs of patients with early RA are met by nurse-led care from the patient perspective. It was also important to understand the extent to which patients agree with the provisional model of early RA nurse-led care developed from the interviews with nurse specialists.

5.2. Aim

This study aimed to determine the extent to which patients’ care needs are met in early RA nurse-led care and the extent to which patients confirm the provisional model of early RA nurse-led care developed from interviews with rheumatology nurse specialists.

5.2.1. The research questions

1. To what extent are patients' care needs met in early RA nurse-led care?
2. To what extent do patients consider the provisional model of early RA nurse-led care important to them?
3. To what extent do patients' experience accord with the provisional model of early RA nurse-led care?

5.3. Methods

5.3.1. Design

This was a cross-sectional study using online survey methods (Fink, 2017; Bowling, 2014). This design is suitable where the aim is to obtain a description of the situation and assess association between variables at one point in time to obtain a description or perceptions at one point in time (Fink, 2017; Bowling, 2014). A qualitative phase with patients using for example focus groups would have been a natural first step for understanding the patient perspective and to provide items for a model of early RA nurse-led care (O'Connor, 2022; de Vet *et al.*, 2011; Polit and Beck, 2008). This method is used in health care when developing multi-item instruments, as for example questionnaires for patient reported outcome measures, together with input from literature and experts (de Vet *et al.*, 2011) or needs assessments (Polit and Beck, 2008).

Originally, a study with observation of consultations and follow-up interviews with patients was planned. However, due to the COVID-19 pandemic and the associated precaution measures, including change of the nurse-led care service to telephone and no access to face-to-face observation, the study was modified and conducted as a survey.

Surveys can be used in deciding policy or in planning and evaluating programs and conducting research when the information needed should come directly from people (Fink, 2017; Polit and Beck, 2008). They can provide data on feelings and perceptions, values, habits and personal background or demographic characteristics (Fink, 2017;

Polit and Beck, 2008). Using online questionnaires is a time- and cost-efficient way of collecting data and by eliminating transcription, and minimising data entry errors.

The survey was hosted by the University of the West of England Bristol. The questionnaire was delivered online using Qualtrics® software accessed via UWE Bristol IT-services (Qualtrics, 2021). The Qualtrics® platform complies with the current GDPR requirements (UWE, 2021c).

5.3.2. Participants

The following were the inclusion and exclusion criteria:

Inclusion criteria:

- Adults (18 years of age and above)
- Self-declared early rheumatoid arthritis
- Disease duration between 0-2 years from diagnosis
- Attending consultations with rheumatology nurse specialists for RA management at hospital rheumatology outpatient clinics (NB patients were asked this in the questionnaire- no recruitment was performed via NHS clinics)
- Residents in England
- Able to access and complete online questionnaire

Exclusion criteria:

- Children or young people (under 18 years of age)
- Other diagnoses with exclusion of rheumatoid arthritis
- Disease duration over 2 years from diagnosis
- Not attending consultations with rheumatology nurse specialist for RA management at hospital rheumatology outpatient clinics
- Residents of other nations than England
- Inability to access and complete online questionnaires

Only residents in England participated as the prior study (Chapter three and Chapter four) with nurse specialists therefore questions about residency in England were part of the survey. Attendance to a rheumatology nurse-led care was defined as 'attending consultations with rheumatology nurse specialists for RA management at hospital rheumatology outpatient clinics could participate'. Patients who did not see a rheumatology nurse specialist at a hospital outpatient clinic were not included in the study. This research was about nurse-led care to adult patients with early RA defined as the first two years of disease (Burgers, Raza and Mil, 2019; Luqmani *et al.*, 2006) which is why participants had to be 18 years old or older and with early RA i.e. disease duration within two years of diagnosis.

5.3.3. Recruitment

Participants with early RA were recruited online via patient and professional organisations outside the NHS. Patient organisations (Versus Arthritis, National Rheumatoid Arthritis Society (NRAS) and Arthritis Action) shared the link to the survey with their members online. Participants who had access to these platforms could access the survey by following this link. The participant information specified what the inclusion criteria were, and these criteria were repeated at key questions. Participants were asked if they had read the participant information and wanted to participate, and they could only move on to the survey if they had responded with a 'yes' to the consent question.

5.3.4. Sampling

As the survey was posted online it was an open approach and could be labelled as convenience sampling (Fink, 2017; Bowling, 2014; Polit and Beck, 2008). Participants were requested to share the survey in their networks and hence, it could also be considered snowball sampling (Fink, 2017; Bowling, 2014; Polit and Beck, 2008).

5.3.5. Measures

To address the aim of this study the following variables were measured: Demographics, clinical data, type of nursing-led care received, satisfaction with care, and the extent to which patient agreed with the provisional early RA nurse-led care model.

5.3.5.1. Demographics

The following demographic data were collected: age, gender, and residency in England. These were important to help confirm eligibility and describe the data.

5.3.5.2. Clinical data

As diagnosis was self-reported, participant responses about medication could confirm an RA diagnosis, as RA medication would include Steroids, disease modifying anti-rheumatic drugs (DMARDs) including conventional DMARDs (cDMARDs), biologic DMARDs (bDMARDs) and/or Janus Kinase (JAK) inhibitors (NICE, 2018). This would help confirm whether the individual participant had RA (and not osteoarthritis alone). To check that the participant had early RA, participants were asked about disease duration (between 0 and 24 months).

5.3.5.3. Type of Nurse-led care received

Attendance at rheumatology nurse-led clinics was checked by asking about which type of consultation the participant had with the nurse specialist. Participants were asked if they had attended a consultation with a nurse specialist at a hospital rheumatology clinic for management of their disease, with the response options ‘yes’ or ‘no’. For this study ‘consultation with nurse specialist’ was used for ‘nurse-led care’, focusing on rheumatology nurse-led clinics at hospitals, which are run by rheumatology nurse specialists. Participants were asked how they attended the last nurse consultation with response options: face-to-face, telephone, video or combinations. To understand if the patient view of early RA care could be on the background of the current COVID-19 pandemic, a text box was provided to complete the day, month and year of the latest nurse specialist consultation.

5.3.5.4. Satisfaction with care

Hill *et al.* defined satisfaction with care as ‘the degree to which patients perceive their needs are met’ (Hill, 1997). Nurse-led care has been shown to improve patient satisfaction with care (Garner *et al.*, 2017; Ndosi *et al.*, 2014; Koksvik *et al.*, 2013; Hill, Thorpe and Bird, 2003; Hill, 1997) and self-efficacy (Ndosi *et al.*, 2016; Zangi *et al.*, 2015). Patient satisfaction has thus been acknowledged as important for patients’ quality of life and a significant factor in the patients’ wellbeing and must thus be included when evaluating health care service provision (Hill, 1997).

Patient satisfaction can be described as ‘the degree to which patients perceived that their needs were met’ (Hill, 1997). Patient satisfaction was tested using the Leeds Satisfaction Questionnaire LSQ, (Hill, 1997) which was specially developed to measure patient satisfaction in a rheumatology nurse-led clinic (Hill, 1997). The LSQ has been tested and found to be reliable (Cronbach’s alpha 0.96), stable (test- retest r = 0.83) (Hill, 1997), and responsive to change in nurse-led care effectiveness studies in rheumatology (Ndosi *et al.*, 2014; Koksvik *et al.*, 2013; Hill, 1997; Hill *et al.*, 1994). These studies were in rheumatology nurse-led care. The tool has also been adapted to assess patient satisfaction in a clinic for cancer patients (Egan and Dowling, 2005), and in a study comparing doctor- and nurse-led care in a sexual health clinic (Miles *et al.*, 2003).

The LSQ measured patient satisfaction with the following aspects of care:

A. General satisfaction: this aspect of care captured the patients’ assessment of how their overall needs were met in early RA nurse-led care
B. Giving of information: this aspect of care captured the patients’ assessment of the information they were given in early RA nurse-led care
C. Empathy with the patient: this aspect of care captured the patients’ assessment of the empathy they experienced in early RA nurse-led care

D. Technical quality and competence: this aspect of care captured the patients' assessment of the technical quality and competence they experienced in early RA nurse-led care
E. Attitude towards the patient: this aspect of care captured the patients' assessment of the attitude they experienced in early RA nurse-led care
F. Access and continuity: this aspect of care captured the patients' assessment of access and continuity of early RA nurse-led care

The questionnaire consisted of 45 statements, which were associated with different aspects of care above (A, B, C, D, E and F), and expressed both positive and negative sentiments to minimised bias. Item on the questionnaire were 5-point Likert scales with response options from 'strongly agree' = 1 to 'strongly disagree' = 5. High scores indicate a high level of satisfaction. The scores were then normalised in each group so that satisfaction with all aspects of care could be compared directly (Hill, 1997).

A scores above three indicate satisfaction and scored below three dis-satisfaction with care. In addition to indicating levels of satisfaction with different domains (aspects of care), the results could be combined to provide a measure of overall satisfaction with care (Hill, 1997).

The LSQ was thus deemed suitable for measuring patient satisfaction with different aspects of nurse-led care in early RA. Permission to use the LSQ patient satisfaction tool was requested and granted. The tool was modified in questions 8, 34, and 36 so instead of 'tablets' the term 'medications' was used to reflect that prescribed medication might include tablets, injections, and infusions.

5.3.5.5. Patient perspective of nurse-led care in early RA

A provisional model of early RA nurse-led care was developed from themes characterising early RA nurse-led care, identified in the prior interview study with rheumatology nurse specialists (Chapter three and Chapter four). The identified sub-themes were operationalised by developing two sets of statements (items) to evaluate the extent to which (i) patients considered the model of early RA nurse-led care important to them (18 items) and (ii) the extent to which patients' experience of care accorded with the model of early RA nurse-led care (18 items).

A 0 to 10 rating scale (Taherdoost, 2019; Preston and Colman, 2000) was chosen as measuring instrument as this would allow for precision of the measurement. According to Preston and Colman (2000), shorter rating scales are rated as relatively quick to use, but scales with 10 and 11 alternatives are preferred to express most respondents' feelings adequately (Taherdoost, 2019; Preston and Colman, 2000).

An example of items of importance was:

> Please consider each statement and indicate how important it is for your care: '*Care is provided with compassion'*, 0 = 'Not at all important' and 10 = 'extremely important'.

An example of items of experience was:

> Please consider each statement and indicate if it reflects the care you received from the nurse-led consultation: *My care was provided with compassion'*, 0 = 'I do not agree' and 10 = 'I agree completely'.

For analysis, the rating scales were transformed to 1 to 11, and for all items, a score of 7 and above was considered high. Participants were also invited to add any item important to their care that they felt was not represented by the items, using a free text box:

> *'Please add any aspect of care that you feel is important to you and is missing from the above statements'*.

5.3.6. Questionnaire development.

The development of questions for the survey had similarities with the development of a new measure in health (de Vet *et al.*, 2011). The researcher developed the draft statements for the questionnaire under the supervision of the supervisor team by creating statements derived from the themes and subthemes identified in the interview study with nurse specialists (Chapter three and Chapter four). These statements thus represented the themes and subthemes of the provisional model of early RA nurse-led care and were to be assessed by participants of the survey. The statements were discussed with the supervisory team, and the patient research partner further reviewed the questionnaire and assessed the items for relevance and comprehensibility (de Vet *et al.*, 2011). Minor corrections were made for clarity and readability before being finalised.

5.3.6.1. Considerations about clarity and inclusion of statements

The patient research partner suggested that some statements needed a lay explanation in brackets to increase the understanding of the statement. Lay explanations were discussed, agreed and added in statements representing a person-centred approach (Q03), a holistic approach (Q04) and an empathetic approach (Q05) (Appendix M. Development of survey questions related to the model of early RA).

Questions regarding the theme characterising the specialist nature of early RA nurse-led care, and the theme describing the COVID-19 impact were considered for inclusion in the questionnaire and for wording. In the prior interview study (Chapter three and Chapter four), the theme ‘A specialist service delivered by experienced rheumatology nurses’ was found to be an important aspect of early RA nurse-led care from the nurses’ perspective. The researcher decided that it was important to understand how this aspect came across and was perceived from the patient perspective. The theme ‘A specialist service delivered by experienced rheumatology nurses’ was for this survey changed to ‘Specialist care’.

The researcher understood that specialism or being a specialist should be defined by practitioner competence, not by patients. Bowling (2014) commented citing Cartwright and Anderson (1981) that as acceptable levels of competence are assumed, patients do not usually evaluate medical care in relation to competence, but make judgements based on human factors such as attitudes and manner, provision of information and service factors (Bowling, 2014). This bias is according to Bowling (2014) also reflected in satisfaction questionnaires, where it can be difficult to assess whether the bias reflects patients' priorities or whether questionnaires contain an organisation bias which does not aim to explore the appropriateness and outcome of the treatment in a satisfaction questionnaire. Bowling (2014) adds, that it may also be because developers of questionnaires do not feel that patients have the expertise to judge the quality of clinical care, though the effectiveness of the care and the patients' perspective on this are some of the most important issues (Bowling, 2014).

The researcher wanted to get the patient perspective on early RA nurse-led care and assumed that patients could determine to what degree they believed that they had received specialist care as a measure of feeling in good hands with the service provided. The matter was discussed with the patient research partner and 'believe' was used to underline that the statement was focused on the patient perception of the care received. Questions were thus developed so participants could determine how important 'to receive specialist care' (3AQ01) was for their care from the patient perspective and determine to what degree they 'believed' that they had received 'specialist care' (3BQ01) (Question numbers referring to Appendix M).

The theme 'COVID-19 challenges and opportunities' was developed as the interview study (Chapter three and Chapter four) informing this survey was conducted in summer 2020 during the COVID-19 pandemic. It described challenges and opportunities caused by the pandemic. As this researcher was developing a model of care not specifically linked to the COVID-19 pandemic, but as a model of care in early RA, it was decided not to include COVID-19 as an item in the model of care. Instead, focus was on the aspects of 'innovation and service improvement' instigated by the COVID-19 pandemic.

The full questionnaire thus contained three sections:

Section 1. 'Questions about you'. This section contained questions about participants' demographics, clinical data, and nurse-led care attendance.

Section 2. Questions about satisfaction with care. This section contained 45 questions about satisfaction with care (LSQ).

Section 3. Questions on the provisional model of care in early rheumatoid arthritis: to determine whether patients' experience of nurse-led care accorded with the model and whether they considered the model (as represented by the items) important to them. This section also provided a free text box for patient comments on early RA care.

5.3.7. Sample size

The online survey aimed at collecting patients' views of how their needs were met in early RA nurse-led care and of the provisional nurse-led care model. The focus was not on detecting effect sizes therefore there was no basis for a power calculation. The Large Sample Condition is that the sample size is at least 30, although some textbooks state that 40 is large enough, but 30 is commonly used (Zach, 2020). A patient satisfaction study in rheumatology nurse-led care (Hill, 1997) had 70 participants. It was an RCT looking at nurse-led care vs. rheumatologist-led care, the data from which allowed for the validation of the LSQ tool. Another RCT looking at rheumatology nurse-led care vs. rheumatologist led care had 80 participants (Hill, Thorpe and Bird, 2003), and a patient satisfaction study in nurse-led cancer care had 72 participants (Egan and Dowling, 2005). A minimum or maximum number target of participants was not determined, although 150 was deemed desirable to provide evidence for the patient perspective.

The researcher had no influence on who participated and relied on participants' information about study eligibility. The aim was to recruit as many participants as possible who had been seen at nurse specialist consultations, virtual (telephone and/or video) and face to face to enable simple comparisons during the analysis of data. Participation was open to any who were eligible according to the study criteria, and the recruitment of participants would continue until the end of the planned recruitment period.

To increase the chance of getting the population wanted for this study, all the key patient organisations were approached. The survey was advertised repeatedly online, once a week. Due to few participants, the original timeframe for the recruitment from Mid-December 2021 to end of January 2022, was extended for an extra month to the end of February 2022. Additionally, the researcher and research colleagues posted a link to the survey on their professional social media platforms.

5.3.8. Testing of the survey

The survey was tested for feasibility, presentation and technical errors by sending the link to members of the supervisory team and acquaintances who agreed to test the questionnaire. They were asked to fill in the questionnaire and comment on the experience. This is a fast and cheap method of checking immediate problems with the survey (de Vet *et al.*, 2011). Four academics with expert knowledge of rheumatology, and one patient research partner with experience of research methods in rheumatology, and knowledge of the disease and its impact, checked and tested the questionnaire. Also, two academics who were not connected to the research environment, i.e. one biologist and one with background in the arts, with no prior knowledge of the research and who did not suffer from the disease, filled in the questionnaire and provided comments. The patient research partner provided extensive feedback on wording, understanding and meaning of the statements as well as visual and technical presentation of the survey from a patient perspective. In all, seven people tested and commented on the survey. Minor adjustments were made, and technical errors corrected.

5.3.9. Distribution of the survey

Patient organisations were approached to ask for their help to distribute the survey online via their social media platforms. An initial email with information about the study and the research team was thus sent to key patient organisations. Three responded. One organisation requested a formal application with a description of the study, and information about the research team as well as a short summary for their social media platform in order to collaborate.

The survey was distributed online with a link to the Qualtrics$^{(R)}$ platform, which the researcher could access via the University of the West of England (UWE).

The researcher could check the number of responses without opening the survey and could thus ask to extend the survey for an extra month, when it became clear that few participants had completed the survey.

5.3.10. Preparation of data for analysis

The preparation of the data file for analysis involved several steps. According to Pallant (2007) this process includes creating the data file, and entering the information contained in the protocol in a format defined in the codebook (Pallant, 2007). Using the Qualtrics platform eased these steps, as the data file was created in the Qualtrics software and could be accessed and downloaded for analysis in statistical software of choice.

A spreadsheet with survey data was downloaded and prepared for analysis. A copy was created with original version of data, which should stay un-touched. Data copies for preparation of data were created: a) a test copy for reference, and b) a copy for preparing data.

Data were checked for any information that could identify or trace the participants. Data reported via Qualtrics were anonymous, with no details of name, occupation, geographical area, or IP addresses. Participant identifiers had been created automatically in Qualtrics platform using numbers and letters. These identifiers were removed as were empty columns which were provided for names, addresses, IP addresses, and dates.

A codebook was developed which involved defining and labelling each of the variables and assigning numbers to each of the possible responses. In the codebook was listed the variables in the questionnaire, the abbreviated variable names that would be used in SPSS, and the way the responses were coded (Pallant, 2007).

The data file was then checked for errors and identified errors were corrected. Responses which were not clear were discussed with the Director of Studies and decisions made about correction. Finally, data were checked for eligibility against the study criteria: adults 18 and over, residency in England, a diagnosis of RA, and disease duration of 0 to 24 months.

5.4. Analysis

The quantitative questionnaire data were analysed using SPSS 25 for Windows (IBM, Armonk, NY, USA). Demographic data were summarised using central tendency and dispersion (age, disease duration) and proportions (gender, medication and type of consultation). Analyses for the other questionnaire items are described below.

For satisfaction with care, the analysis involved: (i) sorting the 45 LSQ items into groups associated with each aspect of care (represented by domains A, B, C, D, E and F), (ii) re-coding some of the scores which needed reversing, (iii) normalising the scores in each domain and combining the scores to arrive at the overall satisfaction. To get the overall satisfaction score, the normalised group scores were added together, and the answer was divided by six, giving a score out of five, with scores above three indicating satisfaction and scores below 3 indicating dis-satisfaction (Hill, 1997).

After descriptive analyses of patient satisfaction, results were presented as medians (*Mdn*) and interquartile ranges (*IQR*) for each specific aspect of care (domains: A. General Satisfaction; B. Giving of information; C. Empathy with the patient; D. Technical quality and competence; E. Attitude towards the patient, and F. Access and continuity) and the overall satisfaction.

Mdn and IQR were used to summarise data and not mean and standard deviation as variables were ordinal (Likert scale and rating scale). In inferential analyses, Mann-Whitney (*U*) test and the associated p-value tested the difference in the overall satisfaction between patients attending face-to-face consultations vs those attending telephone/telephone combined with posted material. The Mann-Whitney (*U*) test is thus used to compare differences between two independent groups when the dependent variable is either ordinal or continuous, and not normally distributed. The Mann-Whitney (*U*) test is often considered the nonparametric alternative to the independent t-test although this is not always the case (Lund and Lund, 2020). A difference with a p-value of less than 0.05 was considered statistically significant.

The items representing the provisional model of early RA nurse-led care, were descriptively summarised using the Mdn *(IQR*). A Mdn of seven and above was considered high.

In the inferential analyses, Mann-Whitney (*U*) test and the associated p-value tested the difference between patients attending face-to-face clinics versus those attending telephone/telephone appointments combined with posted material for patient perceived importance of the model as presented in questionnaire statements, and for experience of care assessed against the model as presented in questionnaire statements. A difference with a p-value of less than 0.05 was considered statistically significant.

Textual data from free text boxes with patient comments on early RA nurse-led care were analysed using content analysis. It had been planned to use thematic analysis (Braun and Clarke, 2013) as this analysis method is flexible and was used to develop the items of the provisional model of early RA nurse-led care. However, textual data were very limited, and therefore content analysis was used as this method does not require in-depth varied data but can be used to analyse any textual data (Hsieh and Shannon, 2005). Content analysis was thus used to categorise the comments into similar topic areas and develop themes (Hsieh and Shannon, 2005). Identified themes were compared with themes of the provisional model of care to assist the interpretation and for potential inclusion in a future optimised model of early RA nurse-led care.

5.5. Ethical considerations

Following ethical issues were considered and addressed: Data storage, access and security, evaluation of risk and participant information.

5.5.1. Data storage, access, and security

The study was compliant with the GDPR requirements (UWE, 2021b). Qualtrics software (Qualtrics, 2021) approved by UWE was used for distribution and storage of questionnaires and responses. Data were downloaded from the Qualtrics online platform on to UWE statistical software and Excel spreadsheets and stored in secure designated folders on the UWE OneDrive server.

Data in the questionnaires were anonymous. Data were only shared between the researcher and co-investigators until publication of results, and only the researcher and co-investigators had access to the data. Anonymous data were stored in the UWE repository.

5.5.2. Risk evaluation

There were no potential risks to participants because of undertaking this project that were greater than those encountered in normal day-to-day life. Participants were reassured that their participation was anonymous, no information would be passed on to the researcher from the patient organisations, and their usual clinical team would not be contacted. Participants were informed that if they were concerned about any aspects which emerged from their participation, they were asked to contact their usual rheumatology team. There were no potential risks to the researchers and any other people as consequences of conducting this research.

5.5.3. Participant information

Potential participants were informed about the purpose of the project, the host of the research and the research team with contact information, data protection information and how to participate and withdraw from the project. They were informed that participation was voluntary, the survey was anonymous, and that responses were strictly confidential. No contact information would be obtained, and no contact information would be passed on to the research team from patient organisations. Potential participants were informed to give their consent to participate by ticking the box that they had read the information and agreed to participate, and by submission of the questionnaire. Participants were also informed that once they submitted their responses they could not withdraw as their data would then be un-identifiable.

5.5.4. Ethical approval

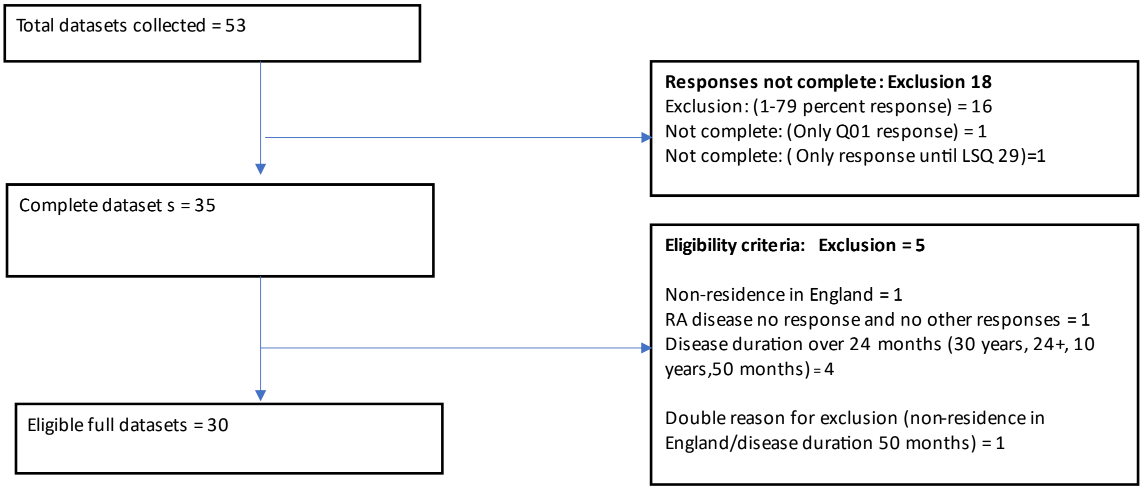
Ethics approval was sought through the University of the West of England’s Faculty Ethics Committee (UWE FREC). As the research was conducted outside the NHS and did not involve direct contact with patients, further ethical approval was not required (UWE, 2021a). Full approval was granted: UWE REC REF No: HAS.21.10.021 (Appendix N). Ethics approved participant information and questionnaire are provided in Appendix O (A). Participant information and questionnaire with minor changes before publication, including suggested lay text from the patient research partner is provided in Appendix O (B).

5.6. Results

A total of 53 responses were received, but only 30 contained complete data. Responses that were not complete were removed in the data cleaning process. The data were checked against the eligibility criteria, and responses that were not within the inclusion criteria were removed. All of the 30 participants were female. Of these, 26 had provided their age with a Mdn (*IQR*) age of 53.0 (43.0 to 58.0) ranging from 30 to 72 years. Data were checked for completeness and errors.

A flowchart of the process of checking the datasets for inclusion and exclusion is presented in Figure 4.

Figure 4. Study flow chart showing the participant data inclusion process



5.6.1. Nurse-led care attendance

All participants had attended nurse-led care appointments. The earliest recorded nurse-led care appointment was in April 2020. The latest was in January 2022. The recorded appointments were thus recent, and within the time period of the COVID-19 pandemic (the first COVID-19 lockdown was March 2020, and the pandemic was ongoing until end of recruitment January 2022).

Of the 30 participants, 16 (53.3 %) had telephone appointments only, two (6.7 %) had telephone appointments combined with posted material. The variables for telephone appointments and telephone appointments combined with posted material were grouped together. Twelve participants had face-to-face appointments (40.0 %).

5.6.2. Medication

Participants could choose more than one medication. Twenty-eight out of 30 participants (N = 30) were treated with DMARDs (93.3 %). Twelve had been treated with Steroids (40.0 %). Eight participants were treated with biologics (26.7 %), and three participants were treated with JAK inhibitors (10.0 %). Some patients took multiple types of arthritis and pain medications, therefore the overall percentages of medication exceeded 100 percent. A summary of the sample characteristics is provided in Table 6.

Table 6. Characteristics of patients with early RA

Valuables studied	N (%)	Median (*IQR*)
Age (years)		53 (43 to 58)
Gender - Number of females	30 (100 %)	
Residence in England	30 (100 %)	
Disease duration (0-24 months)		16 (9 to 20)
Arthritis medication*		
• Steroids	12 (40.0 %)	
• DMARDs	28 (93.3 %)	
• Biologics	8 (26.7 %)	
• JAK inhibitors	3 (10.0 %)	
Pain medication*		
• None	3 (10.0 %)	
• Paracetamol	17 (56.7 %)	
• NSAID	11 (36.7 %)	
• Opioid based	10 (33.3 %)	
• Other**	4 (13.3 %)	
Nurse-led care consultation form		
• Face-to-face appointment	12 (40.0 %)	
• Telephone appointment	16 (53.3 %)	
• Video appointment	0	
• Telephone combined with digital solution	0	
• Telephone combined with posted material	2 (6.7%)	

IQR, Interquartile range; *Percentages will exceed 100 because some patients took multiple types of arthritis and pain medications ** Specification in free text box: Co-codamol, Zapain, Amitriptyline

5.6.3. Satisfaction with care

The total Mdn (*IQR*) score for patient satisfaction was 3.09 (2.8 to 3.74). The lowest score was observed in domain C: Empathy with the patient (*Mdn* = 2.81, *IQR* = 2.25 to 3.5) and the highest score was in domain D: Technical quality and competence *(Mdn* = 3.88, *IQR* = 3.13 to 4.13). Satisfaction with RA nurse-led care for all participants was observed for B, Giving of information (*Mdn* = 3.33, *IQR* = 2.83 to 3.83); D, Technical quality and competence (*Mdn* =3.88, *IQR* = 3.13 to 4.13); E, Attitude towards the patient (*Mdn* = 3.41, *IQR* = 2.50 to 4.17); and total score (*Mdn* = 3.09, *IQR* = 2.80 to 3.74). The satisfaction with care LSQ Mdn (*IQR*) scores are presented in table 7.

Table 7. Satisfaction with care LSQ for domains and total score. Median score (IQR)

Domain	Median score (*IQR*)*
A. General Satisfaction	2.83 (2.33 to 3.33)
B. Giving of information	3.33 (2.83 to 3.83)
C. Empathy with the patient	2.81 (2.25 to 3.50)
D. Technical quality and competence	3.88 (3.13 to 4.13)
E. Attitude towards the patient	3.41 (2.50 to 4.17)
F. Access and continuity	3.17 (2.33 to 3.67)
Total score	3.09 (2.80 to 3.74)

Legends*:* *IQR*, Interquartile range; *A score of 3 and above indicates satisfaction with care (Scores ranging from 1 =Strongly disagree to 5)

5.6.3.1. Difference between face-to-face and telephone consultations

Differences in satisfaction with care were observed between face-to-face consultations (12 respondents with face-to-face appointment) and telephone consultations (16 respondents with telephone appointments + 2 respondents with telephone appointments combined with posted material).

For face-to-face consultations, the highest score was observed for E, Attitude towards the patient (*Mdn* = 4.08, *IQR* = 3.00 to 4.42), the lowest score was observed for F, Access and continuity (*Mdn* = 3.33, *IQR* =2.33 to 4.00). For telephone consultations, the highest score was observed for D, Technical quality and competence (*Mdn* = 3.69, *IQR* = 2.88 to 4.00), and the lowest score was observed for A, General satisfaction (*Mdn* = 2.33, *IQR* = 2.00 to 3.00).

For face-to-face consultations, satisfaction with care was observed for all domains, including total score. For telephone consultations, satisfaction with care was observed for B, Giving of information (*Mdn* = 3.08, *IQR* = 2.83 to 3.33); D, Technical quality and competence (*Mdn* = 3.69, *IQR* = 2.88 to 4.00), and E, Attitude towards the patient (*Mdn* = 3.25, *IQR* = 2.50 to 3.83).

Mann-Whitney test suggested that total satisfaction with care was greater for patients who had face-to-face consultations (*Mdn* = 3.73, *IQR* = 3.02 to 4.09) than for those who had telephone consultation (*Mdn* = 2.95, *IQR* = 2.32 to 3.41), *U* = 56.00, *p* = 0.028. In the specific domains, only two domains were shown to have significant differences in satisfaction levels. These were general satisfaction (*U* = 44.00, *p* = 0.006) and empathy (*U* = 42.00, *p* = 0.005), all in favour of face-to-face consultations. Other domains did not show differences between the two groups. The results of between group differences in the specific domains of satisfaction and total satisfaction are presented in Table 8.

Table 8. Satisfaction with care. Group differences between face-to-face consultations and telephone consultations

Domain	Face-to-face Median score (*IQR*)	Telephone/ telephone combined with posted material Median score (*IQR*)	*U (p)*
A. General Satisfaction	3.50 (2.83 to 3.83)	2.33 (2.00 to 3.00)	**44.00 (0.006**)
B. Giving of information	3.75 (3.33 to 4.00)	3.08 (2.83 to 3.33)	63.00 (0.056)
C. Empathy with the patient	3.50 (2.88 to 4.06)	2.44 (2.25 to 3.00)	**42.00 (0.005)**
D. Technical quality and competence	4.00 (3.75 to 4.38)	3.69 (2.88 to 4.00)	62.00 (0.051)
E. Attitude towards the patient	4.08 (3.00 to 4.42)	3.25 (2.50 to 3.83)	63.50 (0.059)
F. Access and continuity	3.33 (2.33 to 4.00)	2.89 (2.22 to 3.44)	88.00 (0.396)
Total Satisfaction	3.73 (3.02 to 4.09)	2.95 (2.32 to 3.41)	**56.00 (0.028)**

U, Mann-Whitney test; *p*, p-value, where $p \leq 0.05$ suggests significant difference (also in bold); *IQR*, Interquartile range

5.6.4. The patient perspective of a model of early RA nurse-led care

5.6.4.1. Patient perceived importance of the early RA model of care

The results indicated that all the items developed from the model of early RA nurse-led care were considered highly important by patients with early RA. The patient perceived importance of the provisional model of nurse-led care to patients is summarised in Table 9. The items of the model of care with the highest patient perceived importance levels were ‘I receive specialist rheumatology care’ (*Mdn* = 10.00; *IQR* = 10.00 to 10.00), and ‘Care is provided with person-centred approach (The care is tailored to my individual needs)’ (*Mdn* = 10.00; *IQR* = 10.00 to 10.00). In all, 14 items had medians of 10.00 with *IQRs* from 8.00 to 10.00, and 9.00 to 10.00. The lowest scoring item was ‘My social needs are addressed’ (*Mdn* = 8.00, *IQR* = 7.00 to 10.00).

Table 9. Patient perceived importance of the provisional model of early RA nurse-led care

Item descriptor	**Median (*IQR*) 0=not at all important, 10 = extremely important**	**Theme**
It is important that….		
I receive specialist rheumatology care	10.00 (10.00 to 10.00)	1
Care is provided with compassion	10.00 (9.00 to 10.00)	3.1
Care is provided with person-centred approach (The care is tailored to my individual needs)	10.00 (10.00 to 10.00)	3.2
Care is provided with a holistic approach (I am treated as a whole person, not just as a disease)	10.00 (9.00 to 10.00)	3.2
Care is provided with an empathetic approach (The nurse specialist is kind and understanding)	10.00 (9.00 to 10.00)	3.2
My disease is controlled well	10.00 (9.00 to 10.00)	2.1
My psychological needs are addressed	10.00 (8.00 to 10.00)	2.3
My social needs are addressed	8.00 (7.00 to 10.00)	2.3
My treatment is monitored to evaluate its effectiveness	10.00 (9.00 to 10.00)	2.2
I am asked about the side-effects of medication	9.50 (8.00 to 10.00)	2.2
I am followed up to see the impact of arthritis on my life	10.00 (8.00 to 10.00)	2.2
The nurse coordinates my care with hospital doctors, GPs and other health professionals	10.00 (9.00 to 10.00)	2.3
The nurse refers me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs	10.00 (9.00 to 10.00)	2.3
The nurse signposts me to relevant agencies, charities or patient organisations	8.50 (7.00 to 10.00)	2.3
I am provided easy access to the rheumatology nurse specialists via a telephone advice line	10.00 (9.50 to 10.00)	3.3
The nurse checks that my questions are addressed in the consultation	10.00 (8.00 to 10.00)	4.2
My opinion about my care is considered important	10.00 (9.00 to 10.00)	4.1
Innovation and service improvement are part of my care	8.50 (7.00 to 10.00)	4.4

IQR, interquartile range.

5.6.4.2. Group differences in patient perceived importance of nurse-led care model (relevance of the model)

A Mann-Whitney test (*U*) and the associated p-value indicated that the patient perceived level of importance of the items of the model was high in both the group that attended face-to-face consultation and the group that attended telephone consultation, with no statistically significant differences. A summary of all themes with group Mdn scores (*IQR*) and group differences in patient perceived importance of the model of early RA nurse-led care is provided in Table 10.

Table 10: Perceived importance of the model of early RA nurse-led care between patients attending face-to-face consultations and telephone consultations

Item descriptor	Face-to-face Mdn score (IQR)	Telephone/ telephone combined with posted material Mdn score (IQR)	*U (p)*
It is important that….			
I receive specialist rheumatology care	10.00 (8.50 to 10.00)	10.00 (10.00 to 10.00)	77.50 (0.081)
Care is provided with compassion	10.00 (9.50 to 10.00)	10.00 (8.00 to 10.00)	94.00 (0.464)
Care is provided with person-centred approach (The care is tailored to my individual needs)	10.00 (9.50 to 10.00)	10.00 (10.00 to 10.00)	100.00 (0.628)
Care is provided with a holistic approach (I am treated as a whole person, not just as a disease)	10.00 (9.00 to 10.00)	10.00 (8.00 to 10.00)	101.50 (0.750)
Care is provided with an empathetic approach (The nurse specialist is kind and understanding)	10.00 (10.00 to 10.00)	10.00 (9.00 to 10.00)	87.50 (0.264)
My disease is controlled well	10.00 (7.50 to 10.00)	10.00 (10.00 to 10.00)	92.50 (0.399)
My psychological needs are addressed	8.00 (7.00 to 9.50)	10.00 (9.00 to 10.00)	69.00 (0.072)
My social needs are addressed	8.00 (7.00 to 9.00)	8.00 (7.00 to 10.00)	89.50 (0.424)
My treatment is monitored to evaluate its effectiveness	10.00 (8.50 to 10.00)	10.00 (10.00 to 10.00)	96.50 (0.531)
I am asked about the side-effects of medication	9.00 (9.00 to 10.00)	10.00 (8.00 to 10.00)	101.00 (0.746)

I am followed up to see the impact of arthritis on my life	10.00 (9.00 to 10.00)	10.00 (8.00 to 10.00)	90.00 (0.388)
The nurse coordinates my care with hospital doctors, GPs and other health professionals	10.00 (8.50 to 10.00)	10.00 (9.00 to 10.00)	91.50 (0.404)
The nurse refers me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs	10.00 (9.00 to 10.00)	10.00 (10.00 to 10.00)	86.00 (0.457)
The nurse signposts me to relevant agencies, charities or patient organisations	8.00 (7.00 to 9.50)	9.00 (7.00 to 10.00)	93.00 (0.781)
I am provided easy access to the rheumatology nurse specialists via a telephone advice line	10.00 (10.00 to 10.00)	10.00 (9.00 to 10.00)	100.00 (0.647)
The nurse checks that my questions are addressed in the consultation	10.00 (8.50 to 10.00)	10.00 (8.00 to 10.00)	92.00 (0.619)
My opinion about my care is considered important	10.00 (9.50 to 10.00)	10.00 (9.00 to 10.00)	99.00 (0.638)
Innovation and service improvement are part of my care	9.00 (7.50 to 10.00)	8.00 (6.00 to 9.00)	79.50 (0.213)

Mdn, Median*; U*, Mann-Whitney test; *p*, p-value, where p ≤ 0.05 suggests significant difference; *IQR*, Interquartile range

5.6.4.3. The patient experience of early RA nurse-led care

The results indicated that patient experience of care was mixed. The item with the highest level of agreement with the provisional model of early RA nurse-led care was 'I was provided easy access to the rheumatology nurse specialist via a telephone advice line'(*Mnd* = 9.00, *IQR* = 5.00 to 10.00). The item with the second highest level of agreement was 'I believe I have received specialist rheumatology care' (*Mdn* = 8.00; *IQR* = 6.00 to 9.00). The lowest scoring items were 'My psychological needs were addressed' (*Mdn* = 3.00; *IQR* = 1.00 to 5.00), 3AQ08 'My social needs were addressed' (*Mdn* = 3.00; *IQR* = 0.00 to 6.00), 'The nurse signposted me to relevant agencies, charities or patient organisations' (*Mdn* = 3.00; *IQR* = 0.00 to 7.00), and 'Innovation and service improvement are part of my care' (*Mdn* = 3.00, *IQR* = 1.00 to 6.00). Levels of agreement with the provisional model of early RA nurse-led care are summarised in Table 11.

Table 11. Levels of agreement with the provisional model of early RA nurse-led care

Item descriptor	**Median (*IQR*)**	**Themes**
I believe I have received specialist rheumatology care	8.00 (6.00 to 9.00)	1
Care was provided with compassion	7.00 (5.00 to 10.00)	3.1
Care was provided with person-centred approach (The care was tailored to my individua needs)	6.50 (3.00 to 9.00)	3.2
Care was provided with a holistic approach (I was treated as a whole person, not just as a disease)	5.00 (3.00 to 8.00)	3.2
Care was provided with an empathetic approach (The nurse specialist was kind and understanding)	7.00 (4.00 to 10.00)	3.2
My disease was controlled well	4.00 (2.00 to 7.00)	2.1
My psychological needs were addressed	3.00 (1.00 to 5.00)	2.3
My social needs were addressed	3.00 (0.00 to 6.00)	2.3
My treatment was monitored to evaluate its effectiveness	5.50 (3.00 to 8.00)	2.2
I was asked about the side-effects of medication	5.0 (2.00 to 9.00)	2.2
I was followed up to see the impact of arthritis on my life	4.00 (2.00 to 6.00)	2.2
The nurse coordinated my care with hospital doctors, GPs and other health professionals	6.00 (2.00 to 9.00)	2.3
The nurse referred me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs	5.00 (1.00 to 9.00)	2.3
The nurse signposted me to relevant agencies, charities or patient organisations	3.00 (0.00 to 7.00)	2.3
I was provided easy access to the rheumatology nurse specialist via a telephone advice line	9.00 (5.00 to 10.00)	3.3
The nurse checked that my questions had been addressed in the consultation	5.00 (3.00 to 8.00)	4.2
My opinion about my care was considered important	4.00 (1.00 to 8.00)	4.1
Innovation and service improvement were part of my care	3.00 (1.00 to 6.00)	4.4

IQR, interquartile range

5.6.4.4. Group differences in levels of agreement

A Mann-Whitney (*U*) test and the associated p-value showed that there were significant differences between the groups attending either face-to-face consultations or telephone consultations for several items. The biggest differences were observed for: ‘My disease was controlled well (*U* = 26.00, *p* = <0.001), ‘My psychological needs were addressed’ (*U* = 19.00, *p* = <0.001) and ‘My social needs were addressed’ (*U* = 13.50, *p* = <0.001).

The results showed that face-to-face consultations had higher scores for agreement with the model of early RA nurse-led care than telephone and telephone combined with posted material consultations. Results also showed that telephone consultations from the patient experience only accorded with the model of care (had high scores) regarding the items ‘I believe I have received specialist rheumatology care’ and ‘I was provided easy access to the rheumatology nurse specialist via a telephone advice line’. The rest of the items had lower scores than those attending a face-to-face consultation. The between group differences of agreement with the provisional model of early RA nurse-led care are presented in Table 12.

Table 12. Between group differences of agreement with the provisional model of early RA nurse-led care. Differences between face-to-face consultations and telephone consultations

Item descriptor	Face-to-face Mdn score (*IQR*)	Telephone/ telephone combined with posted material Mdn score (*IQR*)	*U (p)*
I believe I have received specialist rheumatology care	9.00 (8.00 to 10.00)	7.00 (5.00 to 9.00)	**59.00 (0.035)**
Care was provided with compassion	10.00 (8.50 to 10.00)	6.00 (4.00 to 7.00)	**37.50 (0.002)**
Care was provided with person-centred approach (The care was tailored to my individua needs)	9.00 (8.00 to 10.00)	4.00 (3.00 to 7.00)	**42.00 (0.005)**
Care was provided with a holistic approach (I was treated as a whole person, not just as a disease)	8.00 (6.50 to 10.00)	4.00 (1.00 to 5.00)	**31.00 (0.001)**
Care was provided with an empathetic approach (The nurse specialist was kind and understanding)	9.50 (8,50 to 10.00)	5.00 (3.00 to 7.00)	**47.50 (0.010)**
My disease was controlled well	7.50 (6.00 to 9.00)	3.00 (1.00 to 5.00)	**26.00 (<0.001)**

My psychological needs were addressed	7.00 (4.50 to 10.00)	2.00 (0.00 to 4.00)	**19.00 (<0.001)**
My social needs were addressed	6.00 (5.50 to 8.50)	1.00 (0.00 to 3.00)	**13.50 (<0.001)**
My treatment was monitored to evaluate its effectiveness	9.50 (4.00 to 10.00)	5.00 (3.00 to 6.00)	**40.50 (0.004)**
I was asked about the side-effects of medication	9.00 (5.50 to 10.00)	4.00 (2.00 to 6.00)	**40.00 (0.004)**
I was followed up to see the impact of arthritis on my life	7.50 (3.40 to 9.00)	3.00 (2.00 to 5.00)	**39.50 (0.003)**
The nurse coordinated my care with hospital doctors, GPs and other health professionals	7.50 (3.00 to 10.00)	5.00 (2.00 to 8.00)	74.00 (0.147)
The nurse referred me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs	7.00 (3.50 to 10.00)	3.00 (0.00 to 8.00)	42.50 (0.064)
The nurse signposted me to relevant agencies, charities or patient organisations	3.00 (0.50 to 8.50)	2.00 (0.00 to 8.00)	75.50 (0.285)
I was provided easy access to the rheumatology nurse specialist via a telephone advice line	8.50 (4.50 to 10.00)	9.00 (5.00 to 10.00)	102.00 (0.791)
The nurse checked that my questions had been addressed in the consultation	9.00 (2.50 to 10.00)	5.00 (3.00 to 6.00)	**55.50 (0.025)**
My opinion about my care was considered important	9.00 (3.00 to 10.00)	4.00 (1.00 to 6.00)	**48.00 (0.010)**
Innovation and service improvement were part of my care	5.50 (1.00 to 9.50)	2.00 (1.00 to 4.00)	**59.00 (0.038)**

Mdn, Median; U, Mann-Whitney test; *p*, p-value, where $p \leq 0.05$ suggests significant difference (also in bold); *IQR*, Interquartile range

5.6.5. Participant comments on early RA nurse-led care

The question for free text box comments, *'Your opinion. Please add any aspect of care that you feel is important to you and is missing from the above statements',* provided textual data from twelve participants. These textual data were short and informative, and provided insights into patient experiences, needs and preferences. A summary of participant comments and the process of coding and categorising into themes is provided in Appendix P.

5.6.5.1. Themes characterising patient comments on early RA nurse-led care

Content analysis of the textual data identified six themes characterising patient perspectives of early RA nurse-led care. These themes indicated that the patients needed general information about the clinics, how they worked and who to contact. They needed information about the medication and how to adjust to their disease for example regarding work and intimate relationship. Data also indicated that patients wanted the nurses to listen to them, and to be involved in the decision process regarding their treatment. The patients appreciated regular follow-up after changes to the medication and their circumstances with the disease, as well as continuity in contact to the nurse via telephone and in face-to-face consultations.

Need of information. This theme captured the emphasis on the need of information, and sometimes lack of information. Practical information about how the rheumatology clinic worked, who did what and who to contact (P1); information about the disease impact on work (P3, P4); access to benefits (P3); and disease impact on intimate life (P4) was lacking; and more information about tests (P8) and medication (P6) was wanted.

Being listened to. This theme captured the importance of listening to the patients, and patients' experiences of not being listened to regarding worries of side effects, new medication (P2, P10). The experience of everything being rushed was reported to make patients feel dismissed (P5), scared and alone (P7). Feeling able to speak up about what was going on in one's life was highlighted as important (P11).

Wanting to be involved. This theme captured the patient preference of being involved in care. An example given was to have discussions about day-to-day management of the disease, vitamins and holistic medication (P5). Another example given was to understand how the medication worked and pros and cons in order to be part of the decision process (P6) and being able to speak up about what was going on in one's life (P11).

Appreciation of timely follow-up and face-to-face consultations. This theme captured the experienced need for regular follow up at changes of medication or issues raised by the patients (P4). It also captured the appreciation for face-to-face consultations with the nurse and physio (P5) as well as experiencing long waiting times at the clinic before consultations. A participant (P9) thus reported to have left the clinic without seeing the nurse as she could not wait any longer. The participant had only managed to see the nurse once (P9).

Access to a supportive telephone service. This theme captured the mixed experiences reported regarding access to the nurse via telephone or email. Telephone contact was experienced as difficult as different people could respond to the calls, and a participant reported to have felt dismissed (P9). It was also reported that telephone and email contact could be available, but responses would be generic. This was reported to make the participant feel like a burden and not listened to (P7).

Continuity in care and contacts. This theme captured the importance of continuity in care. Seeing and talking to the same people and not having to keep explaining issues were reported to be important (P12). Appreciation of face-to-face contact to the nurse and the physio (P05), and of care in general (P10) were reported, although a participant's worries about medication had not been acknowledged or understood by her nurse (P10). Themes and illustrative quotations are presented in Appendix Q.

5.7. Discussion

This study aimed to determine the extent to which patients' care needs are met in early RA nurse-led care and the extent to which patients confirm the provisional model of early RA nurse-led care that was developed from interviews with rheumatology nurse specialists. The findings need to be interpreted with care as the sample size was smaller than in previous studies using the LSQ (Ndosi *et al.*, 2014; Koksvik *et al.*, 2013; Hill, Thorpe and Bird, 2003; Hill, 1997). Small sample sizes may not have enough power to detect differences in subgroups of patients (type 1 error), therefore in this study, lack of difference between subgroups may not be conclusive. The main findings suggested that in this sample, patient care needs generally were met as exemplified by their satisfaction with care scores. Patients confirmed the provisional model of early RA nurse-led care by endorsing each item as of high importance in their care. However, the data from the patients' experience of care assessed against the model were somewhat equivocal. These observations are discussed below.

5.7.1. Meeting patients' care needs in early RA

Based on the total satisfaction scores, early RA nurse-led care in general met the needs of the patients in this survey. Two specific satisfaction domains: General satisfaction and Empathy with the patient suggested dissatisfaction. This could indicate that patients' needs relating to these two domains were not met for patients participating in the study. As holistic, person-centred and empathetic approaches have been shown to characterise nurse-led care in early RA (van Eijk-Hustings *et al.*, 2013; Bala *et al.*, 2012; Larsson *et al.*, 2012), this could be a concern.

In focus group research conducted in the UK (Ryan *et al.*, 2013), patients with RA compared their pain to the pain of cancer patients' and regretted that the service level was not the same for RA patients experiencing pain. Other research has identified issues such as fatigue (Primdahl *et al.*, 2019; Hewlett, Choy and Kirwan, 2012), psychological needs (Dures *et al.*, 2014; Ryan, 2014), sex and gender issues (Flurey, 2022; Feddersen *et al.*, 2018; Flurey *et al.*, 2018), as well as influences of ethnicity on early RA outcomes (Adas *et al.*, 2022). All these issues will need more exploration and consideration for inclusion in a model of early RA nurse-led care to meet patients care needs.

However, looking into group differences, patients who attended face-to-face consultations, consistently affirmed satisfaction with care across all domains, while those attending telephone consultation/telephone combined with posted material did not have consistent satisfaction scores, mainly in the area of empathy – this group showed satisfaction in giving of information, technical quality and competence, and attitude towards the patient. The results suggest that face-to-face consultations might cater better to patients' care needs in early RA than telephone/telephone combined with posted material consultations, especially for these domains.

However, other factors may have impacted the results which were not captured in this research. The sample for this survey was small, limited to one gender, and possibly limited regarding ethnicity, therefore, the results can only suggest areas of interest for further research in this population. Furthermore, this survey was conducted during the hight of the COVID-19 pandemic with rapid changes of the service, therefore results cannot be conclusive. A survey with more participants and conducted at another time could have different findings. In this survey, the researcher happened to get responses from patients who had been seen face to face and had good care versus those using the telephone who received poor care. It is thus important to be cautious about over interpreting these data and it is important to state that the researcher cannot draw conclusions about the quality of care and the mode of care delivery for all these reasons.

5.7.2. Patient perceived importance of the model of early RA nurse-led care

The patients who completed this survey agreed that the items representing the model of early RA nurse-led care were important for their care by giving them high scores (seven or above). The patient perceived importance of the provisional model of care was thus high for all items assessed by the patients. Both groups of patients attending the face-to-face and telephone consultations/telephone combined with posted material considered the items as highly important with no group differences. The high scores given to items concerning compassion in delivery of care, and the use of person-centred, holistic and empathetic approaches suggested that these items were important to patients in this sample. The current EULAR recommendations for the role of the nurse (Bech *et al.*, 2020) advocate that nurses should engage in shared decision making, address psychosocial issues and provide need-based patient support, but do not mention compassion, person-centred, holistic and empathetic approaches. The current Competency framework for Rheumatology Nurses (RCN, 2020) briefly mentions the provision of person-centred care and support. However, the framework does not go into detail about how to follow a person-centre approach and does not mention compassion and empathy (RCN, 2020).

For the items that were developed from the model-of early RA nurse-led care, the participants agreed that they were important for their care. This gives credit to the findings of the interview study with the nurse specialists and suggests that the model is relevant to patients with early RA as presented to them in the survey. However, according to textual data, participants provided information about needs that had been missed in early RA nurse-led care such as *Need of information, Being listened to, Wanting to be involved Appreciation of timely follow-up and face-to-face consultations Access to a supportive telephone service* and *Continuity in care and contacts.* These aspects of care had been reported in data from the interview study (Chapter four) but had not been specified in the developed questionnaire. A further developed and detailed questionnaire with input from more patients in early RA is thus needed to provide robust results to develop a model of early RA nurse-led care.

5.7.3. Patient experiences of care measured against the early RA care model

The patient experiences of care in this survey did not consistently accord with the model of early RA nurse-led care as presented in the survey, and there were mixed results with high and low scores. High scores were seen in the items ‘I believe that I received specialist care’, ‘Care was provided with compassion’, and ‘I was provided easy access to the rheumatology nurse specialist via a telephone advice line’. The rest of the assessed items had low scores, especially for addressing psychological and social needs.

Similar results were found in a study by Sloan *et al.* (2021), where the authors examined telemedicine in rheumatology in a mixed methods study exploring acceptability, preferences and experiences among patients and clinicians. Patients and clinicians rated telemedicine as worse than face-to-face consultations in almost all categories. Building trusting medical relationships and assessment accuracy were great concerns. and Telemedicine was perceived to have increased misdiagnoses, inequalities and barriers to accessing care. Participants reported highly disparate telemedicine delivery and responsiveness from primary and secondary care (Sloan *et al.*, 2021). It was noted that the results could be impacted by the COVID-19 pandemic with a stretched service (Sloan *et al.*, 2021), which was also possible in this study. These findings are thus in contrast to other studies of rheumatology nurse-led care, where patient have had very positive experiences (Bala *et al.*, 2012, 2017; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011).

The results could seem disappointing for early RA nurse-led care, and the model of care derived from interviews with nurse specialists. However, analysis of group differences between patients who attended face-to-face consultations and those who attended by telephone/telephone combined with posted material offered more nuanced results. It revealed that patients who had attended face-to-face consultations had high level of agreement with the model of care compared to the group attending consultations delivered as telephone/telephone combined with posted material.

5.7.4. Face-to-face consultations versus telephone consultations.

In this sample, telephone consultations did not receive favourable scores compared to face-to-face consultations. While these findings need to be interpreted with care, it is possible that using telephone consultations only is not optimal in early RA management. It is known, that for interview purposes, telephone interviews can have some drawbacks compared to face-to-face interviews as the interviewer and the interviewee can only communicate verbally and the communication medium itself can influence the conversation (Block and Erskine, 2012). It is likely that these drawbacks would apply to telephone conversations between nurse specialists and patients as well. It is also known that telephone follow-up in RA is comparable with face-to-face consultations regarding disease control among patients with low disease activity or remission (de Thurah *et al.*, 2018). Furthermore, a systematic review on telemedicine for patients with rheumatic diseases found that telemedicine may provide a well-accepted way to remotely deliver consultations, treatment and monitoring disease activity in rheumatology (Piga *et al.*, 2017).

According to research from Denmark, patients in routine follow-up were found to have a positive perception of PRO-based telehealth follow-up and saw it as a flexible and resource-saving solution (Knudsen, de Thurah and Lomborg, 2018). However, patients in the Danish study had established RA, the consultations were planned routine follow-ups, and it was reported that some patients had missed face-to-face contact with health professionals (Knudsen, de Thurah and Lomborg, 2018).

A survey from the UK (Raizada *et al.*, 2021) aimed to investigate the perspectives of rheumatology patients on the use of telephone consultations compared with the traditional face-to-face consultation. It was found that most interviewed patients were happy with their routine face-to-face appointments being switched to telephone consultations due to the COVID-19 pandemic. However, patients over 50 years old were less likely than their younger counterparts to want telephone consultations in place of face-to-face appointments, although most patients in the study would prefer a telephone consultation for urgent advice (Raizada *et al.*, 2021). The consultations in the study from the UK (Raizada *et al.*, 2021) were also routine follow-ups with established patients.

Findings from the two studies (Raizada *et al.*, 2021; Knudsen, de Thurah and Lomborg, 2018) suggest that the use of face-to-face consultations and telephone consultations should be carefully considered depending on patient needs and preferences.

In early RA, patients experience major changes in their lives with fright, pain, new medication and side effects, and have complex care needs (Ryan *et al.*, 2022; Pedraz-Marcos *et al.*, 2020; van der Elst *et al.*, 2016; Kristiansen *et al.*, 2012; Ryan, 2014), with pain, and the psychosocial dimension being particularly big issues (Elst *et al.*, 2020b; van der Elst *et al.*, 2016; Ryan, 2014; Ryan *et al.*, 2013). Findings of this thesis (Chapter two and Chapter four) suggested that the development of a special relationship and trust between the nurse and the patient were essential in early disease, and the basis for treatment, and of a collaboration to meet patient needs.

The importance of the relationship between nurse and patient was supported by qualitative research from Denmark (Primdahl, Wagner and Hørslev-Petersen, 2011) and Sweden (Bala *et al.*, 2012; Larsson *et al.*, 2012), which found that the relationship helped patients to feel confidence and security and helped them manage the disease. This type of relationship may be challenging to develop using only telephone consultations with limitations on non-verbal communication and observation, and no access to touch and physical examination (Sloan *et al.*, 2021). Results from studies with patients in established RA using telephone follow-up consultations (Raizada *et al.*, 2021; Knudsen, de Thurah and Lomborg, 2018) may therefore not apply at the early stages of disease where patients are newly diagnosed, start intensive treatment and may need extensive support to adjust to the disease.

Evidence from studies one, two and three indicated that patients in early RA have complex care needs which may be different from established RA, where patients have become more familiar with the disease, which is consistent with research by van der Elst et al (2016). This means, that care needs in early RA must be taken into account and adopted into future guidelines for early RA nurse-led care. It also means that these care needs must be taken into account and adopted into guidelines for tele-medicine to ensure that patients’ care needs are met in early RA.

This study also suggested that the model of care derived from interviews with nurse specialists (Chapter three and Chapter four) was perceived as important for participating patients, with emphasis on statements representing specialist care, delivered with compassion using person-centred, holistic and empathetic approaches. Guidelines for management of early RA, be it for face-to-face consultations, telephone consultations or a combination, should thus reflect these findings to meet patients care needs in early RA.

5.7.5. Further development of the model of early RA nurse-led care

Themes developed from textual data highlighted the participating patients' need of general information, information about medication and tests, benefits, impact of the disease on work and intimate life, being listened to, being involved in decisions, having regular follow-up at changes (medication and circumstance), as well as continuity in contact to the nurse via timely telephone and in face-to-face consultations. A model of early RA nurse-led care will need to include and further develop these aspects of care.

Research has been conducted to understand which treatment expectations patients have in early RA (van der Elst *et al.*, 2016), and to understand how patients experience rheumatology nurse-led care (Bala *et al.*, 2017; Larsson *et al.*, 2012; Primdahl, Wagner and Hørslev-Petersen, 2011). However, this study specifically addressed the patient perspective of early RA nurse-led care and of a provisional model of early RA nurse-led care, with the aim to develop a model of early RA nurse-led care that has the potential to meet patients holistic and complex care needs. It is thus important that the model is being developed with patients in early RA to ensure that their needs are being met. This study provided insights into patient experiences, needs and views of early RA nurse-led care, that can inform further research and development of a model of early RA nurse-led care.

The model of early RA nurse-led care could be tested in a pilot study before being tested in the wider population (de Vet *et al.*, 2011). However, according to Fawcett (2013), four steps are required before a conceptual model such as this model of care can be tested. Firstly, the conceptual model must be formulated, which is what this thesis aimed to do. Secondly, a middle-range theory must be derived from the conceptual model. Thirdly, empirical indicators must be identified, and fourthly, empirically testable hypotheses must be specified (Fawcett, 2013). As warned by Fawcett (2013), failure to distinguish between a conceptual model and a theory leads to misunderstanding and inappropriate expectations about the work (Fawcett, 2013). It is thus acknowledged, that the provisional model of care is the beginning of the development of a model of care in early RA. Improvement of the conceptual model and testing of the model will thus need further research.

5.7.6. Strengths of this study

This research had some strengths. The patient satisfaction tool, the LSQ, was developed for rheumatology nurse-led care (Hill, 1997) and thus ideal for this study and for this purpose. The fact that the tool was validated, meant that it had been tested and found to be reliable, stable and responsive to change in nurse-led care effectiveness studies. That the tool was developed to assess rheumatology nurse-led care meant that the researcher could be confident that the tool could measure nurse-led care in rheumatology and that it was sensitive to aspects of care as defined in the five dimensions of care in the tool.

Using the LSQ tool provided insight into the patient experience of early RA nurse-led care within the dimensions: General satisfaction, Giving of information, Technical quality and competence, Attitude towards the patient, Access and continuity, and overall satisfaction with care. The results can help answering how patients' needs are met in early RA nurse-led care and can inform further development of a model of early RA nurse-led care.

Although only 30 participant responses were included in the analysis, this survey provided results that could give an indication of the patient perspective of early RA nurse-led care, what was important for participating patients in their care as well as how their care needs were met. Participating patients' assessment of the provisional model of early RA nurse-led care as presented to them in the survey suggested that it was relevant and important for their care. Although only few patients participated in the survey, the results were important as they endorsed the model and gave credit to the findings of the interview study. Participating patients' free text comments generated important themes of needs and views about early RA nurse-led care. The survey results can inform the further development of a model of early RA care.

5.7.7. Limitations

The present survey had several limitations. The evaluable sample size was only 30 participants. The limited number of participants meant that the findings were not generalisable to the whole population of patients with early RA, and care was needed in interpreting the results. However, the aim was to assess if participating patients would confirm the provisional model of early RA nurse-led care. The findings suggested that this was the case, and it provided more items to include in a future model. Therefore, while not claiming generalisability, the overall aim of the study was achieved. More research is needed to further develop the model of early RA care.

All participants were women, which means that views of men were not included. The recruitment strategy accessed participants via patient organisations, which may have reflected that participants had membership of these organisations, and were interested in or had energy to engage in research about early RA. This means that the study may have a degree of selection bias. Patients who did not have access to the patient organisations or did not see the advertised survey on social media may not have participated in this study. Their perspectives may have provided important assessments and insights.

Demographic questions about co-morbidities, educational background, professional background, family status, ethnic background, geographical data, access to the internet and IT-literacy were not asked, all of which may have given interesting context to the responses. As a result of this, confounding bias cannot be excluded. However, there is always a risk for 'questionnaire burden' (Rolstad, Adler and Rydén, 2011) which researchers have to consider. In this study, the Qualtrics Expert Review score was 'fair', meaning that it was close to being too ‘long’, and risk non-completion. It is acknowledged that not knowing key data such as educational and ethnic background could limit the relevance of data. Many of these demographic data are important for the development of final model of early RA nurse-led care and will need to be explored in later research.

The survey was self-reported which also brought some limitations. This survey addressed early RA and people who attend consultations with rheumatology nurse specialists for early RA management. Questions about diagnosis, disease duration and attendance at consultations with nurse specialists were self-reported and could not be checked. However, steps were taken to try to address this by asking questions about which medication the patients took for their arthritis. If they chose response options with medications specific to RA, this increased the chance that they had a diagnosis of RA.

Textual data for patient comments on early RA nurse-led care in the free text boxes were limited as only twelve participants responded and provided short text responses. However, the data provided important insights into the patient experience of early RA nurse-led care, and their thoughts on what was lacking and what would have been helpful for them in their situation. Themes identified using content analysis thus assisted the interpretations of the results and could inform the future model.

5.8. Conclusion

Results of this cross-sectional survey study indicated that care needs of participating patients were met in some assessed aspects of care, but not in all. Results suggested that participants endorsed the provisional model of early RA care and provided information about patient needs to inform the development of a model of early RA care. This study had few participants, and research is needed with more participants in early RA to get robust results that can inform the further development of the model.

Chapter 6: Development of an optimised model of early nurse-led care in early rheumatoid arthritis

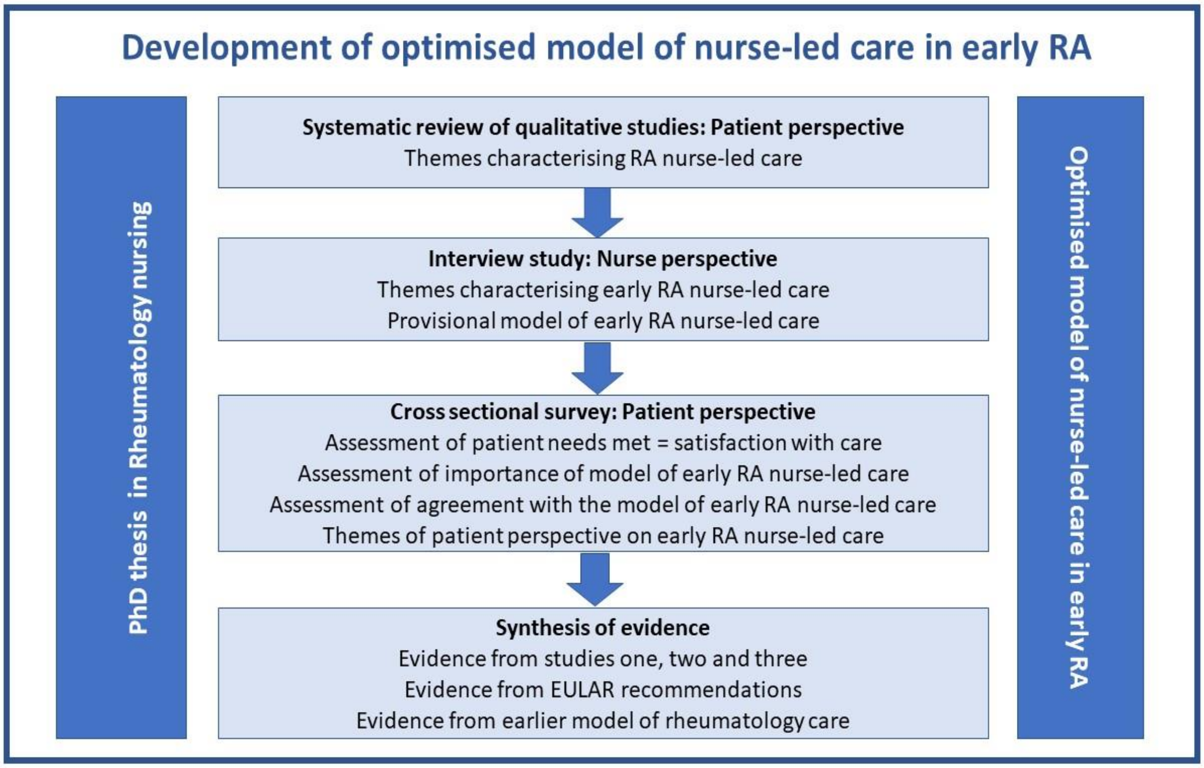
6.1. Introduction

This chapter aims to develop an optimised model of early RA nurse-led care by synthesising the evidence from three studies in this PhD and existing models and recommendations for rheumatology nursing and early arthritis.

Terms such as theories, models and frameworks are used in connection with the conceptual context for research; there is some overlap between them, and they are used differently by different writers (Fawcett, 2013; Polit and Beck, 2008). According to Polit and Beck (2008), much of the conceptual work that has been done in connection with nursing practice falls in the category of conceptual models (Polit and Beck, 2008). These models represent conceptualisations of the nursing process and the nature of nurse-client relationships (Polit and Beck, 2008). According to Fawcett (2013), a conceptual model is an abstract and general frame of reference addressing all four concepts of the metaparadigm of nursing: human, environment, health and nursing (Fawcett, 2013; Smith, 2001). However, the various conceptual models define these concepts differently, link them in diverse ways, give different emphases to relationships among them, and emphasise different processes as being central to nursing (Polit and Beck, 2008). For this research, conceptual model and conceptual framework are used interchangeably (Fawcett, 2013; Polit and Beck, 2008). A conceptual model (or conceptual framework) is seen as broadly presenting an understanding of the phenomenon of interest and reflecting the assumptions and philosophic views of the model's designer (Polit and Beck, 2008).

This chapter develops the optimised model of nurse-led care in early RA by synthesising available evidence from studies one, two and three with current EULAR recommendations for the role of the nurse in inflammatory arthritis (Bech *et al.*, 2020); EULAR recommendations for managing early arthritis (Combe *et al.*, 2017); and findings from the Pandora project documenting the complex clinical dimensions of rheumatology nurse specialist work (Oliver and Leary, 2010, 2012). The chapter will conclude with a proposal of an optimised model of early RA nurse-led care which can be tested in future studies. An overview of the development of the optimised model of early RA nurse-led care is provided in Figure 5.

Figure 5. Development of optimised model of nurse-led care in early RA



6.2. EULAR recommendations for the role of the nurse in inflammatory arthritis

The EULAR recommendations for the role of the nurse in inflammatory arthritis (Bech *et al.*, 2020) were first developed in 2011 (Eijk-Hustings *et al.*, 2012) and updated in 2018 (Bech *et al.*, 2020). They were developed to provide evidence as a basis for optimising rheumatology nursing across Europe and can therefore be seen as a good standard for rheumatology nursing. The updated recommendations comprise of eight statements (Table 13).

Table 13. EULAR recommendations for the role of the nurse in inflammatory arthritis

1. Patients should have access to a nurse for needs-based education to improve knowledge of CIA and its management throughout the course of their disease
2. Patients should have access to nurse consultations in order to enhance satisfaction with care
3. Patients should have the opportunity of timely access to a nurse for needs-based support; this includes tele-health
4. Nurses should participate in comprehensive disease management to control disease activity, reduce symptoms and improve patient-preferred outcomes; this leads to cost-effective care
5. Nurses should address psychosocial issues to reduce patients' symptoms of anxiety and depression
6. Nurses should support self-management skills to increase patients' self-efficacy
7. Nurses should have access to and undertake continuous education in the specialty of rheumatology to improve and maintain knowledge and skills
8. Nurses should be encouraged to undertake extended roles after specialised training and according to national regulations

Recommendations 1 to 6 directly map to the evidence obtained from studies one to three on early RA nurse-led care. However, while the six recommendations align well with the evidence from this thesis, they do not explicitly mention early arthritis care, although this is implied in recommendation 1, where it states: 'throughout the course of their disease'(Bech *et al.*, 2020).

EULAR recommendation 1 is about patients having access to the nurse for needs-based education. Recommendation 1 does not specify education and information in *early* disease, although it recommends *needs-based education to improve knowledge of CIA and its management throughout the course of their disease* (Bech et al., 2020). The recommendation only mentions *education*, but it is assumed that *information* is part of education.

The provision of patient education was identified in findings of study one in the subtheme *Information and education* (Chapter two). Evidence from patient quotations illustrated that nurse-led care involved professionalism, which provided a sense of security, and the patient felt that the nurses knew what they were doing. Evidence for the importance of education and information was illustrated by quotations from patients in early RA, such as a patient who highly valued the experience of being informed by the nurse at a time when everything was new. There was also evidence illustrating how a patient in early RA was taught to self-inject and managed despite initial doubts.

Education was also identified as important in study two (Chapter three and Chapter four), in the subtheme *Early disease management with treatment, education and support.* There was evidence that patient education was an essential part of the nurse specialist's role and that this was provided from the first meeting with patients to explain the importance of starting treatment and monitoring blood and side effects. Interview data suggested nurse specialists introduce patients to DMARD treatment at the first consultation with the nurse after diagnosis. Further, nurse specialists reported providing timely and balanced information about the disease and its treatment. Thus, the amount and timing of information were considered important: enough early information for safety but not so much that the patients felt overwhelmed. Nurse participants reported aiming to get patients started in treatment and keeping them in treatment. Once patients knew more about the disease, education would include conversations about lifestyle and co-morbidities.

The importance of education in early RA was supported by data from the survey with patients in early RA (Study 3, Chapter five). Evidence from patient comments generated the theme *Need of information,* with the examples: practical information about how the clinic works, who does what and whom to contact, access to benefits, disease impact on work and intimate life, tests and medication.

Evidence from studies one, two and three aligned with the recommendation, emphasising the importance of education in early RA. Furthermore, the findings of study two emphasised the importance of timely and balanced education and information, and the findings of study three provided topics important to patients.

EULAR recommendation 2 states that patients should have access to nurse consultations to enhance satisfaction with care. According to the evidence provided in the recommendation, patient satisfaction can be an indicator of the quality of care, and there is strong evidence to support a significant positive long-term effect (2 years) of nurse consultations on patient satisfaction (Bech *et al.*, 2020). Aspects of care such as enabling a positive experience of the continuing relationship between patient and the nurse, promoting a sense of confidence, familiarity, security and participation are highlighted in this recommendation. Taking a holistic and professional approach to care is important as confidence in nurse competence, and supportive, less fact-based interaction styles may be related to patients' satisfaction.

Study one (Chapter two) had evidence that emphasised patients' appreciation of having access to a rheumatology nurse. Data suggested nurses were accessible via telephone advice lines, which provided a sense of well-being and security as well as quick solutions and timesaving. Evidence from patient quotations showed that the nurses' warmth and kindness made the patient feel welcome and that the nurse cared.

Study two (Chapter three and Chapter four) reported that needs-based access to nurse specialists was highly important in early RA, either in face-to-face or telephone consultations and via the telephone advice line run by the nurse-specialists. Evidence showed that nurse specialists prioritised access for patients in early RA, as it was seen as essential to address their queries or worries as soon as possible to avoid unnecessary suffering, risk of side effects and risk of discontinuation of treatment. Study two also suggests that rheumatology nurse specialists routinely check quality of care by asking patients if their questions have been answered in the consultation, checking that patients responded to the treatment, and adapted to the disease. Data suggested that patients generally were satisfied with the service provided by nurse specialists. However, the patient views could not be verified in study two, as only nurses were interviewed.

Study three (Chapter five) had evidence about easy access to the rheumatology nurse specialists via a telephone advice line and that the nurse specialists checked that the patient had received answers to their questions. Evidence suggested that participating patients had access to the nurse specialists, but that the service in some cases had not been optimal. Furthermore, evidence from (twelve) patient comments suggested that there was a need for information for who to contact and access to a supportive telephone helpline and consultations when needed. The same study (Chapter five) also provided evidence on satisfaction with rheumatology nurse-led care. Domains of care such as 'Access and continuity' received high scores of patient satisfaction, but 'Empathy with the patient' and 'General satisfaction' did not get high scores in the surveyed group of patients. There was some evidence that face-to-face consultations with the nurse specialist had higher patient satisfaction than telephone-consultations, including telephone consultations supported by posted material.

Findings of studies one, two and three aligned with this recommendation and strongly supported the importance of access to a rheumatology nurse in early RA for patient satisfaction. Study three had evidence suggesting that face-to-face consultations may cater better to patients' needs than telephone consultations only regarding general patient satisfaction and empathy.

EULAR recommendation 3 states that patients should have the opportunity for timely access to a nurse for needs-based support, which includes tele-health. The unpredictable, fluctuating nature of the disease and expanded treatment options with increasing complexity of therapeutic strategies, such as treat-to-target, require rapid and timely access to care (Bech *et al.*, 2020). Nurses thus have an important role in the treat-to-target principles. It is noted that the accessibility to care traditionally ensured by telephone helplines, provides a valuable clinical service as an adjunct to face-to-face consultations.

Evidence from studies one, two and three strongly supported the importance of having timely access to the nurse for needs-based support, including access to telephone advice lines. Being able to call the nurse for advice and support when needed was highly valued.

Study two (Chapters three and four) had strong evidence for the importance of timely support in early RA, and especially for psychosocial support. It was found that patients could need much support in early disease. The study also provided evidence, that access to the nurse for support could help patients start and stay in treatment as they could ask questions, get confidence, report side effects and get quick adjustment of treatment. Additionally, study two had evidence about the rapid change of the service with implementation of extensive use of telephone and virtual solutions in rheumatology care. There was evidence that IT access and IT literacy were important factors to consider to meet individual patient needs. These aspects of care were not captured in recommendation 3.

Study three (Chapter five) provided evidence that supported the importance of timely access to a nurse for needs-based support, including access to the nurse via a supportive telephone advice line. Evidence from patient comments further emphasised these aspects with themes such as *Appreciation of timely follow-up and face-to-face consultations,* and *Access to a supportive telephone service.*

Findings of all three studies of this thesis thus aligned with the recommendation and emphasised the importance of timely access to rheumatology nurse specialists for support, including access to supportive telephone advice lines.

<u>EULAR recommendation 4</u> states that nurses should participate in comprehensive disease management to control disease activity, reduce symptoms and improve patient-preferred outcomes, and that this leads to cost-effective care. As the

management of RA has become increasingly complex with new treatment possibilities and available evidence (Bech *et al.*, 2020), the involvement of rheumatology nurses as part of the multidisciplinary team is needed in the treat-to-target strategy for proactive disease management based on patient education, tight disease monitoring, and adjustment of the pharmacological treatment.

Evidence from study one (Chapter two) captured this aspect of care in RA and early RA with the subtheme *Professional knowledge and nurse expertise*, where a patient quotation illustrated nurse involvement in disease management such as assessment of disease activity by examining joints and checking up on blood tests.

However, study two (Chapters three and four) provided detailed evidence of nurse specialists' involvement in management of early RA from the start of the disease. The theme *Addressing patients' complex care needs* with subthemes: *Early disease management with treatment, education and support; Monitoring treatment, disease impact and patient outcomes; Coordinating care, referring and signposting,* and *Addressing psychosocial needs* captured these aspects of early RA nurse-led care. There was strong evidence not only for involvement in early RA management, but for nurse specialists being responsible for early RA management in the context of the multidisciplinary team. Evidence from participating nurse specialists illustrated the nurse specialists' responsibility for treatment and monitoring in collaboration with the clinicians, the nurses and the patients.

Findings from studies one and two aligned with this recommendation. However, findings of study two went further than the recommendation, as they showed that nurse specialists not only were involved in management of early RA but were responsible for early RA management in collaboration with the multidisciplinary team.

EULAR Recommendation 5 states that nurses should address psychosocial issues to reduce patients' symptoms of anxiety and depression.

Evidence from all three studies highly emphasised the importance of this recommendation. Study one had evidence from illustrative quotations which showed that patients highly valued the psychosocial support they received from the nurses. According to evidence patients experienced that they could talk with the nurses about all their problems when feeling low, and the nurses would listen and be a great support.

Study two (Chapter three and Chapter four) had strong evidence for the importance of the psychosocial aspect of care in early RA. The subtheme *Addressing psychosocial needs* had evidence of the psychosocial impact on the disease and its treatment and outcomes. According to evidence, patient concerns and worries could thus interfere with the patient's ability to take in information, start treatment and stay in treatment. Evidence suggested that nurse specialists acknowledged the challenges the patients faced in early RA, knew how stress could impact the disease and the way patients adapted, and wanted to help to the best of their ability. Essential aspects of early RA care were the establishment of a relationship with the patients right from the initial meeting between nurse and patient. This relationship helped secure patient trust in advice about treatment, and that the nurse would listen and take patient concerns seriously. Evidence showed that nurse specialists encouraged patients to call if they experienced anything unusual to secure a safe and effective treatment. There was thus strong evidence that nurse specialists reassured patients they had the support of the nurse from the start and throughout the course of the disease. Findings highlighted the need for psychological support for patients in early RA and indicated that nurse specialists generally provided the psychological support. Findings also highlighted that access to psychology supervision for nurses who provided psychological support, and access to expert psychology referral were warranted and had the potential to enhance early RA care.

Data from study two suggested that nurses provide social support such as helping with work and benefit issues, providing information and in some cases help filling in forms for work benefit, which could be challenging for patients in early disease. However, there was limited evidence that nurses addressed issues relating intimate relationship in early RA, as the topic was experienced as awkward, and it was mainly addressed by handing out written information.

Study three (Chapter five) indicated that psychological support was important as participants in the study endorsed this item. Evidence from patient comments with themes such as *being listened to* and *Access to a supportive telephone service* captured some of the psychological support aspect in early RA nurse-led care.

Findings of studies one, two and three aligned with this recommendation and endorsed the importance of psychological support in early RA as discussed above.

EULAR recommendation 6 states that nurses should support self-management skills to increase patients' self-efficacy. Self-efficacy is linked to the patient's self-management skills, and self-management support offers patients the opportunity to gain the necessary knowledge, skills and confidence to deal with physical and psychosocial consequences of living with a chronic condition (Bech *et al.*, 2020). Supporting the patients' self-management is a collaborative activity that expands the role of the healthcare team from delivering information and traditional patient education to include activities that support self-management.

Study one had evidence which related to this recommendation captured in the subthemes *Empowerment and psychological support* and *Security and confidence*. Evidence suggested that these aspects of care were connected as meetings with the nurse specialists, and the education, information and support they provided helped patients to feel empowered and psychologically supported, which gave them a feeling of security and confidence. Evidence from a patient quotation in early RA supported this aspect of care, as it was stated that because of the education delivered by the nurse, the patient was now able to self-inject medication despite initial doubts.

Study two (Chapters three and four) suggested that most patient support was needed at the beginning of the disease, when everything was new for the patient, and that needs changed or were more limited later in the disease, as patients then knew more and had learned what to do, including at set-backs due to the fluctuations of the disease. This study thus indicated that nurse specialists helped patients to get control at a time that could seem out of control with pain and uncertainty by developing strategies for setbacks. Strategies could for example be rescue boxes with painkillers and whatever the patient felt had worked in the past, until they could contact the nurse on the telephone advice line (Chapter four). The contact to the nurse via the telephone advice line was repeatedly highlighted in the research as an essential part of the support system, so patients could feel confident that they could get help and advice from someone who knew them and their disease when needed it, for example if the patient experienced side effects of medication, or if the patient felt that the medication did not work.

The recommendation used the concept *self-efficacy* instead of the former *empowerment* (Eijk-Hustings *et al.*, 2012). However, the concepts are very close in meaning. Self-efficacy refers to an individual's beliefs in his or her capacity to execute behaviours necessary to produce specific performance attainments, and it reflects confidence in the ability to exert control over ones' own motivation, behaviour, and social environment (Carey, 2009; Bandura, 1977). The World Health Organisation (WHO) defines patient empowerment as a process where patients understand their role, are given the knowledge and skills by the health care provided to perform a task in an environment where there is an awareness of community and cultural differences, and where patients are encouraged to participate (Kärner Köhler *et al.*, 2018; WHO, 2009). According to WHO (Kärner Köhler *et al.*, 2018; WHO/Europe, 2013), patient empowerment is viewed as a key factor for improving health outcomes, enhancing communication between patients and health professionals, bringing about better adherence to treatment regimes, and ensuring the efficient use of primary resources.

Empowerment was identified as an aspect of care in RA and early RA in study one (Chapter two), and although not explicitly highlighted as a theme in study two (Chapter three and Chapter four), it was included in the subtheme *Early disease management with treatment education and support s*uch as when patients were provided education and supported in developing strategies for management of the disease. Study three had evidence from patient comments that emphasised patients' preferences of being involved and understanding their own care, which was part of the definition of empowerment.

Bala *et al.* developed a conceptual framework of outpatient person-centred care in nurse-led rheumatology clinics, focusing on the person-nurse meeting (Bala *et al.*, 2018a, 2018b). The framework had holistic nursing and partnership as overarching principles and five dimensions of care: social environment, communication, personalisation, shared decision-making, and empowerment, which were consistent with findings from this thesis in early RA.

The concept of *empowerment* was consequently included in the model of early RA nurse-led care, as it was supported by Bala *et al.* (2018b, 2018a), and was seen as having emphasis on the working relationship and togetherness between nurse specialists and patients. Also *self-efficacy* was included as it was supported by the current EULAR recommendations (Bech *et al.*, 2020), and seen by this researcher as having emphasis on the patients' own agency in early RA.

Findings from studies one, two and three aligned with this recommendation, supporting self-management skills to increase patients' self-efficacy. Study one identified *empowerment* as theme in nurse-led care, which was echoed in study three with themes such as need of being informed and being involved in decision making. Findings of study two emphasised the importance of giving the patient control, providing strategies for setbacks, and of the togetherness between nurse specialists and patients in early RA care. The focus in early RA care was thus that patients should not feel alone but timely supported from start and throughout the course of the disease to help them manage and adapt.

The two last recommendations (EULAR recommendations 7 and 8) are about nurse specialists' access to education and undertaking extended roles in rheumatology, and thus not directly linked to early RA nurse-led care, but to what it takes for nurse specialists to provide the care, such as education and specialised training. Study two had extensive evidence on this dimension of care.

6.2.1. Summary

Studies one, two and three had strong evidence for the importance of education and information in early RA (EULAR recommendation 1), and that it was an important aspect of care in early RA nurse-led care. Findings emphasised that education in early RA should be timely and balanced according to patient needs such as safety in treatment and ability to take in information. Identified topics were disease, treatment, tests, access to benefits, impact of the disease on work and intimate relationship, which were not clearly captured in recommendation 1.

Evidence from all three studies supported the importance of patient access to rheumatology nurse-led care in early RA to enhance the patient experience in alignment with recommendation 2. However, evidence from studies two and three went further than the recommendation as it highlighted the importance of approaches in early RA, such as compassion and the combination of person-centred, holistic and empathetic approaches. These aspects of early RA care were not fully captured in recommendation 2.

Evidence from all studies also supported the importance of timely access to a nurse for needs-based support, including telephone advice service according to recommendation 3. However, the importance of considering IT access and IT literacy when increasing the use of telehealth and digital solutions in care was not addressed in recommendation. Study two had evidence for nurse specialists not only participating in management of early RA (recommendation 4) but being responsible for treatment and planning of care in collaboration with the rheumatologist and the multidisciplinary team depending on experience and organisation of care, which was not captured in the recommendations.

All three studies aligned with the recommendation regarding access to a rheumatology nurse to address psychosocial issues to reduce patients' symptoms of anxiety and depression (recommendation 5). Finally, study one and two had evidence that patients should be supported in empowerment whereas recommendation 6 used the term self-efficacy which was a change from the earlier recommendation. Self-efficacy was included in the model of early RA nurse-led care. However, empowerment was also included to underline the collaboration and togetherness between nurse and patient as opposed to the weight on self in early RA agency.

6.3. EULAR recommendations for the management of early arthritis

The EULAR recommendations for treatment of RA were updated by ACR in 2015 (Singh *et al.*, 2016), and by EULAR in 2016 (Combe *et al.*, 2017; Smolen *et al.*, 2017) and in 2019 (Smolen *et al.*, 2020). They recommended the 'treat-to-target' strategy, with early detection and treatment target being remission (Smolen *et al.*, 2020; Combe *et al.*, 2017). This strategy was shown to have better clinical outcomes and better quality of life, and helped prevent further structural damage, functional disability and job loss (Smolen *et al.*, 2017; Combe *et al.*, 2015).

The updated EULAR recommendations specifically addressing management of early disease (Combe *et al.*, 2017) comprise of 12 statements (Table 14).

Table 14. 2016 Update of the EULAR recommendations for the management of early rheumatoid arthritis

Recommendation 1.	Patients presenting with arthritis (any joint swelling, associated with pain or stiffness) should be referred to, and seen by, a rheumatologist, within 6 weeks after the onset of symptoms
Recommendation 2.	Clinical examination is the method of choice for detecting arthritis, which may be confirmed by ultrasonography (US)
Recommendation 3.	If a definite diagnosis cannot be reached and the patient has early undifferentiated arthritis, risk factors for persistent and/or erosive disease, including number of swollen joints, acute-phase reactants, RF, ACPA and imaging findings, should be considered in management decisions
Recommendation 4.	Patients at risk of persistent arthritis should be started on DMARDs as early as possible (ideally within 3 months), even if they do not fulfil classification criteria for an inflammatory rheumatologic disease.
Recommendation 5.	Among the DMARDs, methotrexate (MTX) is considered the anchor drug and unless contraindicated, should be part of the first treatment strategy in patients at risk of persistent disease.
Recommendation 6.	Non-steroidal anti-inflammatory drugs (NSAIDs) are effective symptomatic therapies, but should be used at the minimum effective dose for the shortest time possible, after evaluation of gastrointestinal, renal and cardiovascular risks
Recommendation 7.	Systemic glucocorticoids (GC) reduce pain, swelling and structural progression, but in view of their cumulative side effects, they should be used at the lowest dose necessary as temporary (<6 months) adjunctive treatment. Intra-articular glucocorticoid injections should be considered for the relief of local symptoms of inflammation
Recommendation 8.	The main goal of DMARD treatment is to achieve clinical remission, and regular monitoring of disease activity, adverse events and comorbidities should guide decisions on choice and changes in treatment strategies to reach this target.
Recommendation 9.	Monitoring of disease activity should include tender and swollen joint counts, patient's and physician's global assessments, ESR and CRP, usually by applying a composite measure. Arthritis activity should be assessed at 1-month to 3-month intervals until the treatment target has been reached
Recommendation 10.	Non-pharmacological interventions, such as dynamic exercises and occupational therapy, should be considered as adjuncts to drug treatment in patients with early arthritis
Recommendation 11.	In patients with early arthritis, smoking cessation, dental care, weight control, assessment of vaccination status and management of comorbidities should be part of overall patient care
Recommendation 12	Patient information concerning the disease, its outcome (including comorbidities) and its treatment is important. Education programmes aimed at coping with pain, disability, maintenance of ability to work and social participation may be used as adjunct interventions.

According to recommendation 1 for management in early RA (Combe *et al.*, 2017), patients who are presenting with arthritis should be referred to and seen by a rheumatologist within six weeks after the onset of symptoms.

Evidence from studies one, two and three supported the premise of nurse-led care, which is addressing patients who have already been diagnosed by the rheumatologist and therefore in the overall MDT care, with nurses working in the context of MDT (Bech *et al.*, 2020).

Study two (Chapter three and Chapter four) had evidence that a nurse practitioner at a GP surgery was involved in checking patients for arthritis, booking necessary tests for diagnosis and referring to a specialist. It was sought to speed up the process to avoid any delay for the patient to be seen by the rheumatologist, diagnosed and start treatment as soon as possible, and that nurse specialists got involved with early RA management after diagnosis.

Recommendations 2 and 3 are about diagnosing the disease, with recommendation 2 stating that clinical examination is the method of choice to detect the disease, with recommendation 2 stating additional tests and examinations if a definite diagnosis cannot be reached.

Recommendations 4 to 9 are about medical treatment and monitoring disease activity until the target (remission or low disease activity) is reached.

Study two (Chapter tree and Chapter four) had evidence about the nurse specialists' considerable involvement in the medical treatment of patients in early RA. Evidence suggested high levels of autonomy in the nurse specialists' clinical practice in the context of the interdisciplinary team, which is not captured in these recommendations for medical treatment of early RA. According to evidence, nurse specialists engaged in assessing effect and side effects of medication, adjusted, changed and added medication according to treatment protocols and rheumatologist prescriptions. There was evidence that some nurse specialists were prescribers, an extended practice skill. This meant they could make treatment decisions, discuss with the rheumatologist and then initiate or change/escalate treatment.

Recommendation 8 states, that the main goal of DMARD treatment is to achieve clinical remission, and regular monitoring of disease activity, adverse events and comorbidities should guide decisions on choice and changes in treatment strategies to reach this target.

Study one (Chapter two) had evidence that nurse specialists and rheumatologists collaborated in delivery of care, and those nurses examined joints and checked laboratory tests. Study two (Chapter three and Chapter four) had strong evidence that nurse specialists were responsible for the early RA management, with monitoring of disease activity, adverse events and comorbidities. These aspects of care included conferring with the rheumatologist, adjusting pharmacological treatment or booking an appointment for review with the rheumatologist**.**

Recommendation 9 states that monitoring of disease activity should include tender and swollen joint counts, patient’s and physician’s global assessments, ESR and CRP, usually by applying a composite measure. Arthritis activity should be assessed at 1-month to 3-month intervals until the treatment target has been reached. Evidence from study two (Chapter three and Chapter four) showed that nurse specialists were highly engaged in addressing this recommendation. The theme *Addressing patients’ complex care needs* with subthemes *Early disease management with treatment, education and support,* and *Monitoring treatment, disease impact and patient outcomes* had detailed evidence of nurse specialists addressing this aspect of care. Evidence emphasised the use of pathways and protocols in clinical practice, with rigid planning and documentation of patient consultations where symptoms and treatment response were assessed according to guidelines.

Recommendation 10 is about considering non-pharmacological interventions, such as dynamic exercises and occupational therapy as adjuncts to medical treatment. Study one (Chapter two) had evidence that patients would like information about exercise and referral to physiotherapy which could help manage the disease and aid mobility. Study two (Chapter three and Chapter four) had strong evidence for the importance of non-pharmacological interventions. Evidence showed that the multidisciplinary team collaborated in assessing and addressing patient needs. Evidence emphasised the close collaboration between the nurse specialist and the physiotherapist, and between the nurse specialist and the occupational therapist. Furthermore, there was evidence that integrated RA pathways addressed non-pharmacological interventions by including referral to the MDT for assessment and relevant interventions.

Study three (Chapter five) indicated that patients found it highly important the nurse *coordinated care with hospital doctors, GPs and other health professionals*; that the nurse *referred to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to [patient] needs*, and that the nurse signposted to relevant agencies, charities or patient organisations.

Recommendation 11 is about smoking cessation, dental care, weight control, assessment of vaccination status and management of comorbidities as part of overall patient care. Evidence from study two (Chapter three and Chapter four) showed that nurse specialists included these aspects of care in their consultations with the patients. Some nurse specialists included smoking habits, vaccination status, weight, and co-morbidities in their care. There was also evidence, that the nurse specialists addressed lifestyle and co-morbidity. However, information in early disease was timely and balanced, which meant that issues that were not immediately important for start of treatment and safety would only briefly be mentioned, and addressed at later consultations or follow-up when patients could manage and take it in. No evidence was recorded regarding dental care and assessment.

Finally, recommendation 12 is about the importance of patient information concerning the disease, its outcome (including comorbidities) and its treatment. As RA involves intensive medical treatment with close monitoring to get disease control (Combe *et al.*, 2017), the treatment itself and the monitoring of treatment response are in focus. However, it is acknowledged in recommendation 12 (Combe *et al.*, 2017) that nurse interventions with education programmes can be used, and in recommendation 11, that patient care should also include assessment of co-morbidities, weight and smoking (Combe *et al.*, 2017). This recommendation connects directly with recommendation 1 in the EULAR recommendations for the role of the nurse in inflammatory arthritis (Bech *et al.*, 2020).

Evidence from study one (Chapter two) strongly supported the importance of education regarding disease, its outcome and its treatment. Evidence from patient quotations suggested that patients valuated the nurses' information in early disease.

Evidence from study two (Chapter three and Chapter four) showed that one of the nurse specialist's main roles is to educate patients from the start and throughout the course of the disease according to needs. Evidence from study two showed that good care in early RA was to make sure that patients were on the right treatment as early as possible, and making sure to give them the right information, and that they were monitored safely. However, evidence from study two indicated, that the nurse specialists' responsibilities went even beyond the recommendations as they were responsible for early RA management with different levels of autonomy, and in the context of the multidisciplinary team.

Study two had extensive evidence on issues relating to pharmacological treatment and alcohol, sexual issues, pregnancy, and family planning, which were reported to be sensitive and important areas of care. Regarding family planning, patients were advised to consider and discuss the matter with their partner before starting treatment, as the medication could be harmful to a foetus. This meant that alternative treatment strategy could be considered, or treatment could be started to get disease control as soon as possible, and a pregnancy therefore postponed. Stopping intake of alcohol because of the medication's toxicity on organs could also be challenging for patients. These aspects of care were not captured in the recommendation.

Study three (Chapter five) had evidence that highly supported this recommendation. Evidence from patient comments emphasised the need for information about the disease, medication, treatment, and disease impact on everyday life.

The EULAR recommendations for management of early rheumatoid arthritis (Combe *et al.*, 2017) do not mention nurses, psychological issues, patient satisfaction with care or support. They recommend non-pharmacological interventions in recommendation 10 (Combe *et al.*, 2017), and state that smoking cessation, dental care, weight control and management of comorbidities is part of care in recommendation 11. In recommendation 12 it is suggested that patient information concerning the disease, its outcome and its treatment in recommendation may be used, including programmes aimed at coping with pain, disability, maintenance of ability to work and social participation (Combe *et al.*, 2017).

6.3.1. Summary

Findings from studies one, two and three aligned with the recommendations 4 to 12 in regard to treat-to-target strategy, monitoring and assessment of treatment response, comorbidities, referral to MDT and provision of education. However, evidence from study two showed that nurse specialists were responsible for introducing and adjusting treatment with DMARDs which was not captured in the recommendations. Neither was the importance of addressing sensitive questions before starting pharmacological treatment due to the toxicity of the medication, such as alcohol, sex, pregnancy and family planning, and the importance of support from the nurse. The EULAR recommendations for management of early rheumatoid arthritis (Combe *et al.*, 2017) do not mention nurses, psychological issues, patient satisfaction with care or support, and nurse specialists' role as responsible for early RA management is not captured in the recommendation. Therefore, the findings of studies one, two and three are important, as they highlight the crucial role of the nurse and these aspects of care.

6.4. Clinical dimensions of rheumatology nurse specialist work. Pandora findings

The dimensions of rheumatology nursing as identified using the Pandora Database (Oliver and Leary, 2010, 2012), supported the multi-dimensional and complex aspects of rheumatology care which were identified in this thesis**.** The clinical dimensions of rheumatology nursing were: Physical, psychological, social, spiritual, and referral (Oliver and Leary, 2010, 2012). See Table 15.

Table 15. Clinical domains captured in the Pandora database

Clinical dimension of RNS work	Physical	Psychological	Social	Spiritual	Referral
Examples	Such as specialist symptom management or drug toxicity	Such as alleviating suffering or dealing with anxiety	Such as mediation with the workplace	Such as supporting spiritual choices	Pathway or case management

Within the clinical physical domain, activities required specialist knowledge and assessment skills to enhance self-management principles, manage unresolved symptoms, manage medication and perform rescue work in regard to medication (Oliver and Leary, 2012). The specialist nature of early RA nurse-led care was described as specialist knowledge and specialist monitoring skills (Oliver and Leary, 2012). Evidence from studies one, two and three supported the specialist nature of early RA nurse-led care, and it was seen as an important aspect of nurse specialists' clinical practice. Specialist knowledge and assessment skills were thus added to the synthesis of evidence.

Study one (Chapter two) found that the psychological support in RA and early RA was important from the patient perspective. Study two (Chapter four) showed that the psychological dimension was a major issue in early RA, and important for nurse specialists to address to meet patient needs. This evidence mirrored the Pandora findings (Oliver and Leary, 2012), where the Psychological-clinical dimensions of the nurse specialists' work were found to be dominated by the management of anxiety and distress (Oliver and Leary, 2012). As in study two (Chapter four), there was evidence in the Pandora findings, that much of the patient distress was caused by diagnosis, a sense of loss, a perceived future loss of function and biographical disruption experienced at the time of new diagnosis, as well as unknown in terms of effect and risks of the drugs being prescribed (Oliver and Leary, 2012). Participants in study two (Chapter four) reported that education was crucial to help patients understand the disease, the treatment and how to deal with side effects and symptoms. It was found that education played an essential role, as it helped patients understand, to get control and adapt. In the Pandora findings, education was part of the physical dimension, where clinical nurse specialists assessed patient needs for information and education, to help them stay safe in regard to medication (Oliver and Leary, 2010, 2012).

The evidence of studies one, two and three supported the dimensions captured in the identified dimensions of clinical nurse specialists' work, except for the spiritual dimension. Interestingly, this dimension was not identified in either study one (Chapter two) or study two (Chapter three and Chapter four). However, if spiritual is defined more broadly as including *hope* and *meaning of life* (Ross, 1995), this aspect of care was addressed in study two (Chapters three and four), as there was evidence that nurse specialists sought to give their patients hope and help them to understand that they would get help and be able to get back to a normal life, or the best that it could be. If spiritual is extended to also include *feeling safe and confident*, this dimension was identified in study one (Chapter two) when patients experienced that they had access to a nurse and could get the help and support they needed. The spiritual dimension may also be associated with compassion, together with empathy, and a kind and understanding attitude (Brown, 2016; Strauss *et al.*, 2016), where the nurse specialists' outlook and personal style add a spiritual dimension into their work, which helps establish a special relationship with patients.

It was found in all three studies, that the patients appreciated when they felt seen, heard, and understood. It was also shown that nurses, especially at the early stages of disease, supported the patients by guiding them, encouraging and assuring them that they were not alone. These aspects of care were important and could be linked to dimensions of care at a higher level, more closely related to personal beliefs than to just every-day clinical work. It may be that the relationship between patient and nurse resonated a spiritual dimension, in that patients could feel the nurse specialists' wish to understand and to help, which helped patients feel respected, encouraged, and provided hope.

6.4.1. Considerations on spirituality in care

The EULAR recommendations for the role of the nurse in 2012 (Eijk-Hustings *et al.*, 2012) and the update from 2018 (Bech *et al.*, 2020) do not mention the spiritual dimension of nursing.

According to (Rachel *et al.*, 2019) spiritual wellbeing has important implications for an individual's health and wellbeing. However, spirituality is complex, there is no agreed definition, and it seems to be difficult to ascertain which factors are the most important when considering how to increase spiritual care delivery (Rachel *et al.*, 2019) While the importance of spiritual care is acknowledged in cancer and palliative care as well as in intensive care (Bandeali, des Ordons and Sinnarajah, 2020; Lee and Ramaswamy, 2020; Wei *et al.*, 2016; McClean, Bunt and Daykin, 2012), it may be overlooked in chronic disease, such as (early) RA (Taylor *et al.*, 2021), and could possibly help patients to find meaning and hope in life with the disease.

In secular and positivistic care settings or at times with focus on production and measurable outcomes in care, space for acknowledgement and discussion of spiritual needs may be limited and dependent on individual nursing beliefs and interaction styles. It may also seem awkward or outside the remit of clinical practice to address these issues. However, it is known that RA and especially early RA is a disease that causes changes in all aspects of life with negative impact on quality of life (West and Jonsson, 2005). It must therefore be addressed as such to meet patient needs.

A recent study (Schoemaker and de Wit, 2021) found that applying the treat-to-target strategy provided some progress, but there was still room for improvement. The reason given was, that decisions regarding disease management were based almost solely on disease activity scores, and the use of pharmaceutical treatments to affect these scores. Other patient relevant outcomes were not taken into account such as pain, fatigue, morning stiffness, daily functioning, which may require other interventions, as for example exercise, physical therapy, specialised surgery or psychosocial support rather than a change in treatment (Schoemaker and de Wit, 2021). Also, Elst *et al.* (2020a) found that one in five patients in early RA had ongoing issues with poor wellbeing despite RA treatment (Elst *et al.*, 2020a). Using a terminology that does not resemble spiritual or religious language such as meaning, hope, understanding and togetherness may allow for a broader population of health professionals to consider the benefits of addressing these aspects of care, which may help patients to achieve other goals than just what Ferreira et al (2018) have called ‘biological remission’.

Evidence from studies one and two indicated that building of relationships, trust, confidence and hope, helped patients to accept treatment, and adapt to the disease. It is known that access to a nurse specialist helps patients to accept and stay in treatment (Bech *et al.*, 2020; BSR and NRAS, 2019). Looking at patients in early RA as comparable to patients in cancer and palliative care, the combination of using holistic, person-centred, and empathetic approaches to deliver care with compassion, may thus contribute to wellbeing, while treating the disease and thereby contribute to positive patient experiences and positive patient outcomes. The combination of these approaches may be an important key to understanding the nature of early RA nurse-led care.

Evidence from study two suggested that compassion, holistic, person-centred and empathetic approaches with a kind and understanding attitude were essential for the patients to feel seen, heard and understood. It meant that patients developed trust and belief in treatment and hope for the future. Especially in early RA, it was seen as crucial to help patients understand treatment benefits, and to provide nurse support.

Evidence from study one suggested that a kind, warm and caring attitude combined with a professional and knowledgeable approach were essential to establish a therapeutic environment with positive patient experiences and patient outcomes in RA and early RA. However, as the spiritual dimension of early RA was not directly addressed in studies one, two or three, it is possible that questions addressing this dimension could have added important insights. As the spiritual dimension was identified in collated evidence from the earlier framework of rheumatology nursing (Oliver and Leary, 2010, 2012), it was included in the synthesis of evidence and the model of care.

6.4.2. Summary

Evidence from studies one, two and three supported the dimensions captured in the identified dimensions of clinical nurse specialists' work in the Pandora findings (Oliver and Leary, 2010, 2012), except from the spiritual dimension. This dimension was not directly identified in any of the studies. However, if *spiritual* was defined more broadly, there was evidence which included aspects of care such as conveying hope and meaning, and delivering care with compassion, empathy and togetherness. Evidence suggested that combining compassion, person-centred, holistic and empathetic approaches with a professional and knowledgeable approach could be essential for good patient experiences and to positive patient outcomes in early RA. The term *holistic approach* was used in all studies, but it was not clear if the spiritual dimension of care was included, as this aspect of care was not addressed in the research. Thus, the spiritual dimension was added to the model of early RA care.

6.5. Proposal of an optimised model of early RA nurse-led care

The following section presents an optimised model of early RA care based on the findings of this thesis and the above considerations. Firstly, evidence from studies one, two and three, evidence from recommendations, and a previous model of RA care were collated in a grid of concepts using colour codes. Green was for concepts only in studies one to three. Yellow was for concepts identified from studies one to three AND recommendations AND previous models (directly related). Red was for new concepts identified from EULAR recommendations and the previous model of rheumatology care. An overview of the concepts is presented in Table 16.

Table 16. Summary of collated concepts from synthesis of evidence

Person-centred approach	Combining approaches	Listening	Fatigue management	Assessment by asking questions	IT-access/literacy assessment	Professional approach	Specialist knowledge
Empathetic approach	Conveying compassion	Conveying hope	Contact /practical information	Pain management	Work/benefit issues	Continuing - working relationship	Tight disease monitoring
Patient feedback	Management of medication & lifestyle - Alcohol, pregnancy, and family planning	Supporting patient control – strategy for setbacks	RA pathways & protocols	Early disease management	Conveying trust & confidence	Vaccination status	Anxiety/distress/ depression/low mood management
Innovation	Autonomy - prescribers/non-prescribers	Therapeutic environment	Patient access to asking questions	Patient participation/ involvement	Specialist assessment skills	Smoke prevention	Holistic approach
Audits - service evaluation	Kindness - understanding	Signposting to agencies, charities or patient organisations	Coordinating care & collaboration with MDT	Promoting a sense of safety/security	Weight control	Exercise/support mobility	Telephone advice line
Person-centred approach	Vitamins/alternative & holistic medication	Patient education & information, Balanced -timely	Addressing psychosocial needs	Empowerment	Referral	Remission/patient goals/patient preferred outcomes	Treat-to-target
Intimate relationship issues	Communication	Pharmacological treatment & adjustment	Outpatient consultations	Timely access to care	Co-morbidities	Psychological support	Vigilance/ medication & side effects
Discussing everyday life issues	Nurse education & specialised training	Holistic approach	Health promotion	Evidence-based outcome measures	Promoting sense of familiarity	Administration	Spiritual needs
Booking/checking blood tests, x-ray, MRI, ultrasound	Collaboration with clinician/MDT	Observation and physical examination	Non-pharmacological interventions	Personalised support	Supportive interaction style	Dental status	Self-efficacy

Green – only in studies one to three. Yellow – from studies one to three AND recommendations and previous models (directly related). Red – new concepts identified from recommendations and previous model of rheumatology nurse-led care (no direct evidence in studies one to three).

Based on the grid of evidence (Table 16.), an optimised model of early RA nurse-led care was constructed. Concepts were considered and organised under six dimensions of care, building on the synthesis of overall evidence. Dimensions and concepts of early RA nurse-led care were interrelated with overlap and presented in a table with columns for clarity. The first column focuses on delivery of specialist Rheumatology care, characterising the knowledge and skill involved for providing care in early RA, as well as the collaboration with the multidisciplinary team. The second column focuses on addressing physical needs. The third column focuses on addressing psychosocial needs. The fourth column focuses on person-centred and empathetic approaches applied to pursue optimal patient outcomes in the fifth column. The sixth column focuses on continued evaluation of the service. The optimised model of early RA nurse-led care is provided in Table 17.

Table 17. Optimised model of early RA nurse-led care

Dimensions of early RA care	**Delivery of specialist Rheumatology care**	**Addressing physical needs**	**Addressing psychosocial & spiritual needs**	**Using person-centred & empathetic approaches**	**Pursuing optimal patient outcomes**	**Evaluation & development of the service**
Concepts	**Patient information & education** Timely & balanced according to needs **Collaborating with MDT** **Planning and Coordination of care** Integrated pathways **Referral & signposting** **Professional knowledge & nurse expertise** **Nurse education-specialised training** **Autonomy**	**Early disease management** Treat-to-target RA pathways & protocols, pharmacological treatment & adjustment **Monitoring treatment, disease impact & patient outcomes** Disease activity, pain, fatigue **Management of comorbidities** **Management of medication & lifestyle** Alcohol, pregnancy, family planning & intimate relationship **Health promotion** Smoke prevention, weight control, exercise, sleep, Vitamins, dental status	**Psychological needs** Addressing anxiety, distress, depression, low mood **Spiritual aspects** Meaning & hope **Communication & therapeutic environment** Listening, relationship, continuity **Social needs** Work, access to benefit & support	**Compassion & empathy** Kindness & understanding **Person-centred & holistic care** **Patient participation & involvement** **Providing a ‘lifeline’** Supportive telephone advice line, need-based consultations	**Disease control** Remission, low disease activity **Satisfaction with care** **Patient preferred outcomes** Patient goals, wishes **Sense of security & confidence** Strategies for setbacks, control, support system **Empowerment & self-efficacy** Gaining knowledge, skill, experience **A ‘normal’ life** Keeping in work, adapting	**Patient feedback** Individual consultations, clinic & service changes **Audits & service evaluation** Individual cases & clinic performance **Innovation & improvement of the service** Telephone consultations, video tutorials & digital solutions **IT-access & IT-literacy assessment**

6.6. Conclusion

A synthesis brought together available evidence from studies one, two and three, and evidence from current EULAR recommendations for management of early RA, the role of the nurse in CIA and a former framework for rheumatology nursing as presented in the Pandora findings. This collation resulted in a synthesis of evidence for rheumatology nursing in early RA and generated an optimised model of early RA nurse-led care with the potential to meet patients’ complex and holistic care needs.

Chapter 7: Discussion and conclusions

This chapter will review the novel findings of the thesis and evaluate the strengths and limitations of the research. The implications for research and clinical practice will be discussed, and the original contributions to knowledge will be summarised.

7.1. What was known and what was not known before this PhD

7.1.1. What was known

Before this PhD it was known from the literature, that rheumatology nurse-led care was clinically effective (de Thurah *et al.*, 2017; Garner *et al.*, 2017; Sousa *et al.*, 2017; Eijk-Hustings *et al.*, 2012; Ndosi *et al.*, 2011), cost effective (Ndosi *et al.*, 2014) and safe (BSR and NRAS, 2019; Garner *et al.*, 2017), and leads to higher patient satisfaction rates than in comparable services (BSR and NRAS, 2019; Koksvik *et al.*, 2013; Hill, 1997). It was known that services and clinical practice vary (BSR and NRAS, 2019; Ndosi *et al.*, 2017; Eijk-Hustings *et al.*, 2012) and that currently, there was an EULAR recommendation for the role of the nurse in CIA (Eijk-Hustings *et al.*, 2012) and a NICE guideline for the management of RA (NICE, 2018). It was known that nurse-led care in the UK had been established as normal RA care (BSR and NRAS, 2019), and that rheumatology nurses in the UK increasingly take on extended roles (BSR and NRAS, 2019) in an area where complex treat-to-target treatment strategies are applied in clinical practice (Combe *et al.*, 2017; Smolen *et al.*, 2010, 2017).

7.1.2. What was not known

However, processes of care in early disease were not well described in the literature, and the role of the nurse in early RA was not well defined in the current EULAR recommendations (Eijk-Hustings *et al.*, 2012) and NICE guidelines (NICE, 2018). It was not known what comprised early RA nurse-led care, there was no model of care in early RA to inform clinical practice, and it was not known how well early RA nurse-led care met patients' complex care needs in early disease.

This PhD thesis aimed to provide new knowledge in understanding what comprises nurse-led care in early RA and how needs of patients in early RA are met by nurse-led care. This would help to design a nursing model that had the potential to meet patients' care needs and thus the potential to optimise patient outcomes.

7.2. The patient perspective of early RA nurse-led care

The systematic review of qualitative studies with thematic synthesis (Chapter two) investigated the patient perspective of early RA nurse-led care. The limited number of identified papers in the initial searches and at the rerun of the searches after 22 months, demonstrated a dearth of literature in this population. Thus, the systematic review provided evidence that there is a gap of knowledge in our understanding of the patient perspective of early RA nurse-led care.

The findings of the systematic review (Chapter two) were presented as themes developed from qualitative data from the papers included in the review. These themes provided evidence that patients with RA highly valued nurse-led care, which was characterised as the provision of knowledge and skill, using a person-centred approach and meeting patients' care needs. However, the evidence was too limited as evidence in early RA nurse-led care, but the findings informed further research in this population.

7.3. The nurse perspective of early RA nurse-led care

To start filling the knowledge gap in early RA nurse-led care and to understand what comprised early RA nurse-led care, rheumatology nurse specialists were interviewed (Chapter three and Chapter four). The study provided in-depth data from experienced nurse specialists across the UK, and thus evidence from current clinical practice in early RA nurse-led care. The findings comprised aspects of care that were important to address patients complex care needs in early RA. These aspects of care were seen from the perspectives of these experienced rheumatology nurse specialists with reference to their background and clinical practice. Four identified themes with subthemes characterised early RA nurse-led care as a specialist service, delivered with compassion, using person-centred, holistic and empathetic approaches to address patients' complex care needs (Chapter four).

The interview study with nurse specialists provided unique insights into early RA nurse-led care which was an original contribution to knowledge in this field. The findings helped build an understanding of what comprised early RA nurse-led care and could inform further research in this field.

The original contribution of this research is the identification of key ingredients in early RA nurse-led care where patients are diagnosed, start treatment and try to come to terms with the disease. In early disease patients thus have specific care needs which may differ from RA nurse-led care in established RA where patients have adjusted to the disease and gained knowledge and self-confidence (van der Elst *et al.*, 2016). It is known from the EULAR recommendations for the role of the nurse (Bech *et al.*, 2020), a national audit (HQIP, 2016), and the relatively recent report on rheumatology nursing (BSR and NRAS, 2019) that access to a rheumatology nurse improves patient outcomes in early RA. However, the lack of a guideline in early RA nurse-led care and limited reference to the nurse specialist in the NICE guideline for management of RA (NICE, 2018) do not reflect the nurse specialists' significant role in early RA (BSR and NRAS, 2019).

The development of a model of early RA care could help inform and document clinical practice in early RA management and has the potential to address patients care needs and thus improve patient outcomes. The newly published Competency Framework for Rheumatology Nurses (RCN, 2020) is currently being implemented in rheumatology in the UK. The defined aspects of care and tasks to carry out for nurses in rheumatology are listed according to the band system. The model of early RA nurse-led care as developed in this thesis and the Competency Framework for Rheumatology Nurses had similar key aspects within RA management, monitoring, referral and signposting, using person-centred approaches, and development of the service. However, the framework only mentioned *person-centred* without explaining what this meant for clinical practice. This research showed that the person-centred aspect of care, was especially important in early RA. In fact, the person-centred approach used by nurse specialists was key in getting the patients onboard to start treatment and to keep them in treatment and establish a working relationship for education and support. This research complemented the competency framework by providing evidence of 'person-centred approaches' as essential in early RA care which had not been captured in the framework and could have an important impact on patient outcomes. *Person-centred approaches* were thus expanded in the theme: *Care with compassion using person-centred, holistic and empathetic approaches*. This theme was further described in the subthemes *Care delivered with compassion, Using person-centred, holistic and empathetic approaches*, and *Providing a 'lifeline'* which also included access to the rheumatology nurse via an advice line.

According to evidence in this research, psychological support was seen as especially important in early RA and helped patients to adjust to the disease. Although the need for psychological support was acknowledged and addressed by nurse specialists (Chapters three and four), the support was found to vary between clinics with little consistency in clinical practice. This is in agreement with previous evidence from England (Ndosi *et al.*, 2017; Dures *et al.*, 2014). Dures *et al.* (2014) studied psychological support provision in 143 rheumatology units in England. Although rheumatology departments identified psychological support as part of their role, they rated provision of this as inadequate. Ndosi et *al*. (2017) studied the composition of rheumatology MDTs in the UK and found a wide variation. While most MDTs comprised consultants and nurse specialists, access to physiotherapists, OTs and podiatrists varied, and no results for access to psychologists were reported (Ndosi *et al.*, 2017). Research in psychological needs of patients in 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. Patients were found to prefer support from rheumatology clinicians and in particular from the rheumatology nurses (Dures *et al.*, 2016). Findings thus suggested that nurses with appropriate training and experience could provide adequate psychological support in early RA, and that the patients valued this service (Dures *et al.*, 2016).

Psychological problems related to early RA can range from low mood to severe psychological problems (Dures *et al.*, 2017; Ryan, 2014). According to the NICE guideline for depression in long-term chronic conditions (NICE, 2009), a four-stepped care model is recommended starting with the least intrusive interventions at steps one and two. Rheumatology nurses can provide the first two levels of psychological support based on their professional experience and training; the next two steps involve medication and therefore require specialist interventions (NICE, 2009).

Given differences in access to psychological support across the UK in rheumatology (Ndosi *et al.*, 2017; Dures *et al.*, 2014), nurse specialists may lack support in training and referral to provide adequate psychological care in patients with early RA. Evidence from the interview study with nurse specialists (Chapters three and four) and the survey with patients (Chapter five) supported that there was a need for psychological support in early RA. According to evidence from the interview study (Chapters three and four), psychological support was mainly provided by nurse specialists. Evidence suggested that by using their professional experience and person-centred, holistic and empathetic approaches, nurse specialists provided important and valuable support. However, they lacked access to specialist psychology supervision and referral. Provision of psychological support needs attention in the further development and implementation of a model of nurse-led care in early RA. This research can inform the need for training and access to specialist psychology supervision and referral.

Evidence from the interview study with nurse specialists (Chapters three and four) and the survey with patients in early RA (Chapter five) suggested that information about intimate relationship was needed, but either was limited or lacking. Nurse specialists reported that they found it challenging and awkward to address these issues (Chapters three and four). These findings were consistent with recent research (Flurey, 2022), which found that health professionals in rheumatology rarely addressed sexual health with patients, despite considering it important (Flurey, 2022; Helland *et al.*, 2013). 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). Patient access to information and specialist referral as well as training of health care staff therefore need addressing to meet patients' care needs in early RA.

7.4. Early RA Nurse-led care model from the patient perspective

The survey study with patients in early RA (Chapter five) addressed objective three. The study provided the patient perspective and identified areas of early RA care that had been missed in studies one and two. From the patient perspective, there were some indications of nurse-led care meeting patients' care needs in early RA in the context of the domains measured with the LSQ tool (Hill, 1997), although with low scores in empathy and general satisfaction. Patient satisfaction with care was high for patients who had attended face-to-face consultations compared to patients who had attended telephone/telephone combined with posted material.

The survey was conducted during the COVID-19 pandemic, and the use of telephone consultations may not yet have been optimised after the rapid change of the service to remote care, or patients in early RA may have had care needs that were challenging to cater for by telephone. Participating patients assessed items representing the model of early RA nurse-led care as highly important for their care and thereby endorsed the model of early RA nurse-led care. Participant comments provided views of early RA nurse-led care, and although the evidence was limited, it could inform further research and indicate areas of importance in early RA.

Overall, the mixed method results indicated that nurse-led care had the potential to meet patients care need in early RA, and that the proposed model of early RA nurse-led care was endorsed by patients in early RA who participated in the study. As so few patients participated, more research is needed.

Further research could include a review of questionnaire items for the model of care, to ensure that the questionnaire items capture all concepts in the model of care (de Vet *et al.*, 2011), and a survey with a wider sample of patients in early RA with the potential to get results that could be generalised in a wider population. Items for further research could for example include an assessment of *education, information* and *support*. These concepts were not included in the survey (Chapter five) but had been found to be important in early RA nurse-led care in studies one (Chapter two) and two (Chapter three and Chapter four) and were included in the provisional model of early RA nurse-led care. To further develop the model of care, a consensus process

(Bowling, 2014) with panels of nurse specialists, rheumatologists and patients could decide which model items should be kept and what the final model of care should look like before it is tested in pilot studies in rheumatology clinics (de Vet *et al.*, 2011). These procedures should follow NICE guidelines for development and implementation of new procedures in health care (NICE, 2019).

7.5. Model of early RA nurse-led care

This research developed a novel model of early RA nurse-led care. The optimised model of early RA nurse-led care was developed by synthesising evidence from this thesis with the EULAR recommendations for management of early RA (Combe *et al.*, 2017), and for the role of the nurse in the management of chronic inflammatory arthritis (Bech *et al.*, 2020), and with the early framework for rheumatology nursing as presented in the Pandora findings (Oliver and Leary, 2010, 2012). The synthesis brought together evidence which was important for the management of early RA and identified areas that had not earlier been captured in relation to rheumatology nurse-led care in early disease.

The model highlights the specialist nature of early RA nurse-led care and the collaboration with the multidisciplinary team. These aspects of care are recommended in the EULAR recommendations for rheumatology nursing (Bech *et al.*, 2020) and supported by the Competency Framework for Rheumatology Nurses (RCN, 2020) which is currently being implemented in rheumatology care. However, this is to the researcher's knowledge the first time that these aspects of care have been clearly linked to a model for early RA nurse-led care.

7.6. How this research relates to wider research

The evidence of this thesis supported the importance of a person-centred approach in early RA nurse-led care. Identified aspects of care were thus similar to research from Sweden that conceptualised person-centred care in a tool for measuring patient perceived levels of person-centred care in rheumatology nurse-led care (Bala *et al.*, 2018a). The tool had five domains, including social environment, personalisation, shared decision-making, empowerment, and communication (Bala *et al.*, 2018a), which were also found to play an important role in the interview study with nurse specialists (Chapter three and Chapter four). The difference was that this research addressed early RA where patients try to come to terms with diagnosis and treatment with everything being new, whereas in Bala *et al.* (2018a), the patients were not new in RA but had persistent symptoms and therefore needed support. Using the tool for this research could possibly have provided useful data on the patient perceived levels of person-centred care in early RA.

Person-centred care can be characterised as care that sees patients as equal partners in planning, developing and accessing care to make sure it is most appropriate for their needs, and it involves patients and their families being at the heart of all decisions (De Silva, 2014). In the Competency Framework for Rheumatology Nurses (RCN, 2020) person-centred care is recommended when providing care, however there is no clear definition of what ‘person-centred care’ means. This is understandable as there is no agreed definition of the concept (AGS, 2016). However, according to De Silva (2014) there are many ways of measuring person-centred approaches in care, using methods such as questionnaire tools and surveys, interview, focus groups and observing. Concepts explored can be the holistic concept of person-centred care, selected subcomponents of person-centred care such as patient satisfaction and experience of care, empathy, compassion and dignity, and behaviours supporting person-centred care (De Silva, 2014). De Silva (2014) refers to The Institute of Medicine (Tzelepis *et al.*, 2014), which listed six dimensions of patient-centred care as crucial to providing quality healthcare. According to the outlined dimensions, care must thus be 1) respectful to patients’ values, preferences, and expressed needs; 2) coordinated and integrated; 3) provide information, communication, and education; 4) ensure physical comfort; 5) provide emotional support – relieving fear and anxiety: and 6) involve family and friends (Tzelepis *et al.*, 2014). Evidence from this thesis strongly supported these dimensions of care in early disease.

As the tool developed by Bala *et al.* (2018a) to measure person-centred care in rheumatology nurse-led care was not yet validated in English, this researcher used a validated tool for patient satisfaction in rheumatology nurse-led care (Hill, 1997) to assess patient satisfaction with care (Hill, 1997). Measuring satisfaction with care could be translated to a measure for patient needs met (Hill, 1997). The researcher also developed a provisional model of care from interviews with nurse specialists, and questionnaire items were developed from the provisional model of care, so each concept in a model item was addressed in separate questionnaires to capture all parts of a construct (de Vet *et al.*, 2011).

7.7. Methodological considerations

The mixed methods approach used in this thesis allowed findings from a number of data collection and analysis methods to be integrated. This research was conducted using sequential explorative mixed method (Creswell and Clark, 2007). Consequently, the mixed method approach was ‘connection’ where results from one study informed the next study (Creswell and Clark, 2007), and the mixing of methods involved one approach being built upon the findings of the other approach (Halcomb, 2019). With the weight on the qualitative phase (Creswell, 2003), the quantitative part of the PhD, assisted in the overall interpretation of the qualitative findings (Creswell, 2003). This design was flexible and provided results that broadened the current understanding of the complex nature of early RA nurse-led care and how it works.

Patient perceptions were firstly explored using systematic review of qualitative studies with thematic synthesis. This allowed a thorough and exhaustive review of current knowledge according to the study criteria and initiated the development of characteristics of early RA nurse-led care using thematic synthesis of findings. Secondly, perspectives of nurse specialists were explored using interview methods with inductive thematic analysis. This phase continued the qualitative exploration of early RA nurse-led care building on the prior study as the interview guide was informed by the identified themes. Thirdly, patient perceptions were further explored using cross sectional survey with validated patient satisfaction questionnaire as well as a questionnaire developed from this research. Using survey methods, the study thus added new aspects to the qualitative findings, as the survey investigated patient perceptions of early RA nurse-led care using a validated patient satisfaction tool, and questionnaires derived from this research. Furthermore, the survey also provided textual data with patient comments on early RA nurse-led care, which were analysed using content analysis.

All these inquiries conducted using mixed method brought different aspects of early RA nurse-led care and helped develop an understanding of what it is and how it works. Using mixed method, the researcher was able to capture the wide range of relevant data to guide the research and the development of the model of early RA nurse-led care. The approach thus facilitated the development of the model of early RA nurse-led care, despite limitations of the research which will need to be addressed in future research. Overall, the mixed method approach worked well for developing an understanding of early RA nurse-led care and for the development of a model of early RA nurse-led care.

7.7.1. Research strengths

This research had several strengths. The research filled a knowledge gap in our understanding of early RA nurse-led care which was not well understood. The research thus addressed the aims of the PhD and provided new knowledge about what comprises nurse-led care in early RA from the nurse perspective, and to some extent from the patient perspective.

This research was conducted with substantial involvement of the patient research partner, and with the intention to conduct research which could inform clinical practice in the provision of optimal care. The patient research partner was actively involved in all parts of the project as supervisor and provided feedback on the relevance of research questions and aspects of care identified over the course of the PhD project. The patient research partner also reviewed survey questions for the patient survey which ensured that the survey was relevant, understandable, meaningful and user- friendly, and thus could provide data relevant to the research.

The research used a sequential explorative mixed method approach which combined qualitative and quantitative methods, informed the research, and assisted the interpretation of results. This provided evidence on early RA nurse-led care which would not have been possible using either qualitative or quantitative methods alone. The research thus brought together data from the literature, clinical practice, and patient perspective. The analysis and interpretation of these data helped to develop an understanding of early RA nurse-led care and to develop a model of early RA nurse-led care with the potential to meet patients complex and holistic care needs in early RA. A strength of the sequential explorative approach was that one approach built upon the findings of the other approach, with each study informing the next (Halcomb, 2019).

The sequential explorative approach was flexible, and the findings informed and guided the research. As a key feature in mixed method is the description of how the mixing or integration and quantitative elements were achieved (Halcomb, 2019; Zhang and Creswell, 2013), the mixing was described as ‘connection’ using Zhang and Creswell’s identified three distinct procedures for mixing data in health service (Halcomb, 2019; Zhang and Creswell, 2013). The individual mixed method components, the three studies were conducted and presented individually and finally synthesised with current EULAR recommendations for treatment and care, and an earlier framework for rheumatology nursing, proposing a model of early RA care.

The final synthesis of evidence brought together evidence from this thesis and evidence from current EULAR recommendations for management of early RA (Combe *et al.*, 2017) and for the role of the nurse (Bech *et al.*, 2020), and evidence from the earlier framework for rheumatology nursing as presented in the Pandora findings (Oliver and Leary, 2010, 2012). This ensured that the aspects of care identified in this research were relevant and within the remit of existing recommendations and frameworks for rheumatology treatment and care. The synthesis also identified aspects of RA care that had not been clearly identified before, such as the specialist nature of early RA nurse-led care, the importance of care delivered with compassion, and of combining person-centred, holistic and empathetic approaches in early disease. The synthesis also identified aspects of care that were not captured or clear in this research such as the *spiritual dimension* of care (Oliver and Leary, 2010, 2012), and aspects of care generated from patient comments in the survey (Chapter five).

The mixed methods approach used in this PhD suited the researcher's pragmatic position. In addition, the individual studies and the overall thesis benefited from designs that valued flexibility, practicality and consideration for the impact of the research (Jones, 2019; Dures *et al.*, 2011; Creswell and Clark, 2007; Creswell, 2003)

7.7.2. Research limitations

This research has some limitations. First, the systematic review of qualitative studies, had eight included studies and only four clearly included patients with early RA. Other limitations might include missing papers published in languages other than English, and unpublished papers with negative results. However, although the evidence was limited in early RA, it could inform clinical practice and further research. Aspects of RA and early RA care were corroborated by evidence from the following studies, such as providing knowledge and skill, using a person-centred approach and meeting patients' care needs for support.

Second, only nurse specialists in England participated, and all were female. Furthermore, race and gender issues were not addressed. It is also possible that voices are missing from those nurses who are less engaged in research, those who may be more stretched in their roles and not able to make time for the interview, and those who worry about level of anonymity who might have fewer positive things to say and who may have different views and different clinical practice. Other participants may have provided other and varied data and thereby provided deeper insights, and other interviewers may have asked other questions, analysed data differently and thereby generated different results. However, the research was sought conducted with rigour and robustness using interview method (Brinkmann and Kvale, 2015; Braun and Clarke, 2013) and thematic analysis (Braun and Clarke, 2013). The in-depth interviews provided rich and varied data that included detailed descriptions of processes of care in early RA. Thematic analysis of data generated themes characterising important aspects of care in early disease.

Third, all interviews were conducted using telephone. Originally, the intention was to let participants choose between face-to-face or telephone. However, the outbreak of the COVID-19 pandemic meant that only telephone interviews could be conducted. It is possible that face-to-face interviews or video calls could have provided more in-depth data, or participants could have made their points quicker. Also, the researcher would have seen the non-verbal cues and the interview process and participant experience may have been enhanced. However, early in the COVID-19 pandemic, access to video was not yet available in all clinics, and telephone was commonly used in clinical practice and easily accessible. Telephone interview allowed the research to proceed despite the implementation of COVID-19 restrictions in research and were time and cost effective. The telephone interviews provided varied and rich in-depth data from experienced nurse specialists across the England. These data would otherwise have been challenging to obtain due to the nurse specialists' busy time schedules and the researcher's limited financial resources (Braun and Clarke, 2013; Block and Erskine, 2012). Using focus group interviews had been considered as they could provide rich data and generate ideas through the interaction between participants (Bowling, 2014; Braun and Clarke, 2013). It is possible that focus group interviews could have provided other data and other results. However, the telephone interviews allowed the nurse specialists to provide in-depth data, and to speak freely without colleagues listening in, at a time which suited them best during their day (Braun and Clarke, 2013; Block and Erskine, 2012).

Fourth, the survey had only thirty evaluable responses and did not have statistical power to provide robust and conclusive evidence that could be generalised to the wider population. Care was thus needed in the interpretation of the results. However, the aim was to get the patient perspective of early RA nurse-led care with assessment of patient satisfaction as a surrogate for patient needs being met, and to assess the importance of the provisional model of early RA nurse-led care and how experienced care accorded with the model with the invitation to supplement with patient comments. While not claiming generalisability, the results suggested that participating patients endorsed the model as presented to them, and they generally had their needs met although to a higher degree in face-to-face consultations than in telephone/telephone combined with posted material regarding empathy and general satisfaction. The textual data was too limited to conduct the planned thematic analysis, but content analysis generated themes that assisted the interpretation and provided important items for the optimised model of early RA nurse-led care.

Fifth, mixed method limitations were that the first two studies were stronger than the third, as they had sufficient data to provide robust results. The weight was on these studies, but a stronger and more robust third study would have provided stronger overall mixed method evidence. This could be achieved by further development of the questionnaire assessment of the model of early RA nurse-led care and by recruiting more participants with early RA from the wider population for a survey and by conducting focus-group or in-depth interviews with patients to get their views. Also, using the mixed method approach had some implications for the timing of the individual studies against deadlines for the PhD, which is an acknowledged limitation using a sequential exploratory approach (Halcomb, 2019). The qualitative components were time-consuming regarding data collection, analysis and presentation of results with revisit and revision of earlier stages of the analysis for the final write-up of the PhD thesis.

7.8. Contribution to knowledge

At the beginning of this PhD, it was known that nurse-led care was effective and cost-effective. Whilst there were recommendations for the role of the nurse in inflammatory arthritis, and the NICE guidance in the management of RA mentioned that patients should have access to the nurse, what constitutes nurse-led care was not well described. This thesis presents novel findings of early RA nurse-led care, what it is and how it meets patients' care needs.

Themes generated from the qualitative systematic review characterised the key aspects of rheumatology nurse-led care from the perspective of patients in early RA. This knowledge was enriched by primary qualitative data obtained from the perspective of rheumatology nurse specialists. The themes from these data were operationalised to develop a provisional model of care in early RA, which was presented to a group of patients with early RA in a survey, the majority of whom endorsed all aspects of the model as important to them. The model was optimised by supplementing with earlier framework of rheumatology nursing, the updated EULAR recommendations for the role of the nurse and EULAR recommendations for the management of early RA. The resulting model contributes to knowledge, clinical practice and training about early RA care.

7.9. Implications for clinical practice

This research is important for current clinical practice as it addressed a knowledge gap in early RA nurse-led care. The results can help clinical practice to ensure that the aspects of care specified in the model are addressed and implemented. The research can also inform the current Competency framework for Rheumatology Nurses (RCN, 2020), so future editions include the specific aspects of care that relate to early RA. This can also be adopted in teaching of undergraduate and postgraduate nursing programmes. The model emphasises the importance of specialist care delivered with compassion, using a combination of person-centred, holistic and empathetic approaches to meet patients' complex care needs. As the current NICE guidelines (NICE, 2018) only briefly mention the rheumatology nurse as a member of the interdisciplinary team and as a possible contact person, the research can inform future NICE guidelines, so they mirror the complex and extended role of the nurse in early RA.

The COVID-19 pandemic became a catalyst for the transformation of the outpatient service, including nurse-led care, which had been discussed and planned prior to the pandemic (NHS, 2019) with change from face-to-face to telephone consultations and use of digital solutions. It is therefore likely that the changes to the service are there to stay, and thus may need adjustments to cater for patients with early RA, rather than going back to the pre-pandemic service. It is believed that this research, and the developed model of early RA nurse-led care will provide a valuable source of information and inspiration for clinical practice and future research.

7.10. Implications for research

More research is needed to further develop and test the model of early RA nurse-led care. The conducted survey only served to seek the patient perspective of nurse-led care and the model of early RA nurse-led care. Further research will be required to develop tools and measures for service evaluations. A larger well-powered survey could be used to assess subgroups of patients who could benefit most and also evaluate the difference between face-to-face and telephone provisions. These procedures should follow NICE guidelines for development and implementation of new procedures in health care (NICE, 2019).

7.11. Reflections on the research process

The researcher continuously considered and discussed the research process with the Director of Studies and the supervisory team. To help the reflective process, the researcher wrote reflective diaries throughout the course of the PhD. The reflective diaries included notes, diagrams, reflections, summaries of discussions with supervisors. These in-depth descriptions of processes helped record the various stages of the research and enhance transparency in the reporting of the research. The researcher understood and acknowledged that her background, values and interests played an active part in the research process and helped shape the research (Braun and Clarke, 2013). In interviews with nurse specialists (Chapters three and four), the researcher used her professional knowledge and experience as a rheumatology nurse to ask questions, which helped provide varied in-depth data. The researcher experienced being acknowledged by participants as a nurse colleague rather than a researcher. Participants were happy to discuss their practice and personal views, and eager to share their experiences. Some participants thanked the researcher for conducting the research to provide evidence of their work and its importance for patients and rheumatology.

The fact that the researcher was acknowledged as a nurse colleague may however have impacted the research. Participants may for example have assumed that the researcher had some knowledge and therefore did not share things they thought the researcher already knew. On the other hand, they may have felt more comfortable opening up as the researcher was 'one of them'. The researcher’s role may also have had an impact in shaping the analysis, so the researcher’s own experiences as a nurse led the researcher to interpret the data in a way that reflected or confirmed her own experiences. However, the researcher shared the analysis with the multidisciplinary supervisory team including the patient research partner, who agreed with the interpretation.

Results of the survey with patients (Chapter five) suggested that the research identified areas of care, which were important to patients in early RA. This was encouraging and confirmed the importance of the research.

Throughout the course of the PhD, the researcher used the *Researcher Development Framework* (RDF) which facilitates reflective, research-based skills development (Vitae, 2010). It is a professional development framework for planning, promoting, and supporting the personal, professional and career development of researchers in higher education (Vitae, 2010). The framework addresses the knowledge, behaviours and attributes needed of successful researchers and is meant to encourage researchers to reflect and to realise their potential (Vitae, 2010). The researcher has undertaken training and courses provided by UWE Bristol, which supported and developed the researcher's knowledge and skill and contributed to the research such as systematic review, qualitative research in health, and research in contemporary context.

This thesis is the result of dedicated work and a wish to generate knowledge that can help patients and rheumatology clinical practice to the benefit of patients in early RA. The research thus seeks to fill a gap in our knowledge of early RA nurse-led care by defining key aspects of care that are important to meet patients' complex and holistic care needs in early RA, and by providing a model of early RA nurse-led care which has the potential to meet these needs.

Implementation of the research may be summarised as a cyclical process comprising analysis of the context, assessing barriers and facilitators, designing of strategies for implementation and evaluation (Loza *et al.*, 2022). As this research is likely to inform practice, nursing education and policy, assessment of the context will depend on these potential routes of implementation. However, specific strategies for implementation could be (i) contacting the task force undertaking the RCN Competency Framework for Rheumatology Nurses (RCN, 2020), so that they can consider these findings in the update. This will ensure the findings of this research are directly translated in competency frameworks; (ii) communicating with the EULAR Task force for developing the role of the nurse, so that the findings may be known to the key players of European rheumatology nursing and the European guidelines for the role of the nurse in chronic inflammatory arthritis (Bech *et al.*, 2020), and that the role of the nurse in early RA eventually will be mirrored in the NICE guidelines for the management of rheumatoid arthritis in adults (NICE, 2018); and (iii) communicating with the BSR HPR leadership and NRAS to make them aware of the new findings for possible inclusion in the next policy document on rheumatology nursing. Other generic dissemination strategies such as conference presentation and publication of the manuscripts have already started, and these will be optimised by developing lay versions for dissemination in non-specialist audiences such as patient organisations and the public.

The researcher encountered expected and unexpected challenges on the way. It is known that the PhD journey is long and can be rocky and take turns which can cause change of direction or adjustment of the original plans for the research (Phillips and Pugh, 2010). This PhD was conducted during the height of the COVID-19 pandemic, which in addition to ordinary and expected research conditions meant that design and data collection methods had to be re-considered and adjusted to allow for the research to continue despite restrictions on social interaction. Also, the research environment and available resources were impacted by the ongoing COVID-19 pandemic. However, the process of adapting the research to the current research environment brought important learning about how the changing nature of research can change the skills necessary to do it, and how it is best done. Efforts were made to meet the aims of the PhD, and it is believed that due to the COVID-19 pandemic the research may have captured changes of the rheumatology nurse-led service that can inform clinical practice and further research.

7.12. Conclusion

Nurse-led care in RA is established in the UK, and rheumatology nurse specialists increasingly take on extended roles in clinical practice. The treat-to-target treatment strategy in RA requires close monitoring, and patients in early RA have complex care needs. This PhD aimed to define early RA nurse-led care and to develop a model of early RA nurse-led care which met patients' holistic care needs. Mixed-method findings provided new knowledge about early RA nurse-led care. It was characterised as a specialist service delivered with compassion, using person-centred, holistic and empathetic approaches in close collaboration with the patient and the multidisciplinary team with ongoing evaluation and improvement of the service. A synthesis of evidence from the three thesis studies, current EULAR recommendations for the role of the nurse in inflammatory arthritis, EULAR recommendations for management of early RA, and an earlier framework for rheumatology nursing provided an optimised model of early RA nurse-led care. This model has the potential to meet patients' complex and holistic care needs in early RA.

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Appendices

Appendix A. Assessing confidence in syntheses findings

Assessing confidence in syntheses findings

The following considerations and quality assessment of the systematic review were carried out prior to the publication of the systematic review of qualitative studies (2020b) which is reported in Chapter two of this thesis, and which was published in 2020 (Sweeney *et al.*, 2020b). To ease the reading, only the publication reference will be used when referring to the systematic review in the text,

Summary of the process of assessing confidence in syntheses findings

Noyes *et al.* (2018) offer guidance in assessing impact of different qualitative methodologies on the synthesis and interpretation of findings. The PhD student (hereafter referred to as the researcher) assessed the systematic review (2020b) using this guidance. Following points are taken from Noyes *et al.* (2018) with discussion for each point.

Assessment of study methodological strengths and limitations:

Noyes *et al.* (2018) state that compared to earlier guidance of using any ‘quality appraisal’ (acknowledging that the use of quality assessment in quality research is widely discussed), they now recommend using a more narrowly defined set of tools to establish qualitative rigor in the research compared with risk of bias in quantitative research. Noyes *et al.* (2018) advocate the use of The CASP Checklists (CASP, 2019).

Thomas and Harden (2008), which the researcher used as guidance in this review, stated that they took the view that the quality of qualitative research should be assessed to avoid drawing unreliable conclusions. However, since there was little empirical evidence on which to base decisions for excluding studies based on quality assessment (in 2008), they took the approach in their review to use 'sensitivity analyses' with their own developed checklist to assess the possible impact of study quality on the review's findings (Thomas and Harden, 2008).

For this review (2020b), the researcher used the JBI assessment tool (Martin, 2017) as it was developed specifically to assess the methodological quality of primary studies (Porrit, Gomersall and Lockwood, 2014; Hannes, Lockwood and Pearson, 2010). Hannes *et al.*(2010) compared three online critical appraisal instruments' ability to facilitate an assessment of validity. They found that CASP appeared to be less sensitive to aspects of validity than the evaluation tool for qualitative studies (ETQS) and the Joanna Briggs Institute (JBI) tool (Hannes, Lockwood and Pearson, 2010). The ETQS provided detailed instructions on how to interpret criteria. However, it was the JBI tool, with its focus on congruity, that appeared to be the most coherent (Hannes, Lockwood and Pearson, 2010).

For this systematic review (2020b), the JBI quality assessment tool allowed the assessment of quality of the research as well as author impact and assessment of participants' voices being adequately represented. All the eight studies in the systematic review were deemed of acceptable quality to provide insights on patient perspective of nurse-led care in RA (Sweeney *et al.*, 2020b).

The researcher's use of the JBI tool with its focus on congruity seems to be justified. Furthermore, JBI's item 8 ('8. Are participants, and their voices, adequately represented?' (Martin, 2017)) was especially relevant for this review which explored the patient perspective. The assessment process was checked by second reviewer and discussed where there were differences in opinion and then discussed until consensus was reached. The supervisor team oversaw the overall process. The process was sought made transparent by explaining the assessment process in detail and by offering a table of the assessment of all included studies. However, it is possible, that other researchers would have conducted quality assessment differently with different impact on the synthesis.

Data extraction and synthesis

Extracting contextual and methodological information from the included studies

According to Noyes *et al.* (2018) it is considered best practice to extract contextual and methodological information on each study and to report this information in an included studies table. It is also important that the context of the primary study data is not lost during the synthesis process because the findings of the primary studies may be misinterpreted (Noyes *et al.*, 2018). To avoid this, they suggest referring back to the original studies during the analysis and synthesis process (Noyes *et al.*, 2018).

For this systematic review (2020b), the researcher extracted contextual and methodological information on each study as well as contextual information, reported the process and included a table with summary of extracted information. During the analysis and synthesis process the researcher continually referred back to the original studies and to tables with extracted data to avoid misinterpretation of primary studies. The researcher and the co-reviewers thus believe that they have followed best practice, but acknowledge that despite best efforts, they may have overlooked and not included some information useful for this review (Sweeney *et al.*, 2020b).

Extracting, analysing, and synthesizing findings from primary qualitative studies

According to Noyes *et al.* (2018), the purpose of their guidance is to highlight methodological issues to consider when selecting methods and to signpost to more detailed external guidance to inform decision-making (Noyes *et al.*, 2018). Methods for qualitative data extraction vary according to the synthesis method selected (Noyes *et al.*, 2018). According to Noyes *et al.* (2018) the Qualitative and Implementation Methods Croup (CQIMG) endorses the INTEGRATE-Health Technology Assessment guidance (Booth *et al.*, 2016) on selecting methodology and methods for qualitative evidence synthesis in a health technology assessment context, as the starting point for selecting an appropriate methodology and methods such as data extraction (Noyes *et al.*, 2018).

For this systematic review (2020b), the researcher used Booth *et al.* (2016) as advised by Noyes *et al.* (2018) to determine and choose an adequate model for analysis and synthesis of data.

According to Booth *et al.* (2016) , thematic synthesis can be seen as epistemological neutral. They refer to Thomas & Harden (2008) who state that thematic synthesis (including Meta-Aggregation) and Framework Synthesis produce findings that directly inform practitioners (Thomas and Harden, 2008).

For this systematic review (2020b), pilot searches had shown that data could be found in studies using a variety of qualitative methods. This review aimed at bringing together the findings of primary studies with qualitative data using various qualitative methods and since data were of qualitative nature (Sweeney *et al.*, 2020b).

Following Booth *et al.* (2016) and Thomas and Harden (2008), The researcher and the co-reviewers deemed thematic synthesis adequate and acceptable approach for analysis and synthesis of the qualitative studies we expected to find during the search and eligibility process (Sweeney *et al.*, 2020b).

Thomas and Harden (2008) had used thematic synthesis in their qualitative systematic review and provided a guidance of the research process, which had been used before in similar health research exploring participant views. The researcher therefore chose to use their approach as guidance for this review.

The published paper (2020b) thus reported a systematic review of qualitative studies, with a thematic synthesis according to Thomas and Harden (2008). 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.

The protocol was developed and registered in the International Prospective Register of Systematic Reviews (PROSPERO) (Sweeney *et al.*, 2019) before the main search was conducted which provided quality assessment by peer review.

By following the guidance provided by Booth *et al.* (2016) and Thomas and Harden (2008) the researcher and the co-reviewers believe that the use of thematic synthesis was an adequate choice of method for analysis and synthesis. However, it is possible that the choice and use of method would have been different with another research team.

Locating qualitative findings in qualitative study reports

According to Noyes *et al.* (2018), qualitative findings may be in the form of quotes from participants, sub themes and themes, explanations, hypotheses or new theory, or observational excerpts and author interpretations of these data (Noyes *et al.*, 2018). Useful findings in qualitative studies may also be found outside of results or findings sections. In qualitative evidence synthesis context, participant quotes have been classified as ‘first order’ constructs, author explanations and recommendations as ‘second order’ constructs, and new insights derived from a synthesis of studies as ‘third order’ interpretations (Campbell *et al.*, 2011).

For this systematic review (2020b), the researcher used an inclusive approach (Noyes *et al.*, 2018), using both participant quotes and author quotes with themes and findings to avoid leaving out data valuable to the synthesis. The data were following Noyes *et al.* (2018) found in results and findings sections of original studies as well as in discussion conclusion sections, depending on the individual reporting style. Both individual participant quotes (first order) and aggregated author findings (second order) were used as data to identify and illustrate themes (Sweeney *et al.*, 2020b). Patient quotes were weighed over original author quotes, and clearly marked (Sweeney *et al.*, 2020b).

For this systematic review (2020b), the researcher and the co-reviewers believe that they have identified and extracted the qualitative data available in the original studies, but acknowledge that despite our efforts, some data may have been overlooked and therefore not included in the synthesis (Sweeney *et al.*, 2020b). It is also possible that the original authors may have left out useful data in their reports (Sweeney *et al.*, 2020b).

Spectrum of method-specific approaches to data extraction

According to Noyes *et al.* (2018), there are several method-specific approaches to the identification, extraction, analysis, and synthesis of qualitative evidence. They state that whichever method is used, the key principle of qualitative data extraction, analysis, and synthesis is that the process is not sequential and linear (Noyes *et al.*, 2018). It typically involves moving backward and forward between these review stages (Noyes *et al.*, 2018).

They also state the importance of regular team meetings to discuss and further interrogate the evidence to achieve a shared understanding (Noyes *et al.*, 2018).

For this systematic review (2020b), the researcher used Thomas and Harden (2008) to guide through the research process, which was characterised by moving backward and forward at all stages of the research process as advised by Noyes et al. (2018). 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 (Sweeney *et al.*, 2020b; Thomas and Harden, 2008). The first stage was free line-by-line coding of findings from primary studies into related areas (Sweeney *et al.*, 2020b; Thomas and Harden, 2008). The second stage was to construct ‘descriptive’ themes across studies, and the third stage was to develop ‘analytical’ themes related to the research question (Sweeney *et al.*, 2020b; Thomas and Harden, 2008). Tables were created to manage coding and themes (Sweeney *et al.*, 2020b). The first reviewer carried out the thematic synthesis, and the process and results were discussed with the second reviewer (Sweeney *et al.*, 2020b). The findings were finally reviewed by the reviewer team (Sweeney *et al.*, 2020b).

The reviewer team for the systematic review (2020b) had expertise within qualitative methods, rheumatology nursing, nurse-led care, rheumatology and chronic disease and psychology and an experienced patient research partner was a full member of the team from the onset of the study. The researcher recorded the research process in detail, including the role of the reviewers and their discussions and decisions which would have an impact on the synthesis (Sweeney *et al.*, 2020b).

The researcher and the co-reviewers believe that they have followed a sound approach to data extraction and followed the guidance provided by Thomas and Harden (2008) for analysis and synthesis of data. However, it is possible that other research teams would have applied other method approaches or used Thomas and Harden (2008) differently.

Using a bespoke universal, standardized, or adapted data extraction template

According to Noyes *et al.* (2018), review authors can develop their own review-specific data extraction template or select a bespoke data extraction template that can be used in a

Cochrane context. Noyes *et al.* (2018) refer to the National Institute for Health and Care Excellence (NICE) guidelines: NICE Methods for development of NICE public health guidance, UK (Noyes *et al.*, 2018). NICE offers recommendation for review of research evidence (NICE, 2019). The NICE recommend, that characteristics of data should be extracted to a standard template for inclusion in an evidence table (NICE, 2022a, 2022b).

However, for this systematic review (2020b), the researcher developed a data extraction template, which included records and data extraction fields, based on the peer reviewed protocol: Country, patient characteristics (age, sex, disease duration, work status, co-morbidity), type of clinic or care offered (overall disease management or specific care such as drug monitoring or patient education), themes or sub-themes related to patient experience, needs or expectations.

Summaries were provided in the result section as 'characteristics of included studies' and in a table with summary of included studies (Sweeney *et al.*, 2020b). Following Noyes *et al.* (2018), the researcher and the co-reviewers believe that it is acceptable that the researcher developed her own data extraction form, which did include important fields from the NICE template regarding: bibliographic reference, study type, setting, intervention, number of participants, participant characteristics, methods of analysis and results. The researcher added the following fields: data collection and main themes (instead of results). It is possible that the use of a different extraction form could have changed the synthesis slightly. However, it was sought to make the process of data extraction transparent by providing details of the process.

Using an a priori extraction conceptual framework to extract data

This point regarding framework synthesis and the ''best fit'' framework approach, which both involve extracting data from primary studies against an a priori framework or conceptual/theoretical framework to better understand the phenomena of interest (Noyes *et al.*, 2018) was not relevant for this review (Sweeney *et al.*, 2020b).

Using a software program to inductively code original studies

Thomas and Harden (2008) used NVivo software, which had proved helpful in working in individual studies and across studies developing concepts and themes. However, it has also been acknowledged by qualitative researchers that the use of software should be considered regarding time for getting to know new technology and levels of experience using it (McClean *et al.*, 2019; Braun and Clarke, 2013). McClean *et al.* (2019) also state that it is important to remember, that the computer programs do not do the analysis, but merely help the researcher to organise the data and establish some patterns in the process of analysis (McClean *et al.*, 2019). They stress the importance of getting a low-tech feel approach to data before using computer software (McClean *et al.*, 2019).

For this systematic review (2020b), the researcher decided to use the software programmes ENDNOTE, Word, Excel and manage data in tables. This review was part of the researcher's PhD and thus part of her development as a professional researcher. The researcher thus decided to prioritise getting a low-tech feel for the research process by using pencil and highlighter on hardcopies and developing tables in familiar software programmes. This approach gave a 'hands on' feel' of data and distractions as technical challenges were avoided. However, it is possible that the use of NVivo or similar coding software could strengthen the overall rigour of the research and make the reporting of the research more accessible and transparent to the reader. However, it was sought to provide a detailed report of the research process in the main text and by providing tables and figure to illustrate and support the report (Sweeney *et al.*, 2020b).

Using a logic model of the program theory to inform data extraction, analysis, and synthesis

According to Noyes *et al.* (2018), review authors are increasingly developing logic models to show how an intervention is intended to work. Logic models can also be developed to show causal mechanisms leading to impacts and outcomes and factors that lead to implementation success and failure, including human factors such as patient preferences and experiences (Noyes *et al.*, 2018). This point was not relevant to this review.

CERQual approach

Noyes *et al.* (2018) offer guidance in assessing impact of different qualitative methodologies on the synthesis and interpretation of findings. This includes methods for assessment of study methodological strengths and limitations, selecting a tool to assess study methodological strengths and limitations, using information on study methodological strengths and limitations to include or exclude studies, extracting contextual and methodological information from the included studies, extracting, analysing, and synthesizing findings from primary qualitative studies, locating qualitative findings in qualitative study reports, spectrum of method-specific approaches to data extraction, assessing confidence in syntheses finding, expressing the synthesis and review author reflexivity (Noyes *et al.*, 2018). Rigour in the research process is seen as key, and Noyes *et al.* (2018) thus recommend the use of thorough quality assessment of the research process as transparency and researcher reflexivity (Noyes *et al.*, 2018).

Noyes *et al.* (2018) recommend the use of the 'Grades of Recommendation, Assessment Development, and Evaluation Confidence in the Evidence from Qualitative Reviews (to assess confidence in synthesised qualitative findings (Noyes *et al.*, 2018).

The CERQual approach includes four components for assessing how much confidence to place in findings:

1) the methodological limitations of the individual qualitative studies contributing to a review finding
2) the relevance to the review question of the individual studies contributing to a review finding
3) the coherence of the review finding
4) the adequacy of data supporting a review finding.

(Noyes *et al.*, 2018)

According to Munthe-Kaas et al. (2018), the methodological approaches used in a primary study may have consequences for how much the findings from a study can be trusted. This could be where there are concerns regarding the appropriateness of these approaches (e.g. data collection or analysis methods), or issues about how the studies were conducted, as study findings could be produced that are not an adequate representation of the phenomenon of interest (Munthe-Kaas *et al.*, 2018). One example given is that we may have less trust in findings from a study where participants were recruited in a manner that did not fully address the aims of the research or where the data analysis methods were not appropriate for the study design (Munthe-Kaas *et al.*, 2018).

Applying the guidance provided by Noyes et al (2018), including the CEROQual components, the researcher and the co-reviewers believe to have conducted a review with rigour, transparency and research reflexivity (Noyes *et al.*, 2018). Where there were any issues identified these were reported (quality assessment of individual studies) and in the limitation section (Sweeney *et al.*, 2020b). It is possible that other researchers would have carried out the review differently leading to other findings (Sweeney *et al.*, 2020b). It was sought to report the individual steps in the research process with transparency and rigour, which should assist the reader to determine the trustworthiness of the findings (Sweeney *et al.*, 2020b). However, it is possible that the use of different methodologies in original studies could have an impact on the synthesis of findings (Sweeney *et al.*, 2020b).

Appendix B. Themes, subthemes and illustrative quotations

Theme:	**Providing knowledge and skill**
Subthemes and codes	**Illustrative quotations, including codes in bold**
Professional knowledge & nurse expertise Involves professionalism and creates a sense of trust The nurse and the doctor are highly specialised If the nurses feel uncertain, they check with a doctor Having opportunity to talk to the nurse and pose questions can make patients take their medications. The nurses show that they are well informed about patients' case history Interest in the patients' present situation, Focused on conveying knowledge, support and trust. Making careful plans for further follow up. Knowledge and skill important for a positive experience of care. The patients are well informed about the illness, medication and self-care The nurse is good at informing the patient at this new situation for the patient The nurse has a professional approach The nurse provides knowledge, skill and support The nurses' expertise, specific knowledge of rheumatology and rheumatology care is greatly valued	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 and 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).

Care is based on each patient's unique disease experience and needs, and therefore seen as competent. The nurse's knowledge of the disease and treatment creates a sense of security The rheumatology (nurse-led) care is important to patients Patients feel safe they have contact to the nurse and can call	**'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). **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).
Collaboration & planning of care Providing a good service: coordination of services and avoiding tiring waiting times: blood samples and X-rays planned in conjunction with appointments	**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**

The nurses are well informed about participants' case history The nurse is interested in the patient's problem and wants to help It important to feel that the nurses really are there for the patients Confident in the nurse's competence The nurse will refer the patient to a hospital doctor when needed	**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, Wagner and Hørslev-Petersen, 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 Support in handling anxiety and fear (result of the course of the disease, test results, medication side effects and self-administration of subcutaneous injections)	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**

Support helps patients to gain control of the situation	**do it myself'** (P2. Patient Female, RA 1½ years duration) (Bala *et al.*, 2012)
Educating and guiding patients in self-injection helps patients to confidence and empowerment	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)
Explanation may help patients to follow advice rather than following advice from a brochure	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)
Showing commitment and support by answering questions	
Knowledge and skill are very important for a positive experience of care	**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)
Care is focused on patient education, individually or in groups.	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).
The nurses are proficient teachers in both theoretical and practical subjects	[. . .] **It was easy to learn from them** (P 13, Patient Female, RA 21/2 years duration) (Bala *et al.*, 2012).
The care is described by patients as competent	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).
It is easy to learn from the nurses	
Good at informing the patient at start of disease when everything is new	Encounters with the rheumatology nurse were experienced as **facilitating involvement** and **influence on decisions made** (Original author) (Sjo and Bergsten, 2018).
Facilitates involvement and influence on decisions made	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**

To stay mobile, patients want to see a physiotherapist to help manage the arthritis	**arthritis** (FG2:3, Patient Female, RA 13 years duration) (Ryan *et al.*, 2013).
Being a full player in the partnership (facts and information, and empowering people to be self-manage)	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 is related to nurses taking patients' needs seriously The patients are treated and taken seriously The nurse is sensitive: can see when the patient is feeling bad and ask how the patient is doing. The nurse is interested in the patients' problems and is there for the patient It is key that the nurse know about the disease and has a degree of empathy with what it means to the individual The care is person-centred and characterised by empathy, knowledge, skill and support The nurse is sensitive, sympathetic and attentive The nurses' expertise, specific knowledge of rheumatology and rheumatology care is greatly valued	**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 year's 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

The care is based on each patient's unique disease experience and therefore described as competent A friendly manner, understanding the patient's problems and being taken seriously constitute complete care The patient can talk with the nurse about all problems, which makes the patient feel well The nurse listens very well The personality of the nurse: the nurse is easy to talk to, the nurse is empathic, the nurse considers me as a whole Patients appreciate being recognised when contacting the clinic Feeling seen, heard and believed increase patients' feelings of trust and hope If the patient feels down, it is easier to tell a nurse than the rheumatologist	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 The nurses make patients feel welcome at the clinic, with warmth and kindness The nurses have a gentle, civil manner so patients feel that they care	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

Accessibility is fundamental, that it is easy for the patient to come to the nurse. There is good accessibility It is important that the patients feel that they and the nurses know each other, so there is a family atmosphere The patients feel that the nurses are interested in their problems and that they really want to help It is important to feel that the nurses are there for the patients Patients value the adequate communication: A nurse should be clear, not soft. It doesn't have to bee to soft, it has to be pure and simple A warm encounter helps patients to feel welcome and taken care of A friendly manner, understanding the patients' problems, and being taken seriously constitute complete care The patients don't say as much to the doctor as to the nurse. It is a different relationship The patients feel more on the same level with a nurse than with a doctor The patients can talk with the nurse about all their problems, which make them feel well The nurse listens very well Support from the nurse and being accessible every day for free telephone advice provide a greater sense of well-being and security, and quick solutions and time-saving The contact to the nurse is the best: If the drugs don't work and the patient call the nurse, the nurse calls back The nurse is empathic, kind, practical and will sort things out	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**

The rheumatology [nurse-led] care is important to the patient. The patient feels safer if the patient has contact to the nurse and can call them If the patient feels down or sad, it is easier to talk to the nurse than to the doctor about it Patients appreciate being recognised when they contact the clinic Feeling seen, heard and believed, heard and believed increase patients' feeling of trust and hope	**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 The patients can talk with the nurse about all their problems. It makes them feel well. The nurse listens very well The friendly manner, understanding the patients' problems and being taken seriously constitute complete care	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 patients feel that the nurses are interested in their problem and that they really want to help It is extremely important to feel that the nurses really are there for the patients. The thought of self-injecting can be overwhelming, and the nurses help patients to do it themselves Patients can talk to the nurses when they feel a bit down or sad. Patients don’t talk to a rheumatologist about such matters Support from the nurses and that they are accessible every day for free telephone advice provides a sense of well-being and security, quick solutions and timesaving Patients have increased contact with the nurse during times when they are in need of support Patients appreciate the support from the nurse with phone contact to and from the nurse The nurse helps patients set targets during regular consultations, which have a focus on well-being. Patients need someone to talk to when they are in pain and feel depressed. Patients want to be able to talk to the nurse Patients with RA want the same level support of counselling as offered to cancer patients, and would appreciate the nurse to help with this Trainers [in goal setting] need to master what they are teaching to make it understandable for patients	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 and 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 and 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).

Some patients expect to receive practical and medical information during the [goal setting] course A [goal setting] trainer may offer support, motivation and help to handle a situation	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 The nurses are well informed about patients' case history, and interested in the patients' present situation The nurses are focused on conveying knowledge, support and trust and make careful plans for further follow up	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)**.**
Patients feel that the nurses are interested in their problems and that they want to help. It is very important for patients to feel that the nurses are there for them	'**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).
Patients feel that meetings with the nurses lead to a sense of security, familiarity and participation which contributes and add value to rheumatology care	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).
Patients value contact with the nurse. If the drugs don't work, the patient can call the nurse who will call back. The nurse is empathic, kind, practical and will sort the problems	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).
Patients appreciate being recognised when they contact the clinic, and feeling seen, heard and believed increase feelings of trust and hope	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).
[Nurse-led care] involves professionalism, which in itself provides a sense of security. Patients feel that the nurses know what they are doing	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).
A friendly manner, understanding the patients' problems and being taken seriously constitute complete care	To my mind, a **friendly manner**, **understanding your problems**, and **being taken seriously constitute complete care** (Patient) (Larsson *et al.*, 2012).
Meetings with the nurse lead to a sense of security, familiarity and participation and adds value to rheumatology care	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)
The patients feel safe and rely on the nurses.	**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 patients trust what the nurses say and try to take it in The nurses are very responsive and open to the patients' illness as well a to the patients as persons, which gives a sense of confidence The rheumatology [nurse-led] care is important for patients Patients feel safer if they have contact to the nurse and can call them: The GP may not be able to help and it can be difficult to find a doctor who can drain a joint	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).

Appendix C. Databases searched and number of records 2019 to 2022

Rerun of search conducted 21-01-2022: Repeat of search from March 2019.
Limitation: 2019 to current (21st January 2022).
MEDLINE and EMBASE via OVID: 100 records
CINAHL Plus and PsysINFO via EBESChost: 53 records
OpenGrey: (0 records)

Appendix D. The search strategy January 2022 (Repeat of search, 2019 to 2022)

1.	(experiences or expectations or perception or views or needs).af.
2.	exp "rheumatoid arthritis"/
3.	exp "chronic arthritis"/
4.	exp arthritis/
5.	("rheumatoid arthritis" or RA or "chronic arthritis" or arthritis or "early arthritis" or "inflammatory arthritis").af.
6.	2 or 3 or 4 or 5
7.	exp nurse/
8.	exp nursing/
9.	exp "registered nurse"/
10.	exp "nurse practitioner"/
11.	exp "nurse clinician"/
12.	exp "clinical nurse specialist"/
13.	exp "physician assistant"/
14.	exp telephone/
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.
16.	7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17.	1 and 6 and 16
18.	limit 17 to "all adult (19 plus years)"
19.	limit 18 to english language
20.	limit 19 to human
21.	limit 20 to yr="2019 -Current"
22.	limit 21 to humans

Appendix E. Screening for eligibility of records from repeated search (2019 to 2022)

Records were collected in Zotero for MEDLINE/EMBASE (100 records) and CINAHL/PsycINFO (53 records), Open Grey (0 record)
Records were pooled in Zotero reference system: 153 records
After doublet removed: 51 records remained
Titles checked for relevance: 49 not records not relevant (other diagnoses)
2 Abstract were checked for relevance: 1 abstract (Arends *et al.*, 2020) was not a qualitative study, 1 abstract (Pedraz-Marcos *et al.*, 2020) was a qualitative study and was chosen for full text reading
Abstracts read in full text: Pedraz-Marcos *et al.* (2020). Living With Rheumatoid Arthritis in Spain **A Qualitative Study of Patient Experience and the Role of Health Professionals.**
Paper by Pedraz-Marcos *et al.* (2020) was relevant and eligible according to inclusion criteria and was included in this review as part of the discussion section
Paper by Pedraz-Marcos *et al*. (2020) was quality assessed using the JBI Assessment tool (Martin, 2017), and deemed of good quality to provide (few) data with the patient perspective (participant quotation and researcher quotation) on rheumatology nursing, care and healthcare professionals.

Appendix F. Data extraction from eligible paper (2019 to 2022)

	Paper included
Data extraction: Place: Spain Type of study: interview Topic: Patient experience (Quotes highlighted in yellow)	**Pedraz-Marcos, A. *et al.* (2020) Living With Rheumatoid Arthritis in Spain: A Qualitative Study of Patient Experience and the Role of Health Professionals. *Clinical Nursing Research*. [online]. 29 (8), pp.551–560.**
	'The invisibility of nurses'
	In all cases, patients want a more "humane" professional care (Pedraz-Marcos *et al.,* 2020).
	Youth and inexperience are offered as explanation for the lack of empathy (Pedraz-Marcos *et al.,* 2020).
	"The humane treatment of the doctor from the point of view of the patient is essential" (EM5) (Pedraz-Marcos *et al.,* 2020)
	Hospital staff are young on the one hand and, on the other, they have not lived disease in their own body, they do not live the daily life of being ill" (EB7) (Pedraz-Marcos *et al.,* 2020).
	Sadly, among our participants, nurses are absent from the discourse of our interviewees (Pedraz-Marcos *et al.,* 2020)
	Only in the case of one patient, who was herself a nurse, did a nurse consultation appear as a landmark in the history of the person with RA (Pedraz-Marcos *et al.,* 2020).
	"The work of Teresa (nurse) is essential, she clarifies things for you, listens, teaches you . . . " (EM8) (Pedraz-Marcos *et al.,* 2020).

Appendix G. Interview guide

Section 1: background

- Introduction from the interviewer
- Check and confirm that the participant has read the Participant Information Sheet
- Re-check consent with the participant, including permission to audio-record the interview [Turn on audio-recorder]
- Collect demographic data (professional background, clinical role, time in rheumatology clinical practice)

Section 2: Interview questions

Research questions	**Interview questions**
Research questions	**Interview questions**
• How do clinical nurse specialists define nurse-led care for people with early RA? What does the specialist nurse provide in early RA. Themes from systematic review Providing knowledge & skill: Professional knowledge & nurse expertise; Collaboration & planning of care; Information & education	• Based on your experience, how would you define nurse-led care? • How is nurse-led care in early arthritis different from nurse-led care in established RA? • Are there any special care needs in early RA compared to established RA? • How do you assess and address patients' care needs in early RA? (disease management and impact of the disease) Probe /follow-on questions • How do you make care decisions in early RA? • How do you organise and plan care in early RA? • What are essential areas in the planning of care? • Which type of support do patients need in early RA? • How do you collaborate with other professionals in early RA clinic? – what do these professionals add to the care that you provide?
	• How would you describe the relationship between patients and you as the specialist nurse?

Themes from systematic review Using a person-centred approach: Person-centeredness & empathy; Communication & therapeutic environment	Probe questions (if not covered) How do you establish this relationship?
Themes from systematic review Meeting patients' care needs: Empowerment & psychological support; Security & confidence	• What would you describe as good care in early RA? • How would you know if patients' needs have been met? Probe questions: • What are challenges in early RA care? • What works/What does not work?

Section 3: Conclusion

- Is there anything you would like to add before we finish the interview?
- Thank you again for being part of this study
- I have now stopped recording.

Appendix H. Final ethics approval of Study 2

Final ethics approval letter page 1.

UWE Bristol

Faculty of Health & Applied Sciences
[redacted]

UWE REC REF No: HAS.20.03.143

1st May 2020

Anne-Marie Tetsche Sweeney

Dear Anne-Marie

Application title: Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: An interview study

Thank you for responding to the conditions raised in my letter to you of 21st April 2020.

I can now confirm full ethics approval for your project, but please note the proviso below.

In light of the current situation regarding COVID-19, we can only authorise an immediate start for activities involving human participant research that do not involve face to face contact, or activities that do not breach either national laws or University policies. In these uncertain times, law and policy may change swiftly and frequently.

We are, however, continuing to scrutinise and grant ethical approval for activities that cannot take place at present, to ensure that once the situation changes and activities can go ahead, the research is not unnecessarily delayed.

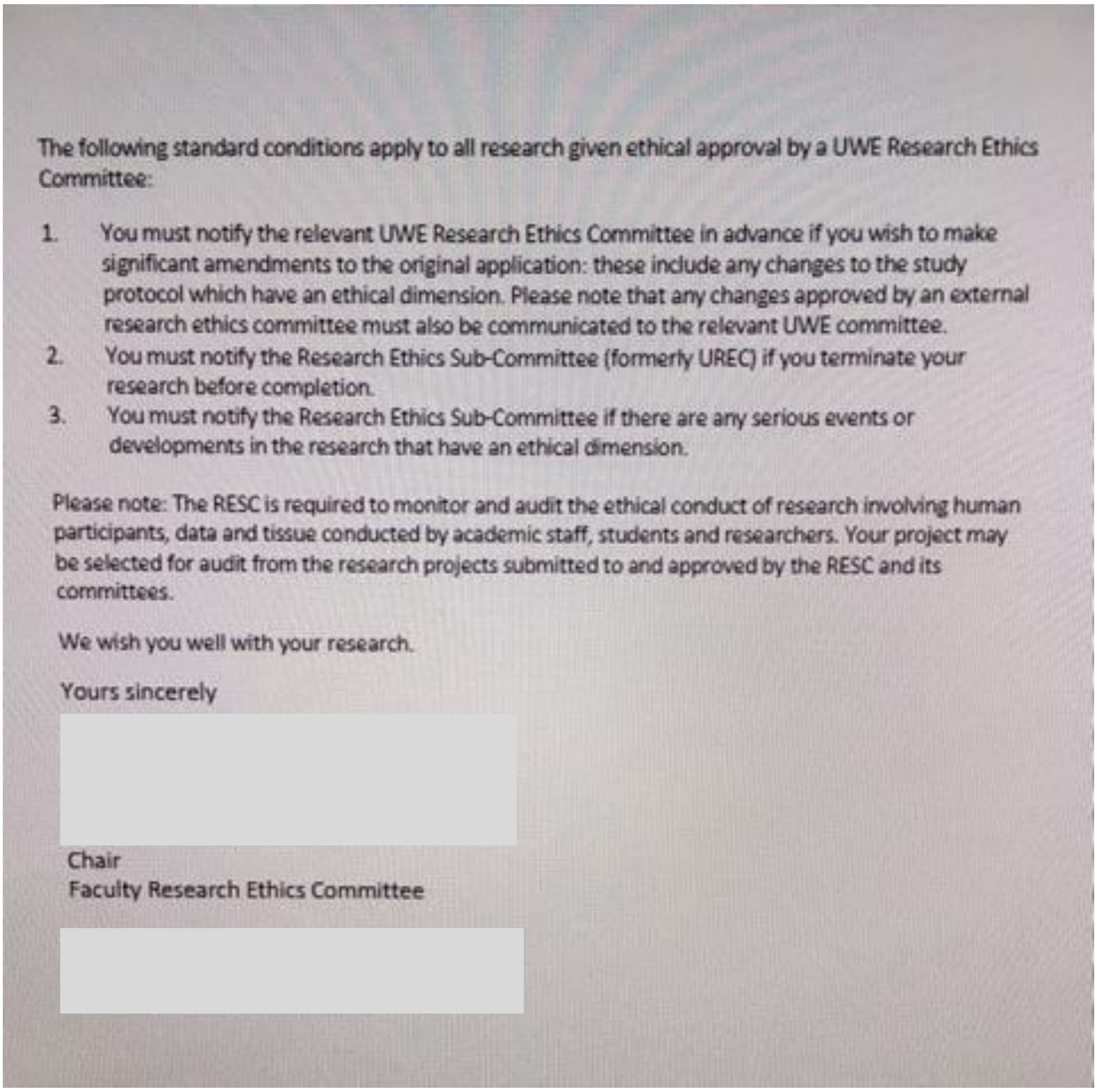
What this means for your application:

1. If your application DOES NOT involve activities affected by the current crisis (e.g. online surveys or telephone interviews etc.) then you may start your research as soon as you receive this formal notification of your ethical approval;
2. If your application DOES involve activities affected by the current crisis then you must not start your research until you are lawfully and safely able to do so, and when it does not breach the University's policies. This will affect the dates you have supplied on your application form in relation to start and finish. When you have new dates, please can you write to us in order that we can add this information to your file?

If you are a doctoral student and this will affect your research timetable, please speak to your Director of Studies and the Graduate School for advice on how time delays will be supported by the University.

RESC Decision letter Full approval Version 14 1/04/2020

Final ethics approval letter page 2.



The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the Research Ethics Sub-Committee (formerly UREC) if you terminate your research before completion.
3. You must notify the Research Ethics Sub-Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The RESC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research.

Yours sincerely

[redacted]

Chair
Faculty Research Ethics Committee

[redacted]

Appendix I. Participant Information Sheet

Participant Information Sheet

Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: An interview study

Version 2: 21stApril 2020

You are invited to take part in an interview study about nurse-led care for people with early rheumatoid arthritis. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Anne-Marie Sweeney:

[redacted]

Who is organising and funding the research?

This study is as part of a PhD programme for undertaken by Anne-Marie Sweeney and supervised by Dr Mwidimi Ndosi, Senior Lecturer in Rheumatology Nursing, Faculty of Health and Applied Sciences, University of the West of England (UWE), Bristol.

What is the aim of the research?

The current standard for managing rheumatoid arthritis (RA) requires early detection, early start of treatment, intensive therapy and tight monitoring of disease until remission or state of low disease activity. The early stages of RA can be challenging for the patients as they might be in severe pain and struggling to self-manage their condition, treatment and complex needs. There is good evidence to support the effectiveness of nurse-led care in RA. Few qualitative studies have explored specific aspects of nurse-led care such as patient education, supporting self-management and interaction styles but we do not have a framework of nurse-led care in early RA.

This study aims to understand from the perspectives of rheumatology clinical nurse specialists what comprises nurse-led care in early RA.

To address the study aim, we plan to carry out interviews with rheumatology clinical nurse specialists who run nurse-led clinics and have experience with nurse-led care for people with early RA. Later, a separate study will explore nurse-led care in early RA from the perspective of patients and both studies will inform a provisional framework for nurse-led care in early RA.

Why have I been invited to take part?

You have been invited because you are a rheumatology nurse specialist with experience in caring for patients with early RA. We are interested in gaining information about your experience and views of nurse-led care for people with early RA, so in the interview, we will ask you about these things.

Do I have to take part?

You do not have to take part. If you do decide to take part you will be given a copy of this information sheet to keep, a privacy notice with information about data security in this study as well as a consent form that you will be asked to sign. You will be able to withdraw from the research without giving a reason until your anonymised data are included in the data analysis.

What do I have to do if I take part?

You will be asked to take part in a telephone interview with Anne-Marie Sweeney. Date and time of the telephone interview will be arranged by Anne-Marie Sweeney at a time convenient to you. The interview will take approximately 30 minutes and it will be audio-recorded and transcribed. Immediately after transcription, the transcripts will be checked for accuracy and the audio-recording will be deleted.

What are the benefits of taking part?

If you take part, you will be helping us to gain a better understanding of what comprises nurse-led care for people with early RA. This could help inform future improvement work of the service. This study will not benefit you directly.

What are the possible risks of taking part?

We do not foresee or anticipate any risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the telephone interview to stop.

What will happen to your information?

We will ask about your professional role and how long you have been working in rheumatology. All the information we receive from you will be kept confidential. We will anonymise the telephone interview transcripts by removing the names of people and places. Hard copy research material will be kept in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements.

Where will the results of the research study be published?

The results of the research will be written up and form a part of the PhD thesis available on the University of the West of England's open-access Research Repository. The findings will also be published in a peer-reviewed journal and presented at rheumatology and nursing conferences. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by the Faculty of Health and Applied Sciences, University of the West of England University Research Ethics Committee. *(This will be written after REC approval).* Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England: Researchethics@uwe.ac.uk

What if something goes wrong?

If you have any concerns, queries and/or complaints about participating in this study, please contact Director of Studies, Dr Mwidimi Ndosi: [redacted]

What if I have more questions or do not understand something?

If you would like any further information about the research, please contact Anne-Marie Sweeney,

[redacted]

Thank you for agreeing to take part in this study.
You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

V2. 21.04.2020. Anne-Marie

Appendix J. Participant Privacy Notice

Notice for Research Participants

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in the project:

Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: An interview study

'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes. If you need to consider this, please contact the Data Protection Office: dataprotection@uwe.ac.uk.

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes. If you need to consider this, please contact the Data Protection Office: dataprotection@uwe.ac.uk.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by Faculty of Health and Applied Sciences, University of the West of England University Research Ethics Committee. *(This will be written after REC approval).*

Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

The research team adhere to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at:

www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers adhere to The General Data Protection Regulation (GDPR), implemented in the UK by the Data Protection Act (2018), states that there must be lawfulness, fairness and transparency in relation to any data subjects.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation you have the following **qualified** rights:

(1) The right to access your personal data held by or on behalf of the University;
(2) The right to rectification if the information is inaccurate or incomplete;
(3) The right to restrict processing and/or erasure of your personal data;
(4) The right to data portability;
(5) The right to object to processing;
(6) The right to object to automated decision making and profiling;
(7) The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager [redacted]

V1. 24.02.2020. Anne-Marie Sweeney

Appendix K. Participant Consent Form

Participant Consent Form

Version 1. 24.02.2020

Nurse-led care for people with early rheumatoid arthritis from the perspective of clinical nurse specialists: An interview study

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet.

If you are happy to take part in a telephone interview, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree that anonymised quotes may be used in the final report of this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time until the point at which my anonymised data are included in the data analysis.
- I agree to take part in the research.

Name (Printed)…………………………………………………………………………….

Signature (Typing your name again is accepted)…………………………………………… Date……………………..

V1. 24.02.2020. Anne-Marie Sweeney

Appendix L. Themes and subthemes with illustrative quotations

Theme:	**A specialist service delivered by experienced rheumatology nurses**
Subthemes Codes	**Illustrative quotes**
Specialist training and experience Using knowledge, experience, and skills to plan and deliver care The specialised nature of the service unknown to many Extensive clinical experience In-house training before running own clinics The need for specialist training is acknowledged by the nurses Access to conferences seen as beneficial and 're-vitalise' the nurses	*Basically what we do is**, we keep them all out of hospital**, because **we treat them**, and I think **this is another thing why people don't understand**, because they think outpatients, they think we just take the notes to the doctors, and they see the patients, but it's not like that at all [...] We have I think, about 14,500 patients in rheumatology (CNS16).* *And it's **to know, know and to have the experience and knowledge** is absolutely critical (CNS04).* ***Working sort of independently**, but equally very much **alongside the rest of the rheumatology team**, in delivering care (CNS02).* *When I first started**, I had no idea how massive or how specialised rheumatology is**. I think that's something that actually **so many people don't know** [...] Nobody could just come into this department and come and help us out for the day, because they wouldn't know where to start. So **we cover each other basically** (CNS16).* *[Nurse-led care] **It's to know, know and to have the experience and knowledge is absolutely critical**. What has happened over the last three months in particular [**the outbreak of COVID-19**] there has absolutely come to the forefront is how the age-old thing of the **specialist nurse being pulled from their role** at the first sign of any deficits that are on the ward. And we are always the ones that are, right specialist nurses, we need you, you need to go on the wards (CNS04).* *Everybody understands the pandemic and what happened but this preceded that, if there was any deficits on the ward, the first people that were looked at were the specialist nurses because **nobody understands the role that we do** (CNS04).*

*I think **we're hugely important in the whole of the rheumatology experience**. I think we play a major part. We are **their support**, we're **their educator**, erm, you know we're sort of like, almost like we're **the corner man** (CNS04).*

***We're there for them, they know that, we're there to maintain and ensure their safety. To ensure that they get their prescription, to ensure that they absolutely understand why they're having** that because it's the most important thing (CNS04).*

***My job is to manage the rheumatology department** on a daily basis. Also looking at **implementing changes** from sort of management perspective and **working very closely with the divisional and speciality managers and our rheumatology lead**. And also **managing my group of nursing staff, and day care staff team** (CNS02).*

***I'm a nurse prescriber so I can prescribe for patients**. So **that's, really crucial actually to my role now**. It's made a **big difference to my practice** (CNS08).*

***A lot of work is going on**, I know **in RCN** [Royal College of Nursing] at the moment **with the framework** (CNS07).*

***So the first few months I spent in Rheumatology, I had an induction** which involved, **which I was able to sit in, on clinics run by my colleagues, the other Rheumatology Nurse Practitioners** and also, **Consultants, Registrars clinics**, and **then sort of gradually I built up** and obviously I did a lot of sort of personal study, you know, sort **of developing my knowledge**, and **then I started off in running an Education clinic** (CNS13).*

*I came in from, a Band Six, on the ward, to a Band Six Rheumatology Specialist Nurse post. And basically **got all my Rheumatology training once I started here**, so I **had a sort of a three month preceptorship period**, whereby **I received the training, so that I could go solo**. But you know, what it's like **with Rheumatology, you never stop learning** (CNS14).*

***I had, quite a long introduction period** but actually, **because it's so specialised I understood**, you know, **why you couldn't be allowed to see patients until you know, the basic, skills and, knowledge to do that** (CNS16).*

***I have extended my practice, so I'm a prescriber** and I do*

	soft tissue and joint injections. I've got a ***Master's in clinical science,*** *so I apply that to my role. Er, I've* ***got a background in, dermatology, rheumatology, cardiac intensive care and neurology,*** *before I came into specialist nurse role (CNS03).* ***I go to a group every, … four times a year*** *where we, we …* ***all the prescribers in the Trust*** *get together and* ***they have speakers and talk and discuss things****.* ***So you're encouraged, obviously, to keep your skills up to date and audit your practice*** *as well. So … I mean there's,* ***there's a lot of education that, that the drug companies prov****ide and then obviously* ***there are conferences as well****. But all of these things are* ***a challenge to get the time off to go to and get the funding to go*** *to (CNS08).* ***A bit more support for nurses to go to the conferences would be good*** *[…] When you go* ***there's just so much to learn*** *and* ***it really does kind of re-vitalise you*** *(CNS08).*
Autonomy in clinical practice Working with a high degree of autonomy Some nurse specialists are prescribers Treatment protocols allow non-prescribers to increase medication Nurse specialists manage patients' medication in early RA Autonomy and independence vary from clinic to clinic Autonomy especially important during the COVID-19 pandemic	***We run our clinics independently*** *(CNS14).* ***We have patients who don't see a doctor for years and years*** *[…] (CNS10).* ***Depo Medrol we have a PGD*** *which* ***allows us to give rescue PGD Depo Medrol*** *(CNS04).* *We also do a lot****, we also have what we call PGD's****, so* ***Patient Group Directives****. So* ***we are able to, with our own PGD****, for example,* ***it's not prescribing****, but* ***we are able to give for example like Intravascular Depo-Medrone injections, just by going by our PGD's****,* ***our Escalation clinics as well, we have like a protocol that we can go by****, so* ***we are able to liaise with the GP's, and basically say can you please increase Methotrexate****? For example, again* ***we're covered by all sorts of protocols*** *like that as well. So you know,* ***we're quite autonomous*** *really as well,* ***and especially during this pandemic*** *(CNS14).* *So* ***in clinic if I feel that there's a need to make clinical decisions on patient care, I can make them, if I'm not quite sure, I can always bring it up****,* ***we have a monthly Biologics meeting****, or* ***I can email one of the doctors*** *or* ***go and speak to my colleagues about it****.* ***So definitely lots of nurse led decision making,*** *and* ***quite a lot of sort of nurse led care, we're quite lone working in clinic****, a lot of the time, even though there's people to go and ask, but yeah* ***quite often we're sort of making a decision*** *(CNS09).*

	**I know I've got the backing of a really good medical team** and **I've got a good team that I work with**. **So I feel safe in my practice** (CNS08). _I **think I work differently to my colleagues, I have a different background to my colleagues** and I **think that's reflected in how I do things. So I'm very conscious of**, you **know looking at the psychosocial side of things and how that impacts, more so than my colleagues**. And I don't mean that in a pompous way, it's just that **I've had a training in counselling** and, you know **the particular interests I have** (CNS07)._ _Well, **I've always worked autonomously**, so **I would define nurse-led care as one where the nurse makes the decision for the treatment of a patient**. I know that other people run nurse-led clinics, but also defer to consultants about treatment changes. So I don't consider that to be nurse-led care (CNS03)._
Collaboration with the multidisciplinary team Close working relationship within the nursing team Relying on each other for advice and backup Good collaboration with MDT - confidence to perform extended roles Colleagues and the MDT - vital for learning and development Clinical practice as a collaboration and joint effort to provide good service Close collaboration with rheumatologist and the medical team The medical team trusts the nurses	_I've worked in a lot of areas, and **personally I think the patients do get a really good service in rheumatology from the nurses**. And I think **a lot of that is down to the team** (CNS08)._ _**I was in and out of the clinics all the time, asking the other girls for advice**, but **that's how you learn** and I think, I **think the patients respect you for that**, that you know, **you don't pretend to now things that you don't know**, because there's no point, because you get found out [chuckling] (CNS13)._ _[Nurse-led care is:] **Working sort of independently, but equally, very much alongside, the rest of the rheumatology team, in delivering care** (CNS02)._ _I think **knowing that you've got a Multidisciplinary team is really helpful** (CNS09)._ _**I'm working, you know as a lone individual in clinic**. **But in the early rheumatoid arthritis side of things there's always a medical person around.** So **we're running in tandem really**, so we can bounce things around, and you know **we can collaborate**, I guess (CNS07)._

Collaboration between the patient, the clinician and the nurses Working together for a common goal.	*So **the first, the visit one is normally about an hour** [...] an hour appointment, so basically the, the set up of it is, **that they come back, we talk to them about how the, the Pathway appointment system is going to work**, so just **first of all what they can expect in terms of appointments** that are coming up you know, **who they're going to see**, **who works for the department,** you know, so you know, and also **again making sure they've got the Help Line number**, so **even if they have an appointment, if they need to access us, before that, they can** (CNS11).* *[Defining nurse-led care] Yeah I think, I think it', it's, it's, **it's a collaboration** I would define it, **between, the patient, the clinician, the nurses**, so that you're, **you're all working together for a common goal**, which is to, you know, **you want to sort of halt the disease process**, to, you know, sort of **prevent long term damage**, you know, **you want a caring approach**, you want, **you want to sort of instil trust, and confidence in your patients** (CNS13).*

Theme:	**Addressing patients' complex care needs**
Subthemes codes	**Illustrative quotations**
Early disease management with treatment, education and support Involved in RA management from start of the disease RA management is evidence-based - Treatment according to international recommendations and national guidelines - Treat-to-target strategy – aiming for remission with intensive treatment	***I do see patients as early inflammatory arthritis***, *and have done the pathway clinics, but there are a couple of nurses in particular that do tend to manage those, so it's, very much nurse led (CNS02).* ***We look after the patients from diagnosis*** *(CNS04).* *So in the trust I work at our role would be **seeing people following diagnosis. Reviewing** them, **measuring the efficacy of any treatments** that have been instigated. And then you would be **more of a collaboration rather than a nurse led** in **terms of actual clinical management**, in terms of medicines, **working with consultant colleagues** as to, you know, **if alterations are required** to that **medical decision in terms of medicines** (CNS07).*

Following RA pathways and protocols To start treatment and keep in treatment	*So **treat to target**...**escalating treatment as necessary**, and **addressing any concerns that the patients might have’** (CNS14).* *Early arthritis clinics were started when it became known that **the quicker people were treated, the more effective the outcome** (CNS06).*
Nurses run various types of clinics Education clinic and start of treatment. Nurses provide timely and balanced information and education (to get the patient onboard) Escalation clinic with close monitoring Review for further treatment or follow-up Follow-up clinics Annual review clinics Direct Access Clinics Biologic clinics	*So **there’s a plan for, the, you know, the categorisation of patients at the beginning is made by the doctor** that diagnoses them and then **they go on one of two pathways** which is then, **a pathway involving different degrees of medication**, and depending on their disease activity obviously it’s treat to target (CNS08).* ***We’ve got the RA care pathway which is an integrated pathway** with, **with input from the medics and nurses, the occupational therapists and the physios** so it’s a little bit more **structured and sort of following the rules**, if you like (CNS08).* *[Good care], well, **quick diagnosis, and being emphatic and being on the patient’s wavelength**, so, ‘**We realise what a surprise this might be, or a shock’** […] So we tend to **try to find out what their concerns are, and address them**, and **get them seen** [by specialist] **as quickly as possible** now, nowadays […] **And make sure we’ve done all the investigations and the assessment to accompany the referral letter**, you know. And then the hospitals get the bloods and the x-ray results off the website, you know, the pathology website. **So it sort of hopefully stops the delay** (CNS05).*
Nurses manage medical treatment Disease-Modifying-Anti-Rheumatic-Drugs (DMARDs) Offering patient choice of DMARDs Biologics treatment Limited patient choice in biologic treatment	*So when patients are **newly diagnosed, within a week of diagnosis, they'll get, … an appointment with a specialist** nurse, and **that appointment will be for about an hour**, and **it'll go through all the medications**, that we want them to start, and that will depend on whether we're having them in to sort of a **moderate pathway, or a more, comprehensive, pathway**, depending on their … their actual type of disease, and how bad their disease is (CNS02).* *And so **we will go through all the medications, the side effects of the medications, make sure that they have good understanding about blood monitoring** (CNS02)* ***I manage their ongoing care from really the time of diagnosis** to, chronic long-term management of their*

Steroid treatment Alternative medicine	*disease basically. So I think* ***my role very much is you know, the listening, the giving information, that's the initial part, giving information and trying to get patients to manage their symptoms and manage their arthritis*** *(CNS15).*
Help patients to adjust to the disease Essential to educate and support Fear of medication Fear of needles	*She doesn't like us as the collective nurses and doctors,* ***she's afraid of us and our medicines*** *[…] And* ***there's a whole issue there about establishing a working relationship*** *with her to find out what's gone on and what she needs and, you know what does she want for herself? (CNS07).*
	Good care is to help with our knowledge*,* ***knowledge of the condition, to help them to be the best that they can be****, with that condition and for them* ***to have strategies for setbacks*** *(CNS06).*
	We all have obviously our designated clinic time*,* ***so we'll either do, Education clinic, we'll either do an Escalation clinic****, we'll either do a Follow Up clinic, we have loads of clinics […] I even do Osteoporosis clinic as well. Oh we have loads,* ***Follow Up****, we have, what other clinics, I'm trying to think,* ***Annual Review clinic****. We have a* ***telephone Annual Review clinic****, and* ***Osteoporosis clinic*** *(CNS12).*
	So the first, ***the visit one is normally about an hour*** *[...] an hour appointment, so basically the,* ***the set up of it is, that they come back****,* ***we talk to them about how the, the Pathway appointment system is going to work****, so just first of all* ***what they can expect in terms of appointments*** *that are coming up you know,* ***who they're going to see****,* ***who works for the department****, you know, so you know, and also again* ***making sure they've got the Help Line number****, so even* ***if they have an appointment, if they need to access us, before that, they can*** *(CNS11).*
	It's quite a shock*, and it's just around****, initially around helping to, help people come to terms with perhaps a diagnosis*** *before you can even start to thinking about, them taking onboard, medication and side effects, and managing their disease, long term (CNS02).*
	We ... ***from the very beginning*** *it's ... I think* ***the biggest thing is the explanation of everything that we do****.* ***Why we're doing that*** *and at any time we give them written ...* ***we designed in the department****, for example for* ***methotrexate and you educate patients****.* ***There's such a***

huge amount of information. *We* ***designed a top ten*** *in order* ***to just give them the top ten salient points*** *and* ***also the same for the arthritis, for their diagnosis of RA.*** *And* ***we spend a lot of time in the early days from the education appointment to explain that actually it is vitally important that they start treatment,*** *but* ***equally it's vitally important that they understand why and what's happening to them*** *(CNS04).*

If they're going to go onto subcutaneous, say, methodrexate…then we will help with that*. Now,* ***the nurse practitioners at the hospital usually start them off,*** *but* ***we always get them in to check that they're happy and make sure they've got sharps box, and they know how to do*** *it (CNS05).*

We see them a lot at the beginning, for example, at six weeks*, they've not really responded that well to treatment.* ***Do they need a bit of Physio? Do they need a bit of OT?*** *Probably almost certainly yes.* ***Most of it is talking and just drawing out bits of information from people*** *(CNS13).*

They [the patients] go through the, nurse led escalation clinic*. So* ***all patients, all early RA patients will go through there,*** *and the drugs escalated according to our pathway.* ***But seen really just by the nurses during this time*** *and then* ***at month six, if they have reached stability and they're in clinical remission defined by DAS28 then they'll then go into annual review or patient initiated follow up*** *(CNS04).*

Nurse led care, that, that's what we do, we also do Escalation clinics*, so for patients that have, they're* ***newly started on medication, they go into the Escalation clinic****, so* ***they're early closely monitored*** *and* ***we have a, an Escalation protocol that we can follow****, so we have, you know,* ***as long as there are no contra indications to it, we start patient on Methotrexate****,* ***escalate the Methotrexate add in Hydroxychloroquine, switch to Subcut Methotrexate, look at adding in a third DMARD****, so* ***we can get all the, things that need to be done, as far as the NICE Guidelines are concerned in that six month period, prior to them going for Biologics*** *(CNS14).*

***Once we are happy with that** [disease control] **and we move them over into a Follow Up clinic, it's much more of a holistic approach**, in the Follow Up clinic, so we're **looking at other comorbidities that might coexist with the Rheumatoid Arthritis**, so **Cardiovascular Disease**, so **we look at their key risks, we're looking at their Osteoporosis risk** […] So we're **looking more around the subject**, we're **still making sure we've got control of the disease** (CNS14).*

***As far as the NICE Guidelines are concerned in that six-month period, prior to them going for Biologics** and **if they fulfil that criteria at six months, we've ticked all the boxes we need to, so we can then just refer them straight for Biologic**s and **we haven't lost any time**. So **they're followed up quite closely**, they're usually, well **used to be seen, now called on the telephone, every four to six weeks** (CNS14).*

*And **then they go to my colleague, the biologics team and the patients then are assessed and, put on biologics and they're managed by the biologics team** (CNS04*).

***I start them off, do the whole lot, also biologics** (CNS15).*

***Mainly what I'm prescribing is biologics**. **The second most common thing I would prescribe would be disease-modifying drugs**, then **rarely anti inflammatories**. It probably is **primarily biologics** (CNS08).*

***We can't prescribe something that's right down the** [list], **we have something called a cost calculator**. So **we couldn't prescribe the most expensive, because it was more convenient for somebody straight away**. If we had a good reason, we could take it to the Finance Board, which pharmacy kind of deal with and they can take the case there and they can discuss whether it's appropriate or not (CNS09).*

***The ideal is that they alternate between seeing a consultant once then us then the, then the nurse then the consultant nurse**, but it doesn't' work out that way. So in honesty, **the vast majority of patients are really reviewed purely by the nurses**. Particularly once we get them, **if we get them established on biologic therapies,** because they then to be the most stable patients, **they mainly get follow up by the nurse almost completely,** with an **occasional sort of once every two/three years input from the consultant** (CNS01).*

***The annual review will basically look at medication, side effects, bloods, cardiovascular risks**, and **if we able to start deescalating, so start reducing their medication** (CNS16).*

***I also, run my own clinics, for direct access review patients**, so **patients that are on the direct access system,** and **haven't been seen for two years,** who … and **haven't requested a medical review before then**, actually **come up to see me, and I review them,** from my perspective (CNS02).*

***They [the patients] would be started on methotrexate**, for example, and then we ... because **we do all our monitoring as well** (CNS04).*

***They also have the fear of all the medication** and **particularly what I've found, is the misrepresentation of, of Methotrexate** really (CNS13).*

*And **she actually responded fantastically** [to biologic therapy] in the first 'three months […] **It was only when she actually got to the point where she had a new baby granddaughter and she couldn't pick the baby up**. And that's what changed her mind […] and then she did fantastic (CNS01).*

***It can be very emotional**, very emotional, especially you know, **if patients you know, we've had a couple of patients who have, maybe put off starting a** family until slightly later in life and **then this has developed** and they were at that point where they were just about to start and **then we're telling them, oh no well you can't, and we need to get your disease under control** first, which could take six months to a year, then you have to come off the medication for six months, before starting and that's a year an a half down the line for them. You know and it's massive. So yeah, **we have very emotional conversations about what's the best avenue to go down** (CNS14).*

***In early RA I think we need to be a lot more, aware of the psychological impact of a new diagnosis**. **People need information**, but **they need information at their own pace,** so **we need to make room for the fact that we might need to see them more frequently**. Not just **because of their arthritis and escalating**, but **also to give the right support and help people to get on track**. (CNS03).*

***We need to be aware** that **we need to have the right information at the right time for the patients**. And also **building up the relationship is very important early on**, an **making sure that we're completely open, honest and trustworthy** […] so that **the patients are more likely to have a better experience**. And **are more likely, where the evidence is good for that particular treatment plan for them**. **And not delay treatment because of anxiety or uncertainty** (CNS03).*

***We do get a lot of patients who are needle phobic**, so **there's lots of kind of talking through different techniques.** The **dummy pens are really good**, um, because I think **lots of needle phobic patients worry that it looks like a needle** (CNS09).*

***Some people will be familiar with self-administration**, they **may have an auntie, an uncle or a relative, a friend who injects something similar**. They might **know somebody who's diabetic who injects** and they may say […] I can do that. And **some people may feel very confident to do that with some coaching** […] I think **it is becoming more commonplace in our trust the self-injecting** isn't it, **we don't do the teaching actually, that's delivered by a home care company** [biologic treatment]. And **for some drugs [Methotrexate] it's done within the hospital but via the chemotherapy suite nurses** (CNS07).*

***We've got four, five nurses in the department, who can show them how to inject Methotrexate**, because **it is like a toxic**, **they need to be really careful** with it. So **lots of patients obviously come in, they're quite nervous about self-injecting**, lots of them **have never had to do it before** (CNS09).*

*We have a **huge number of patients that are on injectable methotrexate** and **it's managed very well**. And **nowadays with the pen it's just so easy** […] So they manage very well, very well and **they have an education appointment, with any drug and you know, especially methotrexate** (CNS04).*

***Whichever homecare company is delivering the drug will go and see them at home and then train them and watch them inject themselves at home** […] **It's a brilliant service but it takes some of the emphasis off us but also, for the patients,** it's **really reassuring for them to be doing it at home, having somebody there**. They **stay with them**, sort of **half an hour after they've done the injection to make sure they're feeing okay**. So it's it's a brilliant service […]*

*Private healthcare company**, and **it's paid for by the drug companies** (CNS08).*

***I would always try and give somebody the benefit of my experience** (CNS08).*

*I **think the sooner that people understand their condition**, and that **if it's not treated, it is going to get worse**, and that you know, it can't be fixed just like that. The sooner they understand that, the more likely they are **to get onto the correct medication**, you know, and **to have a better outcome**. Yes, that's why I think it is important, very important. **And to have the support**, because **it's very frightening** isn't it, to sort of maybe suddenly wake up and your hands are painful and swollen and you can't move them properly? (CNS06).*

*I mean obviously**, we always tend to go for … because, for Methotrexate first,** if we can. But **there are many patients who won't have Methotrexate**, no matter what you tell them. So obviously, the … but we do leave it, you know. Obviously, we sort of go to them with what we'd like them to have, but **if a patient really doesn't want to, then we, we think again and have a choice** (CNS01).*

***I do see patients that are newly diagnosed and talk about disease modifying therapies** […] So currently I run three nurse-led clinics a week, primarily seeing patients that are on biologic therapy […] **So screening them to start therapy, assessing their response to therapy and then switching therapy** if they, um, if they're failing to respond to treatment (CNS08).*

***Regarding biologics, er, we do have a pathway again that we have to work to** […] So **we go by the NICE guidelines** […] So they obviously suggest to, anti-TNF first, but without the specific reason why a patient should have one drug rather than another, **we tend to leave it to patient choice** (CNS01).*

*We can't prescribe something that's right down the**, we have something called a cost calculator. So we couldn't prescribe the most expensive,** because it was more convenient for somebody straightaway. If we had a good reason, **we could take it to the Finance Board**, which pharmacy kind of deal with and they can take the case there and they can discuss whether it's appropriate or not [...]But **as nurses, we can't really make that decision**, we can suggest it, but **if there isn't a clinical reason for someone to***

***have the more expensive drug**, we generally wouldn't, we wouldn't give it (CNS09).*

***The consultants are the ones that, did the joint injections**, but **we can give an intramuscular, steroid if we feel it's appropriate** [...] So **that would be if a patient was in a real, really bad flare**, and, you know, and it isn't settling down at all, but sort **of assessing on an individual basis**. And obviously, **not to keep, to administer them all the time, but just as a one off**, a short, **quick fix** answer or for instance, I've even given them if patients, you know, come in and they're going to a wedding on the Saturday and need to be really well or going on holiday and they want to have a really, bit of a boost. But then you'd be looking at, the steroids would be the short, quick fix, **then you'd be looking at changing medications to get them better under control.** Because obviously, **you need to use as little steroid as possible** (CNS01).*

*[The patient says] I'm **going to go down the herbal route** [instead of taking Methotrexate], **I'm going to take cannabis,** whatever... And you say yeah, that's absolutely fine, **that's completely your decision**, but **cannabis will help with the pain,** but **it won't stop the destruction of your joints**. You know, so it is just all about you know**, informed consent, giving them all the information, and if they want to make that decision that is entirely up to them**. That's their body you know, they … **we would never force anyone to do anything they didn't want to** (CNS16).*

***I think that we're hugely important in the whole of their rheumatology experience**. **We are their support, we're their educator, you know, we're sort of like, almost like we're the corner man**. **We're there for them, they know that, we're there to maintain and ensure their safety.** To **ensure that they get their prescription**, to **ensure that they absolutely understand why they're havin**g that because **it's the most important thing** (CNS04).*

*You know, **they must understand why, why we're giving this, to reassure them that we can keep an eye on their safety, that we've got their backs**, that **we're watching their bloods, we're watching everything**. And **that we can help them**, that **when they come to us it's the worse that they're ever going to be** and we can make sure that, you know, **we're there to get them back to where they were before**. To **make them more productive** and **go back to work** and **to get their identity back, to being a mother,***

***being a wife, being a sister, being a brother**, whatever. And I think we are hugely important (CNS04).*

***There are now two, I think two or three biologics that are safe to continue throughout pregnancy**. But obviously, **that again is down to individual choice** (CNS01).*

*What I do is I say you [the patient] know**, I'm going to give you the information, for you to make an informed decision, so I let them take control** and I'll say, you know, **don't feel any pressure whatsoever**, **you go away, you think about it**, **talk about it with your family**, **you call me when you've made a decision** […] **If you think of any other questions in the meantime, give me a call**, **I'll answer any questions that you have**, and kind of **let them know it's okay to be like that**, it's fine, it's absolutely fine, **we will support any decision** that you make **and if you change your mind, then that's absolutely fine** (CNS14).*

*[How to approach education] The … **how do we approach, what when we educate the patient**s?*

INT: Yeah, for a new patient sitting there in front of you, or …?

*RES: Okay, so er, **I've got a list here** this afternoon actually, **for education**, so I've got er, **various medications on there**. So what I would do is um, obviously **ring the patient, and I'd have a look at their last letters**, **have a look at their bloods**, and then ring them and say you know, this is er, obviously … you know, you saw whoever at your last appointment, and **they've asked me to talk to you about this medication, is that what you expected**? Yes. So t**his is the condition you've got** and t**his is how this medication works on your particular condition.***

*So I sort of **give them a bit of background**, because it's amazing the amount of patients that say I don't know what I've got. Um, oh, I haven't got arthritis then? You're like no, this is very different. Um, **so you explain it to them,** er, **explain to them all about the medications**, so it would be kind of er, **what the doses ar**e, **how to take it**, **what the side effects could** be, **about the blood monitoring, about medications that they can't have with that**, with that. Um, **alcohol, conception, we go through all of it with them** (CNS16).*

*[…] **we explain about the disease activity score and joint examination**. When we're going along, **we're also teaching***

	patients and explaining to them the different joints and what we're looking *for because* ***we're educators as well*** *(CNS04).* ***So patients do get some quite bizarre things into their minds*** *that they* ***think they can't do this anymore because they've got rheumatoid arthritis****. And actually,* ***it's about talking to them to say that really, it shouldn't be stopping them doing anything*** *if, you know,* ***if you had a good outcome, it shouldn't stop them doing anything. They should lead, lead a totally normal life*** *(CNS01).*

Monitoring treatment, disease impact and patient outcomes Monitoring treatment – response and side effects Monitoring disease activity/disease impact - disease control - managing disease impact, managing medication and side effects - wellbeing - keeping in work Using RA protocols - to check necessary blood tests - ask relevant questions Using validated outcome measures Assessing disease activity/ impact & treatment response - Blood tests for and x-ray - DAS28, HAQ and VAS - observation of movement	*[How to know when patients' needs have been met?]* ***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).* ***First of all, you, you literally look at the patient when they walk through the door, how they've walked through the door*** *[chuckling],* ***number one****, that's always my key.* ***The second one is I always say, can you, would you mind just taking your jacket off for me****, um that way* ***I can see what their, their movement of their shoulders and arms*** *are like (CNS12).* *But you know,* ***swelling, that sort of level of information isn't always that obvious****,* ***as the hand looks particularly swollen****, and* ***you need to do a physical examination****, and obviously* ***we can't do that at the moment [COVID-19 pandemic****]. So, so* ***that is difficult*** *(CNS02).* *So in the trust I work at our role would be* ***seeing people following diagnosis. Reviewing*** *them,* ***measuring the efficacy of any treatments*** *that have been instigated. And then you would be* ***more of a collaboration rather than a nurse led*** *in* ***terms of actual clinical management****, in terms of medicines,* ***working with consultant colleagues*** *as to, you know****, if alterations are required*** *to that* ***medical decision in terms of medicines*** *(CNS07).* ***We use an electronic system*** *… so* ***everything that I request, whether it's a blood test, an MRI, an ultrasound, an X–ray, it all pops up on my desk every day*** *[…] And* ***then I can record my actions****, and* ***then I can, um, contact the***

- examination of joints Assessing by asking questions - fatigue - pain - low mood and depression - quality of life - co-morbidities	***patient accordingly***. *Um, and we always,* ***I always give verbal feedback, not from the routine monitoring. If it's all fine,*** *it's all fine. Um,* ***but I'd always say to them, "If you're worried then you can call me*** *and* ***we can talk them through***.*" But* ***that doesn't happen very often*** *(CNS03).* ***We would do the DAS28 at every appointment*** *and certainly, you know the regularity of it over ... because* ***in the escalation clinic they're seen six weekly until stability***. ***Usually six weekly during the first six months.*** *And* ***when we're examining their joints we're explaining to them what we're doing and what we're looking at*** *and* ***these are your NCP joints, and these are your PIP joints***. ***So that patients become familiar with the terms*** *because* ***all too often terminology is used and patients are in absolute ignorance of this***, *you know and I think* ***it's utterly unacceptable to examine a patient and not even explain what you're doing*** *(CNS04).* ***We used to use HAQ, but they've stopped using it now, I think the consensus was form the department that it was quite outdated*** *(CNS09****).*** ***We used to … [to use HAQ] and then we stopped,*** *because we found that,* ***it was taking up a lot of time them filling it in in the waiting room***. *And actually* ***we didn't face any treatment choices on it.*** *And because* ***we're really lucky in the clinic,*** *and* ***we have more time with them, and we do a really holistic assessment of them, […]*** *but actually****, we cover most of those things, anyway, in our discussions*** *(CNS10).* ***We do the, the Visual Analogue Scale, for looking at their sort of pain their sort of pain (CNS11).*** *So we use the* ***DAS28*** *and we use the, the um* ***the VAS pain score to go alongside that*** *(CNS14).* *Well, we* ***did have them doing the DAS Score***. *But* ***we don't tend to do that***, *we tend to* ***really just have a conversation with people***, *and* ***ask them about how they are***, *and about* ***if they're depressed***, *or* ***if they're sleeping***. *And* ***how the pain affects that***. *So* ***we'd have more of a conversation about that***, *rather than a,* ***I'm not very good at questionnaires and things*** *(Laughs).* ***I tend to like just to have a chat with peopl****e, and um, you know, as we say in xxx [East of England],* ***take a view on it.*** *(Laughs) (CNS05).*

We ***review each appointment*** *that they come to* ***during the escalation period*** *and we* ***look back at the DAS***, *we'll* ***do another DAS*** *and* ***another global assessment and VAS*** *and* ***we look at that*** *(CNS04).*

Sometimes it's really difficult to remember *that just* ***because we don't have to assess their feet and ankles, doesn't mean to say they might not have a problem with them****...So you have to remind yourself and to,* ***to remember to ask about their feet***, *because they might say, "Do you know what, actually, I've got really, really bad disease on my foot." And,* ***and what we have done on some occasions,*** *if a patient …* ***because NICE say we have to use the DAS28...But if a patient's got no disease in their hands and they've got the most atrocious disease in their feet***, *what* ***we will sometimes do is use their feet, we'd count their feet rather than their hands to get the Disease Activity Score.*** *Because* ***otherwise, you wouldn't' get them on medication sometimes*** *(CNS01).*

The blood test doesn't tell us the whole picture. *It's actually the patient,* ***the patient will tell us*** *and we have the ...* ***we review each appointment*** *that they come to* ***during the escalation period*** *and we* ***look back at the DAS***, ***we'll do another DAS and another global assessment and VAS*** *and we look at that. And* ***we compare it to the previous visit***. *So* ***looking at the efficacy of treatment***, ***the response and how they feel***. ***Have they improved?*** *(CNS04).*

It's looking at […] how it's affecting them on day to day, on their day to day life, and ***depending on what those scores are, it gives us an idea of how they're feeling***. *And* ***it's about trying to do those each time***, *that and* ***the HAQ*** *and* ***the VAS*** *um each time they come in, so we can see if there's been any change (CNS11).*

We've had no formal pathways but that is my next plan, *in my next life I'm going to have pathways because the way nurse are trained these days if you want my totally honest opinion we're back to you know,* ***they call it pathways, it's task nursing*** *[…]* ***it's all about you know pathways and following protocols*** *[…] and we haven't got them, but we've got very good guidelines out there you know, do I agree with them ? […] Well you know,* ***but actually I do agree because it makes it much, much, if you're a junior coming into our department*** *it makes it much easier format for them to follow (CNS15).*

***We would do an initial assessment**, and **I would spend an hour with them,** and **I would do the, HAQ scoring**, you know, **attitude of daily living, the HAD**, so **hospital anxiety and depression score,** and then **we would do a joint count, talk through fatigue, answer all their questions** basically (CNS04).*

***I tend to say to patients, "Do you think you're more tired than you should be for your age and fitness level**?" And then **we have a discussion about scale from zero to ten** […] We **talk about what factors**, what **other factors might be contributing** […] **Fatigue does often take up a big proportion of time in an appointment** (CNS10).*

*Oh, **that is a massive** [fatigue], massive area, and **that is something again, that is discussed in education**, about **how to manage fatigue** […] **We always ask that question**, you know, **do you feel like extra sort of, everything's really effort at the moment for you**? Do you feel like you know, **you want to sleep more than you normally do. We always ask, we early try hard and get that question in about fatigue**, because I think that's a really important one, and I think **sometimes that does get missed**, I'll be honest. But **I think we are quite good at asking that** (CNS12).*

*And … **and also a big thing with fatigue, understanding that the fatigue is part of the condition**, and that there's not something else seriously wrong, because **quite a few people will think there must be something else like cancer** or something. So at least you could understand you know, that that's part of it (CNS06).*

***Their inflammatory markers, that's how we monitor their drugs**. **And also, interactions** because, **don't forget, we're also looking after their other co-morbidities**...as well, you know […] **So a lot of people have other things going on, maybe heart problems**, and so on. So **we have to take that all into account** (CNS05).*

The blood tests**. So **for the first three months, we will be monitoring the blood tests** […] So, now **that is where it does get difficult** in that, **because we don't know if the patient has gone, had had bloods done**. So what we tend to do**, for the first few weeks, we'll say to the patient give us a quick ring when you've had a blood test done so that I

can reassure you that all I okay. *Because otherwise, we don't know if the patient's …we've got to, you know, so many patients to be able to check on everybody****. But we have no system in place to sort of flag up any abnormal blood results****, and that is what, that is,* ***we know that's a failing****. But unfortunately, we haven't got anything (CNS01).*

We send out questionnaires to look at the severity of symptoms *[…] and we* ***also include functional, a functional questionnaire*** *[…]* ***I think it was E25D [EQ5D****], and things that we call* ***pain and fatigue****. We also use* ***the PHQ9****, and the* ***anxiety rating scales just to look at how they're managing, sort of from a psychological perspective*** *[….] and* ***then we follow those up.*** *After that* ***we do an annual functional score. We haven't put in place a follow-up on the others at this point*** *in time.* ***We have got a self-management lead, who's a clinical psychologist, so she's looking at the right time periods to repeat those other questionnaires****. If I feel that someone has ongoing issues […]* ***We've also got pain psychology within our service*** *(CNS03).*

[Depressed] ***Often it's to do with things point on in their family,*** *and because* ***we get to know patients over years,*** *they, you know,* ***they'll often say that we're the people that they can talk to about that kind of thing****. And* ***sometimes just talking about it, is enough. If I'm concerned*** *that they, because* ***we have had people,*** *you know,* ***expressing suicidal ideation then we, we can talk about it as a team. I have contacted safeguarding****, the safeguarding team before about patients', and I've spoken to…****I've spoken to GPs to make sure that they're aware of what's going on*** *and* ***asked them to give a sort of courtesy call, a check-up call, which they're usually happy to do*** *(CNS10).*

We have a lot to go through, and **we have to talk about smoking,** and **try and get them to stop smoking**. **We have to talk about weight**, **we have to talk about exercise** […] and **what they should be aiming for exercise-wise**. **We often will talk about work** and **whether they're in work and coping** and **whether they want to be in work** and **what support they might be able to get if they want to be in work** *(CNS10)*

[What is good care?] It is ***checking as how the patient are getting on*** *and* ***how safe it all is, making sure that the patients are kept safe*** *(CNS06).*

	*So **our consultations are now all on forms on the computer system** so…It's **called a Clinical Note for a Biologic Review** so **we work through everything in there, with them** […] So the plan, you know, **action for the patient; action for the doctor, the GP**…it's **quite a sort of structured** and I mean **you don't always follow that**, you know? **If at patient comes in and burst into tears because of whatever's going in their life**, you know, **you don't' follow that** […] **But it gives you a framework, for the things that are covered** (CNS08).* *I tend to like just to have a chat with people**, and you know as we say in [geographical area in England]**, take a view on it** (Laughs) […] **just put everything in together**, just, **do the assessment, their wellbeing, their physical wellbeing, how they're coping with it, if there's any problems** (CNS05).* *So **we initiate and we monitor for three months**, and **then we hand that over to the GP** (CNS03).*
Coordinating care, referring and signposting Following RA pathways with planned visits Referral to the rheumatologist Organising consultations with other members of the MDT - Physio-therapist - Occupational therapist - Fatigue management - CBT - Pain psychologist - Lack of access to psychology referral and supervision - Acting on test results and patient outcomes - Rheumatologist - Medic team	*Basically **the new RA patients will see first of all, the doctor. Then they'll come to us for the education**, and **then there is a pathway** which **because of Covid and because of converting a lot of clinics to tele clinics**, that will change. But…but at the moment, how it was, was that **they'd see the consultant, then education asap, so hopefully that week, or the week following, get them started on the medication**. And **then it would be six weekly appointments with ourselves**, or **if the doctor's appointment fell within that time, then obviously they'd have that instead of us**, to **escalate them quickly, till they're stable** (CNS16).* *So **we used to pre COVID, we used to get the patient's notes, the patient's hospital notes, then it was written in there** and **we would communicate with the Consultants, either just by going and talking to them**. […] or **by copying letter to them**, so there are some Consultants that maybe work more remotely than others **[And actually it's easier to, to copy your clinic letter to that Consultant**, so that's basically how we used to communicate, **now we generally do a lot more over email**, so **we will email the Consultant if we have any questions or queries, which works really really well**. The majority of the time, **we get really prompt responses back from them**, or **we can just copy them into the letter** (CNS14).*

Signposting to charities and relevant services - Versus Arthritis - NRAS - Helplines - Psychology support – charities Helping to sort out Addressing intimate relationship may feel awkward, but is important (need for advice, referral, or signposting) forms for benefits, handing out leaflets for employers and employees Coordinating shared care with GPs Creative solutions Contact system can be complicated for patients Helping patients to navigate healthcare contacts	*So **we were able to see the patients**, but if we had **any concerns**, or if there was **need for a medication change**, or anything, we **could then pop next door to the consultant**, and you know, **get things sorted or get advice** (CNS06).* ***We don't personally do those [joint injections]**, so that **it's another consultant to do the joint injections**. I mean I know **there are some nurses who train to do joint injections**, but none of us have. And so **the consultant are the ones that did the joint injections**, but **we can give an intramuscular, steroid if we feel it's appropriate** (CNS01).* ***We're pretty good at referring straightaway in the early arthritis, for Physio and OT** [occupational therapy] **I think that's really helpful for them as well to have that extra sort of support** as well (CNS12).* ***With fatigue management, we do often refer to Occupational Therapy**, because **our Occupational Therapy Service do a really good um, body of work on fatigue management** and **they do a, course of sessions where patients are keeping diaries** and one thing and another and **looking at what are the, things that are prohibiting them from getting a good night's sleep** (CNS14).* ***Often we're the only people that they [the patients] feel they can talk to**, but we don't ever bring it up [sex]. **So we did put that on there as something that they could talk about**. And then when (Laughs**), when people started circling it, everyone was like, "Oh God, why did you put that on there?"** (Laughter). **Everyone was really awkward about it** […] **We've got some leaflets now.** (Laughs) […] **We try our best, and some of us are better than others. And we're very much like, you know, we're always kind of like, "Okay, open body language, you know, turn and face the patient, let them talk about it.**" (Laughs). But **it's not our favourite topic to talk about** (CNS10).* ***I've helped to sort out forms for benefits, I've talked them through how to do things like that**, you know**, giving them** obviously … there's obviously the, **I want to work you know, the leaflets for employers and employees** (CNS05).* ***They** [patients with early RA] **also need psychological support, they need information of other sources of support**, so, er, **we always give out information about third sector**. So, **NRAS, Versus Arthritis**, um, **and other charities** (CNS03).*

***We’ve also got pain psychology within our service […] We’ve got, we’ve just appointed three psychologists**, and **this is for the whole of MSK**, that you, **they cover all the pathways** […] **including pain**. So **if I felt people needed pain psychology**, or **even the pain programme, then I can send them** (CNS03).*

***That’s very difficult** [if the patients **are depressed or very sad** and anxious] you know, **we do our best to provide reassurance**, but we**, we don’t have access to any kind of counselling service, apart from the Occupational Therapists, again, who are brilliant and I mean they do CBT**, so **we can refer them in for that service** (CNS14).*

***Mental Health and sort of CBT access**, although again I think **those** [patients in early RA] **could be quite overwhelmed**, and you know, it’s, **I think it’s an area that’s lacking**, **and it’s something that we could really do with anyway** (CNS11).*

*We would you know, **if people were suffering with anxiety**, um, you know, **and wanted some sort of talking type therapy**, um, **they could self refer to xxx** [anonymised], which **is like a local, a local organisation**. **They run courses**, so … **and they're quite frequent, for anxiety, low mood** […] It's called xxx [anonymised] [...] And**, patients could refer themselves, but if they were quite frail, I'd sit with them**, and we'd go … only for a few minutes, and they could … you know, **we'd just do it on the computer**, and they'd refer themselves, so it'd be **… it wasn't ideal, could have done with our own um, psychologist, but at least it was something** (CNS06).*

*But those would be sort of, **we kind of signpost people to those sorts of support**, you know**, provide people with a bit more information or maybe direct them to websites**, and **you’ve got things like the NRAS**, and you know, **Versus Arthritis that might have a bit more information** and you know, **maybe support Help Lines from them as well that they can tap into**. Some people like **maybe using social media groups**, or things like that. So maybe you know **if there are support networks around like those sort of thing, with other people that have similar experiences** maybe **seeing if people might want to access those** (CNS11).*

*And you know, that **we listen to them, we don't dismiss anything** […] and **they know how to contact you**, you know, **leaflets, knowing, yes, which are the correct, the best websites to go onto**, you know, **there's a lot on the internet that's scary and not accurate**. But **knowing the correct** sources to go to that are most up to date, and useful information (CNS06).*

***We only monitor them until they're stable**. And **then our shared care agreement** is that **we monitor for … until they're six weeks stable on their new medication. But if** you remember, like at the beginning, **we're adding new things so you know, we're constantly extending that period to another six weeks**, another six weeks, sort of thing (CNS16).*

***Probably the biggest thing for us is when, when to take over the care of the patient**, as in **taking over prescribing their treatment, and doing the routine blood monitoring** [...] **It's a shared care**, **we have a shared care agreement**, um, **and some GP surgeries are, are very, very militant** and, **and follow the shared care to the letter,** and **will take over that care when we give them an instruction to do so**, which is, you know, **which is what it says in the shared care,** and that is absolutely fine. There are **other surgeries that as soon as they get the Education letter**, this patient is starting on Methotrexate, **the Methotrexate will go straight onto their repeat prescription** and **the patient will be able to order it through, through the GP surgery**, which is fine, **but the shared care does state that the hospital should be providing the prescription until that patient is stable** (CNS14).*

*But **I do enjoy rheumatology**, I do really like it, so […] **And it sits really well in primary care**, because, I think it does anyway, because, you know, if we, um, **we know them**, you know, and **we have a little bit more information about the arthritis and the drugs and things**, I think, you know, **people can be managed in primary care far more** […] And **maybe that will happen now, because of this Covid** (CNS05).*

We also have, sort of, online Medway**, **sort of audit information <u>to try</u> and fill in**. **Not just audit**, but also just kind of if it's, we have sort of **Pathway forms that we try and fill out** if we can, around, i**f they've got any concerns or if there's anything they're worried about**. Do they, **what's the home set up, are they independent, have they got

***dependents**, just **to get a background of how it affects them** (CNS11).*

*So, I would say**, despite what I've said about access, I think access for some people is still and issue. Even though we've got all of those ways of contacting us.** And I think **part of that is confusion** about, **because they've seen the consultant, and they know there's a nurse adviser** on, because **they get give that information, sometimes they try and get hold of their advice line, and aren't sure whether they should phone them or us.** And that's **purely because the service, haven't joined u**p the way they should have (CNS03).*

***We're all, paper–light now**, so **all our nursing stuff goes straight onto Medway** […] **We don't really write**, I'm trying to think if we, **we don't really write anything down**, […] so **they [the multidisciplinary team] have access to all our, reviews of screenings, our […] phone calls and everything** (CNS10).*

***We use an electronic system** […] so **everything that I request**, whether it's a **blood test**, an **MRI, an ultrasound, an X–ray**, i**t all pops up on my desk every day** (CNS03).*

*So we tend to try to find out what their concerns are, and address them, and get them seen as quickly as possible now, nowadays […] And, make sure **we've done all the investigations and the assessment to accompany the referral letter,** you know. And t**hen the hospital can get the bloods and the X–ray results off the, website**, the, you know, **the pathology website**. So it sort of **hopefully stops the delay**, you know (CNS05).*

*We have um, on our **<u>Medway system</u>**, we have a **proforma of sort of lots of tick boxes**, there is [ph] text boxes. So the first four tick boxes, do you have **flares**? **Early morning stiffness**? **Pain from overuse and fatigue**? And then later on when we go through, we **discuss exercise**, **weigh**t, and **do they smoke**? Um, talking about if they're **being safe in the sunshine**, keeping an eye out for any sort of **new moles** or things. Um, so but also as well, **if they don't get talked about**, **we just put in there, we put on our proforma**, not talked about today, um patient wanted to discuss something else (CNS09).*

*We've got like, again, our **consultations are now all on, forms on the computer system** so … **It's called a Clinical Note for a Biologic Review** so **we work through everything***

	***in there, with them,** and **then that automatically** … **we fill it all in** and then **that automatically produces the letter at the end of the consultation for the patient**. So **the plan,** you know, **action for the patient; action for the doctor, the GP** … so, um, **it's quite sort of structured** and I mean **you don't always follow that**, you know? I**f a patient comes in and bursts into tears** because of **whatever's going in their life**, you know, you don't follow that (CNS08).* *[…] We **run it independently** now, xxx [OT] who's **the OT [occupational therapist], and I**. So we **see people** and **we do their annual review**, and **she does their joint protection**. And as I say, still **goes to their house**, if needed, to **look at how she can help there**. We often **talk to relatives, monitor their drugs**, obviously **looking at their cardiovascular diseases**, and all that sort of stuff. So **looking, holistically**, if possible (CNS05).*
Addressing psychosocial needs Patients experience shock, fear anger while feeling unwell with pain and fatigue - Lifechanging diagnosis can be overwhelming - Postponing of getting a family - Changing of lifestyle regarding alcohol and sex challenging – especially in young patients - Challenging conversations about sex and alcohol – especially in young people - Issues with body image in early RA - Starting intensive treatment with risk of side effects can be scary - Worries about job and future Building a relationship - Getting an understanding	***It can be quite an enormous shock for some patients** [to get the diagnosis of RA**].** They've obviously **been feeling poorly anyway**. So **that's one side of it which they're having to cope with**. They're **then faced with this diagnosis of a long term life changing chronic illness** They also **have the fear of all the medication** (CNS13).* ***So the early arthritis patients we recognise the incredible fear and distress and anger** and all of those things **in the very early days** and of course **the impact that that can have on their decision to, accept treatment, accept diagnosis** […] Erm, and **it's very different from those patients who are well established who have gained the confidence** and t**here is the trust that has been built up over time with the** nurses and the rheumatology team **and the understanding** (CNS04).* *It's also about, particularly if you've got a **young lady**, about, talking about, um, you know, **sexual contact**, um, has … um, **contraception**, er, you know, are they **thinking about children**, so sometimes **it's those whole, um, sort of, um, conversations to have** (CNS01).* ***We asked about sex and contraception**, and it turned out that she was sexually active, but **mum was totally unaware**. Er, so, but we had that conversation with her and everything, **because if we were going to be starting her on Methotrexate**, and, and she was **drinking alcohol**, that was the other thing, because sometimes, you know, getting to*

- Communication helps to create trust - They have a voice- we have to listen - Getting the patient onboard	*17, let's face it,* ***most 17-year-olds are probably drinking alcohol*** *at some point, but don't always want their parents to know that they're doing it (CNS01).* *They [patients in early RA] want to go out and see their friends (CNS09).*
Providing psychological support - Help the patient to adjust to the disease - Leading the patient - Giving the patient control - Access to asking questions - Strategies for set back - Somebody to talk to - Lack of access to psychology expertise	***Conversations about medication and pregnancy, they can be very emotional****, very emotional especially if patients we've had a couple of patients maybe* ***put off starting a family until slightly later in life*** *and then this has developed (CNS14).* ***B****ecause I've* ***seen patients not have treatment and decide not to have methotrexate*** *because maybe they* ***want to have children in the future*** *at the very beginning really aggressive disease and then their disease has just, you know, ravaged them […] M****y approach is always that it's better to get the disease under control first and then maybe switch around*** *(CNS08).* ***How does it make you feel****? You know,* ***body image****,* ***what you can see****, the example to you,* ***what does it mean*** *to you* ***to be a young person,*** *you know* ***how does it feel to be young and with a disease****? But, you know* ***there's a whole level of experience isn't there to tap into*** *and that will be ... yeah there* ***may be things*** *but of course* ***we're all unique*** *aren't we?* ***We're all individuals*** *so there will be little* ***... there will be facets of that which are very individual to****, you know,* ***any given person*** *(CNS07).* ***People still have the image of rheumatoid arthritis of being crippled in wheelchairs*** *(CNS15).* ***Good care. It' s a collaboration*** *I would define it,* ***between the patient, the clinician, the nurses. It's definitely a team effort*** *(CNS13).* ***There's an education facet to how people work through loss and adapt.*** *But I think, you know* ***my belief, or my knowledge base is if you're to be effective at that you've got to be very patient or person centred*** *(CNS07).* *Something I try and do and* ***I'm very conscious about doing*** *is perhaps* ***areas we traditionally have done very well at as nurses, not just in rheumatology****. So care around the*

	***psychological and the social side of things** and the **impact they have on a patient's experience of the illness and how they manage and can be encouraged to self-care**. So **that kind of side of things** I think there's much **more of a, independent**, kind of a **nurse led approach** (CNS07).* *What works is **being responsive to someone**, and trying **to build a relationship** and therefore **a dialogue** where people can ... you know **building trust** I guess **where people can tell you what's going on** and **how they feel** and **what they want** and **what they don't want** (CNS07).* *I think that our **really established patients** are, **a lot of them become really expert in managing their own conditions**, and **we can often be led by them** […] so, you know**, you have to very much work in partnership with them […]** Whereas **in early arthritis**, they're **often needing a lot more guidance** and saying, **"Is this normal**? […] And so it's often **they need a lot more guidance,** and a lot more, you know, **this is kind of broad brushstrokes and generalising**, but **they prefer to be told what to do**. Whereas, you know, **in more established, lots of them do still want to be told**, t**hey don't want to make decisions, they want you to do what they feel is your job** […] but I personally, **I find that with the early ones, they're much more wanting you to educate and guide, really** (CNS10) **I generally try to get to the bottom of it. If it's something that's very RA–related, like pain or fatigue or something, then we'll talk about the specifics of managing that** (CNS10).* ***Normally it's trying to establish with the patient, what's causing the underlying issue** if we can, **sometimes it's a longstanding thing, sometimes it's acute** [anxiety], **because of what's been going on** (CNS14).* ***It is a long term journey**, **we are going to be there with the patients…It's a partnership and we're doing it together** (CNS14).* *[How to create a relationship?] I think it's you know, **being calm, being kind, listening to them, appreciating their feelings**, and **not sort of, undermining how they're feeling about anything**. **Trying to you know, find out what it is you know, what's the thing that's worrying them most perhaps?** […]*

And if it's work*, I mean* ***I've helped to sort out forms for benefits, I've talked them through how to do things like that****, you know,* ***giving them obviously*** *[…]* ***the leaflets for employers and employees*** *[…]* ***Even if it's reassuring them, and saying look, you know, your joint count is much better****, you know [...]* ***just trying to keep them positive, and listened to and respected*** *I think (CNS06).*

But education, a setting and helping someone manage how they feel psychologically, looking at their social needs *and* ***then you've got the very clinical side of things*** *of* ***what do we need to do to halt the progression of this disease*** *(CNS07).*

Because it all relates*, and* ***if they're 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).*

I have a set of counselling skills and I try and look at the whole person *so I'm, you know,* ***using counselling skills*** *I guess.* ***Active listening, reflective listening, time, and trying to collaborate with the patient****.* ***So working out a pack****age and, you know,* ***taking cues, are we ready to do medicine today****? (CNS07).*

[…] a ***lot of it is psychological****, you know****, helping people to come to terms with it****, to understand it, to educate people, um, to reassure them and to explain the options. And also to give them control I think […] (CNS06).*

I've helped to sort out forms for benefits, I've talked them through how to do things like that*, you know,* ***giving them*** *obviously … there's obviously the, I want to work you know,* ***the leaflets for employers and employees*** *(CNS06).*

If it's, other stuff related*, sometimes* ***it's to do with work pressures that are to do with RA, they're feeling like they're not performing at work****, or* ***they're feeling pressured because of the time off they've had to have****.* ***So then we'll talk about how they can approach that with their work****, and* ***I'll try and give them leaflets to let them feel confident in approaching their bosses and managers****, and things (CNS10).*

Managing pain, managing flares*, yes so* ***they're advised to have a flare box in their house****, that* ***they keep things that they find, are useful for them when they're having the***

***flare up**, and **that could be things like plain Paracetamol, Ibuprofen, it can be gels and rubs** that they find useful, **heat packs**, things like that, **so that they can go and, and grab that flare pack** and **they know, they're always going to have something there, whenever the flare attacks** (CNS14).*

***It's talking about them**, to them about, you know, **what they want to achieve from things**. And s**ometimes it's quite surprising what patients, what patients want to achieve rather than what you want to achieve**, **can be very, very different**. I mean obviously, **we're very medical-minded, even the nurses, we're very medical-minded** is that **we want to, get their disease under control**... whereas **sometimes, it's important to the patient that, just that they can do their knitting or … they can hold their grandchild** and things like that (CNS01).*

***We're the psychological support at the … at the moment**, and certainly we are … **we do have an ongoing business case, within our service, to form some psychological suppor**t**, from a psychologist,** and unfortunately, **that's sort of, on the back burner, just at the moment**. But I think that **moving forward, it's something that we, as a team, we all recognise that that's … that's incredibly important** (CNS02).*

***You are there as a listening board absorbing it all** […] **My approach as well is we can't go backwards we have to go forwards** (CNS15).*

*it would be really … well we know **it would be really helpful for a number of our patients, to be able to have some sort of** … **whether that's sort of, input directly from a psychologist, with an individual patient, or whether that would be support for us, from a psychologist**, you know, **that they can give us tips** and **help, and suggestions** on … **on consultations with patients, who are particularly struggling** (CNS02).*

In the biologic clinics we have what we call a pro-forma.** It's like **a pre-consultation questionnaire that the patients fill out and that asks lots of questions about**, you know, **what they want to talk about** and **we've got things they can circle** on there **so they can talk about finances, or relationships, or sexuality**, or whatever. So **that's an opportunity for them then …they hand that to us when

	***they come in** and **then we then go through it and hen talk through the things**, **they've circled** […] That's also **quite a good way of making sure you've addressed all their needs** (CNS08).* ***If I am worried** [if the patient seems depressed] **I will say to them, I have had this conversation with you, do you mind if I write to your GP**, it'll be on your letter because I am worried […] It's **just to see whether there's any services that we can offer you**, that **your GP could offer you** (CNS15).* *And **whilst most of us have got some degree of understanding of…self-management, or psychology…we're not psychologists** (CNS02).* ***We don't have access to any kind of counselling services, apart from the Occupational Therapist**. **OT, they do CBT**, so **we can refer them in for that service (**CNS14).* ***I think we're the ones that offer that** [psychological support], **we would love to have like a Psychologist here or someone, but we don't**, is the bottom line**. I know some other Trusts do**, um, we do not have that facility, um so I think you know, **we are a lot of the counsellors as well to be fair** (CNS12).* *So **often these days, you just can't speak to anyone**. **All they want to do is speak to someone a lot of the time, even if it's not rheumatology related**. It's just **to rule out that actually it's not your arthritis** that's **causing these problems, it's something else**... **you need to go and see the GP**. Then **they've almost got like permission to say to the GP**, you know**, I've spoken to rheumatology, it's not my rheumatology condition** (CNS16).* *So, because patients do get some quite bizarre things into their minds that **they think they can't do this anymore because they've got rheumatoid arthritis**. And actually, **it's about talking to them** to say that really, **it shouldn't be stopping** them **doing anything** if, in a good, **if you had a good outcome, it shouldn't stop them doing anything**. They should lead a, **lead a totally normal life** (CNS01).*
Theme:	**Care with compassion using person-centred, holistic and emphatic approaches**

Subthemes Codes	**Illustrative quote**
Care delivered with compassion Speaking with one voice Feeling upset by the patients' situation Helping to sort out problems that can feel overwhelming for the patient (for example forms for social benefit, work) Acknowledging the challenges patients face Any of the nurses will try to help the patients Wanting to help Going the extra mile Helping with individual needs Overbooking to see patients as soon as possible to limit distress A privilege to meet and work with patients	***I feel really upset that this poor ... you know she's a young woman, her life ahead of her, she's got a disease which is really badly controlled and she's frightened*** *and* ***she's angry about this and maybe other things*** *(CNS07).* ***I've helped to sort out forms for benefits,*** ***I've talked them through how to do things like that,*** *you know,* ***giving them*** *obviously … there's obviously the,* ***I want to work you know, the leaflets for employers and employees*** *(CNS05).* ***We always give out information about third sector.*** *So,* ***NRAS, Versus Arthritis, and other charities*** *(CNS03).* ***Any of us will try to help them…and if they're really struggling…we try to do this…we book patients in…we'd overbook out lists.*** ***We'd see patients in lunch break if we could find a room to seem them,*** *do you know what I mean? [….]* ***We do appreciate that patients, when they're struggling, they're really struggling,*** *and you know,* ***if we can help them, let's get them in today, rather than tomorrow,*** *or* ***let's get them on Friday so they don't have to wait until Monday*** *(CNS16).* ***This is probably going to sound really cheesy,*** *but I mean I think, I feel in some ways, God this is going to sound really cheesy,* ***but I feel quite privileged as well in a way because I feel very you know, lucky and glad that I can meet people in this way,*** *and hopefully and you know,* ***I've been with people and around people, one of the big reasons I do my job, but I do, because I love being around people and talking to people*** *[…]* ***You try and be sort of have that professionalism there,*** *but you know,* ***I also just hope that it is sort of a trusting relationship*** *and* ***that they feel that they can, can you know, feel that they feel supported*** *(CNS11).*
Using person-centred, holistic and emphatic approaches Holistic: It all relates to one another: work, stress and arthritis	***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).* ***They have to have a voice and we have to listen*** *(CNS13).*

Combining approaches Getting the disease under control Patients must be seen as individuals Sometimes surprising what the patients want to achieve – Patients have a voice, the nurses have to listen Important to listen to the patients – what they want and what is important to them to achieve (knitting, holding a grandchild) Taylor care The nurse belief or knowledge base is that to be effective, nursing must be person-centred	***Sometimes it’s quite surprising what patients, what patients want to achieve rather than what you want to achieve, can be very****, very different. I mean obviously,* ***we’re very medical-minded, even the nurses, we’re very medical minded is that we want to, get their disease under control (CNS01).*** ***We can get all their disease under control and if they still can’t do their knitting or, pick up their grandchild up or something like that,*** *then that’s* ***… it’s what important to the patient I think is the most important aspect of all our care*** *(CNS01).* ***The nurse’ belief or knowledge base is, if you're to be effective you've got to be very patient or person centred*** *(CNS07).* ***So I'm a firm believer,*** *and I've instilled it into my team,* ***that all of our patients must be seen as individuals****.* ***Their needs are not going to be, the same as the next patient that you see who may have all the support in the world and not need anything from you whatsoever*** *(CNS04).*

Providing a ‘lifeline’ The telephone advice line is the primary contact for the patients Somebody to talk to Access to asking questions They know that they can always call the nurse The advice line is busy Encouraged to call with worries, side effects or questions Solving problems without delay	***After the initial diagnosis, obviously they come back and they see, a doctor at various times, but the initial port of call is always the nurse … the nurses, whether that's through routine appointments, or whether they are contacting us via our nurse led helpline****, if they're* ***having issues with their side effects from their drugs****, or if they're* ***struggling with anything in particular****, whether they* ***want to ask more questions*** *and things like that (CNS02).* ***Especially with our Early, Rheumatoid Arthritis patients,*** *um we,* ***we are literally the first port of call really for that patient*** *(CNS12).* *INT: So they* ***can always contact you on the helpline if they need it****, or how is that?* *RES: Yes, yeah, so* ***always****, always, and obviously* ***that's a really important part of the service****. Um, and um,*

The nurse knows that patient and the disease and can take action The patients can call if they have side effects The patients can call if they are in pain Patients can call if they have problems with medication	*it's … yeah, you know,* ***it's an extremely busy part of the service***, *but yeah,* ***it's highly valuable*** *(CNS02).* ***They know that they can call at any time and the phone is always manned***, *so* ***they would never get a non-response***. ***There’ll always be someone picking up the phone***. ***It’s a bit like a call centre, the way they manage it*** *[…]* ***they can ring in at any time,*** *and* ***my team can put them onto a ledger for me to call them back*** *(CNS03).* ***The advice line has been a lifeline to them, to be able to speak to someone, to be able to get a response quickly to their questions, they feel very well supported, they know that they can always call us*** *(CNS16).* ***We have Rheumatology Advice Line*** *and they are* ***and that number is kind of drummed into them from Education onwards,*** *so* ***if they have any problems, they can give us a call on that number, it gets them though to an answer machine,*** *and* ***then our administration staff call them back and book them a time slot*** *and* ***say right the nurses will call you between nine and ten or ten and eleven*** *[…] Or whatever it might be, and* ***then we can give them a ring***, *so* ***that is run like a clinic in itself, the Advice Line clinic*** *(CNS14).* ***The initial port of call is always the nurse*** *… the nurses,* ***whether that's through routine appointments, or whether they are contacting us via our nurse led helpline***, *er,* ***if they're having issues with their side effects from their drugs***, *or* ***if they're struggling with anything in particular***, ***whether they want to ask more questions*** *and things like that (CNS02).* ***A lot of it*** *[calling the helpline]* ***is to do with side effects of medication*** *(CNS14).* ***That’s probably one of the biggest ones, side effects of medication, they don’t think it’s working, because there’s so much to take in***, *when* ***they’ve been newly diagnosed and started on quite intensive medication***, *they don’t really*, ***they don’t always take everything in and a lot of it*** *you know,* ***after three weeks, the patient will call and say it’s not working***, *it’s not working,* ***so it’s reassurance***, *saying,* ***no it is, you just need to give it a bit more time, do we need to be looking at your pain management, to help***

	you just get through those next couple of weeks*? **Do we need to be looking at a short course of steroids?** You know, **what exactly are the issues you’re having?** Um and **just providing support, so they know they’re not on their own with it** (CNS14).*

Theme:	**Continued evaluation and development of the service**
Subthemes Codes	**Illustrative quotations**
Patient feedback At consultations: - Important to ask what the patients expect - Check if patients got answers to their questions - Talking about intimate relationship can feel awkward, but is needed Patient feedback - The nurses generally get good feedback - Complaints are rare Few complaints: - Not being able to get through on the telephone (confusion who to contact) - Waiting times in the outpatient The whole experience is important: - Feeling welcome in the clinic	*...**It's really important to ask them initially what they expect to have from the consultation** (CNS02).* *__We have an agenda setting process, whereby patients can write notes before their appointment__. **So we know what they're expecting to talk about** (CNS03).* *__Often we’re the only people that they [the patients] feel they can talk to__, but we don’t ever bring it up [sex]. **So we did put that on there as something that they could talk about**. And then when (Laughs**), when people started circling it, everyone was like, “Oh God, why did you put that on there?”** (Laughter). **Everyone was really awkward about it** […] **We’ve got some leaflets now.** (Laughs) […] **We try our best, and some of us are better than others. And we’re very much like, you know, we’re always kind of like, “Okay, open body language, you know, turn and face the patient, let them talk about it.”** (Laughs). But **it’s not our favourite topic to talk about** (CNS10).* *[…] **We do** [use questionnaires], and **we have had various questionnaires at various points**, you know, **that we send out to all, that the patients complete**, that get sent out to them, **or in clinic** and that sort of thing, **that have asked them about perhaps they’re, you know, for their appointments with the specialist nurse** and that sort of stuff. So sort of, which has been, you know, **completely anonymous** sort of stuff […] and **we've always had really good feedback in general from those as well** (CNS02).* *__We've always had really good feedback in general…__ (CNS02).*

- Staff attitude Having needs met: - Disease control - Wellbeing, - Keeping in work	*I mean* ***I think people remember the simple things, the caring approach, the attitude.*** *I think* ***a lot of the time the compliments are about the attitude of the nurses in the service*** *[...]* ***So it can be really, really simple things*** *just at the …* ***whoever took their blood then made sure they knew how to get out, or they called them a taxi,*** *or they* ***made them a cup of tea*** *because they were … you know, so* ***it's just really little simple things that, that people do but for the patients it's a big thing and they remember*** *it because* ***for them it meant they had a really positive experience here*** *(CNS08).* ***So right from the beginning when they walk in the receptionist, through to the nurse that takes their bloods after they've seen the doctor,*** *and* ***obviously involved in the consultations, the nurses*** *[…]* ***I think a lot of patients appreciate that it's a very friendly, warm and welcoming department*** *and that* ***there's a caring approach and I think that comes from the top down*** *and* ***everyone is working towards the same goal,*** *which* ***is to make it a good patient experience,*** *and* ***that often comes out in the compliments that we get (****CNS08).* ***In terms of rheumatology,*** *we,* ***I can't think of any negative feedback.*** *I think* ***we had one patient, who said that they couldn't get through to us. But they hadn't read the new telephone number on the letter, and were trying to get through …… to the old advice line*** *(CNS03).* ***Well complaints can be really varied from the physicality of the department if they were kept waiting to be seen.*** *Mainly I would say* ***they're not about the care they've received from us,*** *thank goodness.* ***Occasionally we've had patients where they've maybe had to make a complaint about their experience,*** *and often it's, you know,* ***when things happen something very simple has happened, gone wrong,*** *it's* ***usually about communication*** *(CNS08).* *[How to know when needs have been met?]* ***They might say you know, they might come bounding in and sort of say, I'm so much better, thank you so much,*** *I have had that. And* ***I have had people ring me up before now and say I've been to the theatre for the first time in a year,*** *and it's wonderful, thank you so much [...] all sorts you know,* ***like people, where you've sorted them out…I managed to sort one man out with, a brace for his leg and we got his medication correct so he could go bowling again,*** *and* ***that changed his life.*** *So I* ***think it's just the look on their faces when they come through the door, and they're so happy.***

	You know, or ***when they send you, send a little letter or a message or something*** *[…] And then also obviously* ***if it's not been successful, but they still know they can talk to you, you have that rapport as well****, where* ***they can come in and say look it hasn't been so good, but you know. I know you're trying your best****, sort of thing (CNS06).*
Service evaluation and auditing Questionnaires are used to evaluate the service Audits are conducted regularly on individual clinics and the service Boxes are placed in the clinic for patient feed back The patients are asked for feedback in the clinic The advisory board are asked about changes to the service The governance body look at complaints/praise Specialist advisory groups [of patient partners] meet regularly, attend conferences and are asked for advice, for example on leaflets and redesign of services	*Good care in early RA?* ***That you get their disease out, under control, and that the patient is able to lead a virtually near normal life****, in honesty, um, because* ***you can see that, um, that we're able to keep them in work,*** *um,* ***particularly if they're young,*** *that* ***we're able to keep them in work, we're able to keep them well,*** *and um, you know****, I would consider that to be a good outcome*** *(CNS01).* *So it is about, you know,* ***asking the patients how they're doing, is there anything that they're finding that they can't do****, and is, you know****, to talk about that, why can't they do it****, and do it like that (CNS01).* *So,* ***because patients do get some quite bizarre things into their minds that they think they can't do this anymore because they've got rheumatoid arthritis****. And actually****, it's about talking to them to say that really, it shouldn't be stopping them doing anything*** *if, in a good****, if you had a good outcome, it shouldn't stop them doing anything. They should lead a, lead a totally normal life*** *(CNS01).* ***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).* *[How to know when needs have been met?] They might say you know****, they might come bounding in and sort of say, I'm so much better, thank you so much, after I have had that****. And I have* ***had people ring me up before now and say I've been to the theatre for the first time in a year, and it's wonderful****, thank you so much [...] all sorts you know, like* ***people, where you've sorted them out…I managed to sort one man out with, a brace for his leg and we got his medication correct so he could go bowling again****, and* ***that changed his life****(CNS06).* *I think again* ***a measure of their needs in terms of their ... from diagnosis to treat to target, to remission****, is* ***to actually see those patients and look at them****.* ***And look through their pathway, through the six months*** *and if you're* ***... if their needs have been met in terms of their***

***pain, their understanding, their education**...and **you can see that and learn from the patients. But patients will tell us really**. But **the audit**, we **audit all of our clinics annually and regularly after each visit we ask for feedback** (CNS04).*

*So **I think it’s just the look on their faces when they come through the door**, and **they’re so happy**. You know, or **when they send you, send a little letter or a message or something** […] And then also **obviously if it’s not been successful, but they still know they can talk to you, you have that rapport** as well, where **they can come in and say look it hasn’t been so good, but you know. I know you’re trying your best, sort of thing** (CNS06).*

***We have governance meetings**, um, **where we then look at the complaints, the compliments and the complaints**, and look at … you know **are there areas of the service that could be improved, and then try and address those** (CNS08).*

***We’ve done various, over the years, sort of different audits** trying to … **when we first implemented a pathway, we had patient involvement and got their feedback** and then **over the years we’ve done various audits** (CNS08).*

***We regularly audit all of the clinics that we do and we ask for patient feedback, we send out questionnaires, we explain to them why we're doing it. This is their service and they need to tell us where** ... you know **what we did well and what we didn't do well** (CNS04).*

***We’ve got lots of, cards in the waiting room for patients to give us feedback** and to **make suggestions about how, their experience was and what could be improved**, and **then in separate parts of the service** we … you know **in the biologic service and then in the Young Adult service that I, I do with one of the consultants, we do feedback questionnaires and we ask patients, um, what they think** (CNS08).*

***We’ve also audited the advice line** as well so **we’ve done sort of little, little focuses on various different bits of the service to get patient feedback** to, **to see how we can improve things**, and then, obviously, **patients also write letters and** cards of appreciation and complaints as well (CNS08).*

We regularly, ask patients for feedback after each visit to pop in to a box what they felt was good, what they felt was

	*missing, **were their needs met? Where they're not how could we have done better**? So **we're constantly asking patients for their feedback** (CNS04).* ***We are really lucky in that we…we have a very close, we even have the Patient Advisory Group who meet regularly […]** They're **a group of patients** who are, obviously **they're always going to be the more motivated, more opinionated**, group of patients. But **they meet regularly** and they, I mean, **some of them attend conferences** and things all over the world […] **We ask them for advice on things like, for example, the leaflet**. **I've written quite a lot of leaflets**…and **I always ask them for feedback on whether** it's clear […] **When we're looking at redesigning services, we get their feedback on all of that** (CNS10).*
COVID-19 challenges and opportunities Disruption of the service Change from face-to-face to telephone clinics Only few face-to-face clinics Could not observe movement or examine joints Had to rely on what the patients told on the phone Teaching patients how to name and assess the joints and report Patients were shielding Stressful time Changes that would have taken years happened within few weeks Nurses worked from home Nurses were deployed to the wards	***For the moment** [during the COVID-19 pandemic], yeah definitely and at the moment, **most of our, appointments that we have are on the telephone**, **or we've got some video consultations as well** (CNS09).* ***We have basically been running video clinics and telephone clinic**s, um, so **we've still been running consultations, but remotely, basically**. **We do have what we call boiling hot clinics**, which we've **had, about three a week**, at the moment, and **they are face to face clinics, for patients who we feel that actually really do need a face to face appointment** and **can't be managed remotely** at all (CNS02).* ***There's all this talk about** actually you know, **how potentially we were going to look at transforming outpatient services and outpatients** systems generally, have been outdated, and **that's been felt for a while**, and **how we use technology moving forward, to actually allow people, to do more from home**, and **not have to come** in for … **into hospitals**, into secondary care. And I think … **so that was already being discussed** and there are already ideas being bounced around, but **actually what this done, Covid has done is as actually pushed these things so much quicker**, um, you know, **to be able to sort of literally within a matter of a couple of weeks, have the ability to do telephone or video consultations, because we've had to, has been unbelievable really** (CNS02}.* ***I think with early RA, I mean, some people may be more comfortable going into a Zoom group** and saying 'hi'**, than actually walking into a room** and baring all. You know,*

Emergency measures Telephone hotlines kept open	***there's a safety behind the screen*** *where you can, you know*, ***give as much as you want to, and leave the rest behind*** *(CNS03).* *You know, like the same* ***with everywhere we were redeployed to the wards, all we could do*** *was* ***manage really the advice line***, *and now we were* ***relocated offsite*** *as well (CNS04).*
Innovation and improvement of the service Adaption of the service Change to telephone more time efficient Development of protocols for telephone clinics a help Documentation of telephone clinics an improvement Using digital solutions: email, e-journals and platforms for booking and acting on blood tests, x-ray and other examinations Using combination of video-tutorials and follow up telephone clinic Communication online between doctors and nurses works well, saves time and streamline prescription procedures Collaboration with GPs and other health partners is important and helps to provide service to patients Pandemic catalyst for change of outpatient clinics	***We still see a significant number of patients who wouldn't even know what a Smartphone was***, *you know,* ***who have a mobile that might be 20 years*** *old. So it's,* ***it's very different*** *and this is, you know I think,* ***it's vital to recognise the absolute unique and individuality of each of our patients*** *(CNS04).* ***We have been seeing new patients and in face, we're starting patients on the pathway,*** *even pathway patients,* ***which is quite odd, because you know, if you'd said this a few months ago***, *you can you know, do …* ***see a patient or conduct a consultation for a newly diagnosed patient, over the telephone, you'd be thinking, no, you can't do that properly*** *(CNS02).* ***I do have to rely on them telling me what's going on, because I can't see it at the moment*** *(CNS14).* ***With Covid we're doing it over the telephone***, *and* ***we're getting them to watch the video*** *[injection tutorial]* ***before we have the appointment with them*** *(CNS04).* *Now* ***what we've done is changed it so that it is a more, it's an appointment based system***, *so* ***they phone, and the answer phone either cuts in, or the admin assistant answers the phone***. ***She books them a time slot, within an hour***, *you know, within … so if she phones them at 10, she might say oh, you'll get a call back between 12 and 1. And we're going to have, at the moment we've got three patients in an hour's slot, but as of not next week, the week after, we're going to have 15 minute slots, and they'll be 20 slots throughout the day.* ***So in effect it's like another sort of two … two clinics really*** *(CNS16).* ***I'm able to manage it quite nicely at the moment because I am at home*** *[working from home] and that's, you* ***know it has it's downfalls*** *but* ***it actually gives me a little, a bit of space to do things the way that I feel works best***. *Erm, so I can do that,* ***I can tailor things***, *you know to people,* ***as we feel we need to do it***. *So, you know, I can work around it*

Use of telephone and digital solutions will stay Video meetings could be used for education in the future Apps could be used for PROMs Mixed service necessary to suit everybody. Not all have access to internet, wi-fi or smartphone Before and after COVID-19: Many changes will stay	*like that, so yeah different ways of doing it.* ***It doesn't always have to be face-to-face, I guess, is the answer*** *(CNS07).* ***At the beginning, the first step*** *when* ***they're diagnosed and treatment is started,*** *we then will* ***get the prescription*** *and* ***everything is on electronic now which is much better*** *[…]* ***that's raised electronically*** *so that's absolutely fine* ***and throughout the escalation pathway we send an email, it's prescribed electronically*** *and* ***it's sent out. The patients receive it at home, within a day or two*** *(CNS04).* *The whole sort of* ***process of Education has changed now,*** *so* ***we've educated over the phone.*** *Once the Education has been done over the phone and we,* ***we've done blood work*** *and stuff and* ***the patient is good to go,*** *we'll* ***then email the Consultant*** *and say,* ***could you do the prescription, that's working really*** *well,* ***they're doing that really quickly.*** *You know, so* ***there's no real delay in the patient starting treatment.*** *So it's pretty good I think on the whole (CNS13).* ***We show them. We have demonstration pens,*** *um, or syringes.* ***So we show them and they practice with the demonstration one*** *but* ***when they actually start the treatment*** *xxx (home care company), or* ***whichever homecare company is delivery the drug will go and see them at home*** *and* ***then train them and watch them inject themselves at home.*** *So* ***whichever homecare company is delivery the drug will go and see them at home and then train them and watch them inject themselves at home*** *[…] And* ***if they need more than one visit they can have more than one visit*** *and then* ***they talk to them about managing the deliveries, rotating their stock in the fridge*** *(CNS08).* *I think the thought at the moment is that,* ***there's no, The British Society for Rheumatology hasn't specifically said that this is the best app to use for this*** *[self reported outcome measures],* ***or this is the best self assessment technique*** *or whatever (CNS02).* ***I think that the telephone clinics work very, very well*** *[…] And* ***I think this is something we will take forward and we will do a lot more of our, especially our follow ups and, and our Educations over the telephone, that seems to work really, really well, for Escalation, we may need to introduce some kind of face to face or video calls,*** *or something like that.* ***So we can visibly assess joints,*** *but* ***certainly a lot of the work that we do, we've realised we***

***can actually do over the telephone** and **we don't need to be brining patients into hospital all the time** (CNS14).*

***We have a huge number of patients that are on injectable methotrexate and it's managed very well**. And **nowadays with the pen it's just so easy** […] **So they manage very well,** very well and **they have an education appointment, with any drug** and you know, **especially methotrexate**. **They will come in to the department, now obviously with Covid we're doing it [education appointment] over the telephone**, and **we're getting them to watch the video before we have the appointment** with them, **running through everything**. And **they can either do the injection while we're on the phone or choose to do it after they've had their telephone call** and **then we've arranged to ring them back to find out if they were okay and if they managed it alright** (CNS04).*

***And there certainly are barriers** you know, **it's not as easy, we can't do, things like we would be doing, a disease activity score and joint count and things like that**, **if we have that patient face to face to us,** so as well **as them reporting how they're feeling with their arthritis, we would get you know a, and actual clinical physical indication of exactly what's going on, by doing a joint count**. Obviously **we can't do that at the moment, we can only take you know what a patient is saying**, and **if we've got a video clinic, then it's slightly easier from the point of view that they can show a hand** and say yeah, **look at my hand's still really swollen**. But you know, swelling**, that sort of level of information isn't always that obvious**, as the hand looks particularly swollen, and **you need to do a physical examination, and obviously we can't do that at the moment. So that is difficult** (CNS02).*

*So **when they phone us on the advice line if they have a flare, we explain that you can tell us specifically the joints** now, you know, **your NCPs or your PIP joints**. And you know it's …patients on the whole, you know **they quite enjoy that actually, it gives them a vested interest really,** it's about them as well. And they enjoy the … actually, you know, **you're taking the time to teach, it's not that you're giving them medication and sending them on their way** (CNS04).*

*I would have the, **we always call it the man with the hand […] it is a really good learning tool to talk about because patients are saying oh why is my feet not** …they're the worst and so we explain all of that. And again **then they understand that** [that feet are not included in DAS28], so* *they understand that when they do ring up, if they ring up and say oh my feet are …but I know now, so* ***I know that’s not in the man with the hands*** *(CNS04).*

I think things have changed *[…]* ***And I don’t’ think they will go back to exactly as they were […] I think as long as we’ve got the ability to do both, I think absolutely remote things could work really well for people.*** *And you know, and* ***it helps people*** *particularly perhaps if they’re … well either* ***if they’re older and they struggle to get in, or if they’re younger, and they’re trying to maintain a job*** *and things like that, and they don’t have to …* ***don’t’ need to take extra time out, to have to come into hospital.*** *But equally* ***there will always be, particularly with something like rheumatoid arthritis, you physically need to be able to examine people,*** *you know,* ***you need to be able to see people,*** *but you know* ***having a mixture of the two*** *is I think, you know,* **is definitely a way forward** *(CNS02).*

And there's all this ***talk about*** *actually you know, how potentially we were going to* ***look at transforming outpatient services and outpatients systems*** *generally,* ***have been outdated,*** *and that's been felt for a while, and how* ***we use technology moving forward,*** *to actually* ***allow people um, to do more from home,*** *and* ***not have to come*** *in for … into* ***hospitals,*** *into secondary care.* And I think … so that was already being discussed and **there are already ideas being bounced around** *(CNS02).*

What this has done, Covid has done is as actually ***pushed these things so much quicker,*** *um, you know, to* ***be able to sort of literally within a matter of a couple of weeks,*** *have the* ***ability to do telephone*** *or* ***video consultations,*** *because we've had to, has been unbelievable really.* When **previously** it probably **would have taken us six months to try and set something up**, you know. Um, so … but I think **things have changed**, I think things have changed, yeah. And **I don't think they will go back to exactly as they were** *(CNS02).*

I think going forward, we’ve been doing a lot of work on our website, *in the last few months, and* ***I think that going forward, having sort of possibly some video type,*** *you know,* ***that we might look at doing ourselves. Classes, training, sort of things,*** *that we can actually put* ***so the patients can watch them themselves.*** *I think, you know,* ***is definitely sort of a good way forward*** *(CNS02).*

I think early arthritis, going forward, from the things that we’ve learnt from Covid, *in terms of* ***virtual clinics*** *and in* *terms of**, nurses’ skills**, I think that **we should look towards a more broad, team approach for early arthritis**. **So that nurse and doctors, all working in partnership, can see, diagnose and treat patients** (CNS03).*

*Because I think **the one disappointment for me is**, in terms of **submitting data for the National Audit**, are that **people aren’t getting treatment early enough** […] So I think **part of the concern is the patriarchal approach** that doctors sometimes have, in terms of thinking “Well, you know, nurses aren’t qualified to do this.” **Actually, there’s a large cohort of highly qualified, highly experienced nurses that they ‘re under-utilising** …that **could easily have been seeing patients first-line. It is happening in some areas**, and **I think it is up to nurses to be responsible for their own competency.** And if they’re not up to it, don’t’ do it (CNS03).*

Appendix M. Development of survey questions related to the model of early RA nurse-led care

Chapter 5. Summary of the development of survey questions related to the model of early RA nurse-led care. Modifications according to patient research partner advice

Nurse-led care from nurse perspective **(Chapters 3 and 4)**	**Nurse-led care from the patient perspective** **(Chapter 5, this study)**	**Nurse-led care from the patient perspective** **(Chapter 5, this study)**
Interview study with nurse specialists: **Main themes and themes**	**3A Survey questions: Assessed importance of model of care items**	**3B Survey questions: Experienced nurse-led care - accord to model of core items**
1. A specialist service delivered by experienced rheumatology nurses	Q01. I receive specialist rheumatology care	Q01. I believe* that I received specialist rheumatology care
1.1. Specialist training and expertise		
1.2. Autonomy in clinical practice	xx	xx
1.3. Collaboration with the multidisciplinary team	xx	xx
2. Addressing patients' complex care needs		
2. 1. Early disease management	Q06. My disease is controlled well	Q06. My disease was controlled well
2.2. Monitoring treatment, disease impact and patient outcomes	Q09. My treatment is monitored to evaluate its effectiveness Q10. I am asked about the side-effects of medication Q11. I am followed up to see the impact of arthritis on my life	Q09. My treatment was monitored to evaluate its effectiveness Q10. I was asked about the side-effects of medication Q11. I was followed up to see the impact of arthritis on my life
2.3. Addressing psychosocial needs	Q07. My psychological needs are addressed Q08. My social needs are addressed	Q07. My psychological needs were addressed Q08. My social needs were addressed

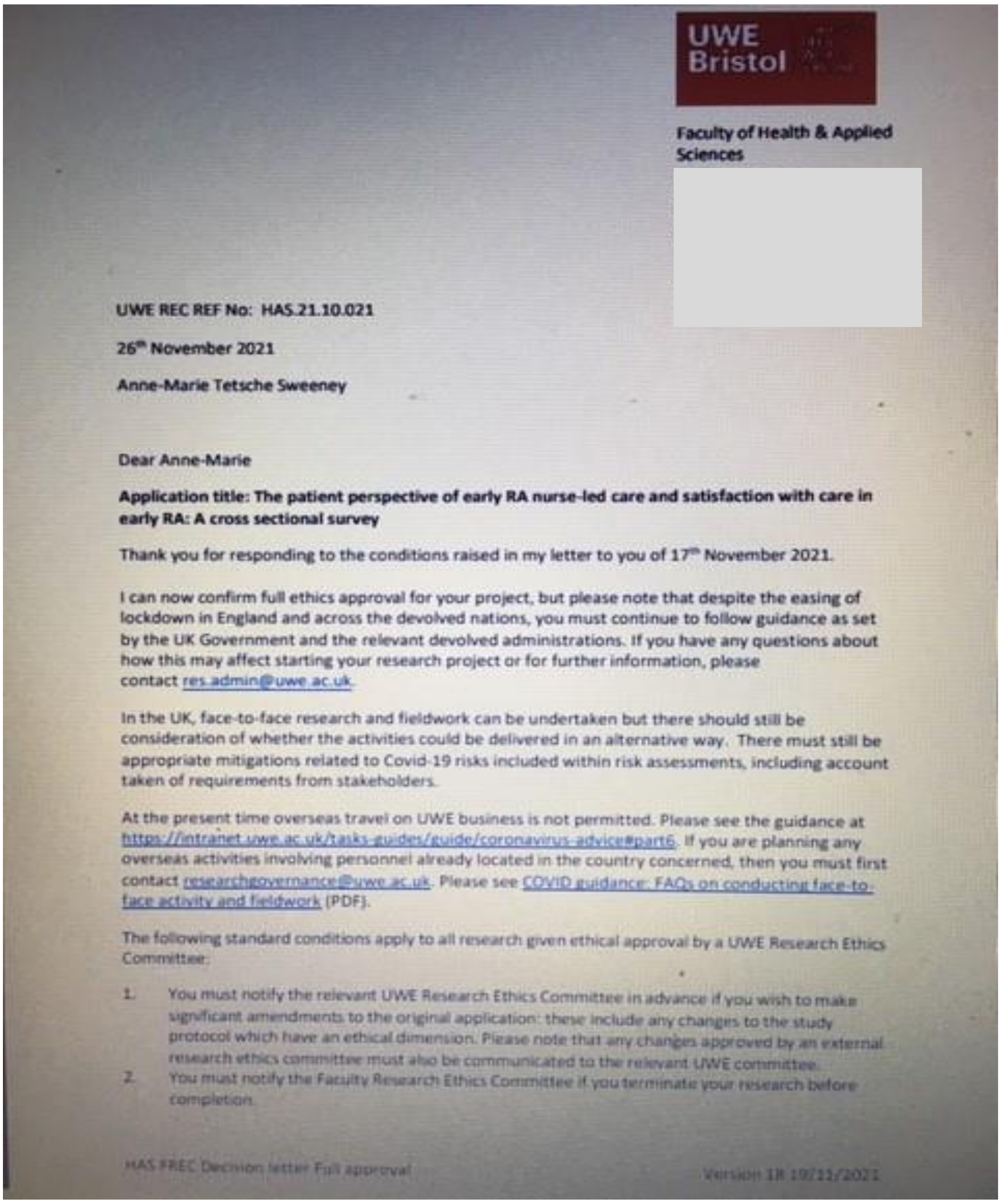
2.3. Coordinating care, referring and signposting	Q12. The nurse coordinates my care with hospital doctors, GPs and other health professionals Q13. The nurse refers me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs Q14. The nurse signposts me to relevant agencies, charities or patient organisations	Q12. The nurse coordinated my care with hospital doctors, GPs and other health professionals Q13. The nurse referred me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs Q14. The nurse signposted me to relevant agencies, charities or patient organisations
3. Care with compassion using person-centred, holistic and empathetic approaches		
3.1. Care delivered with compassion	Q02. Care is provided with compassion	Q02. Care was provided with compassion
3.2. Using person-centred, holistic and empathetic approaches	Q03. Care is provided with a person-centred approach (The care is tailored to my individual needs)* Q04. Care is provided with a holistic approach (I am treated as a whole person, not just as a disease)* Q05. Care is provided with an empathetic approach (The nurse specialist is kind and understanding)*	Q03. Care was provided with a person-centred approach (The care was tailored to my individual needs)* Q04. Care was provided with a holistic approach (I was treated as a whole person, not just as a disease)* Q05. Care was provided with an empathetic approach (The nurse specialist was kind and understanding)*
3.3. Providing a 'lifeline'	Q15. I am provided easy access to the rheumatology nurse specialists via a telephone advice* line	Q15. I was provided easy access to the rheumatology nurse specialists via a telephone advice* line
4. Continued evaluation and development of the service		

4.1. Patient feedback	Q17. My opinion about my care is considered important	Q17. My opinion about my care was considered important
4.2. Service evaluation and auditing	Q16. The nurse checks that my questions are addressed in the consultation	Q16. The nurse checked that my questions had been addressed in the consultation
4.3. COVID-19 challenges and opportunities	xx	xx
4.4. Innovation and service improvement	Q18. Innovation and service improvement are part of my care	Q18. Innovation and service improvement were part of my care
	Q19. (Free text box for participant comments)	
	Your opinion Please add any aspect of care that you feel is important to you and is missing from the above statements	

*Modifications of the survey statements before publication in consultation with the patient research partner

Appendix N. Final ethics approval of Study 3

Final ethics approval letter page 1.



UWE Bristol

Faculty of Health & Applied Sciences

[redacted]

UWE REC REF No: HAS.21.10.021

26th November 2021

Anne-Marie Tetsche Sweeney

Dear Anne-Marie

Application title: The patient perspective of early RA nurse-led care and satisfaction with care in early RA: A cross sectional survey

Thank you for responding to the conditions raised in my letter to you of 17th November 2021.

I can now confirm full ethics approval for your project, but please note that despite the easing of lockdown in England and across the devolved nations, you must continue to follow guidance as set by the UK Government and the relevant devolved administrations. If you have any questions about how this may affect starting your research project or for further information, please contact res.admin@uwe.ac.uk.

In the UK, face-to-face research and fieldwork can be undertaken but there should still be consideration of whether the activities could be delivered in an alternative way. There must still be appropriate mitigations related to Covid-19 risks included within risk assessments, including account taken of requirements from stakeholders.

At the present time overseas travel on UWE business is not permitted. Please see the guidance at https://intranet.uwe.ac.uk/tasks-guides/guide/coronavirus-advice#part6. If you are planning any overseas activities involving personnel already located in the country concerned, then you must first contact researchgovernance@uwe.ac.uk. Please see COVID guidance: FAQs on conducting face-to-face activity and fieldwork (PDF).

The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the Faculty Research Ethics Committee if you terminate your research before completion.

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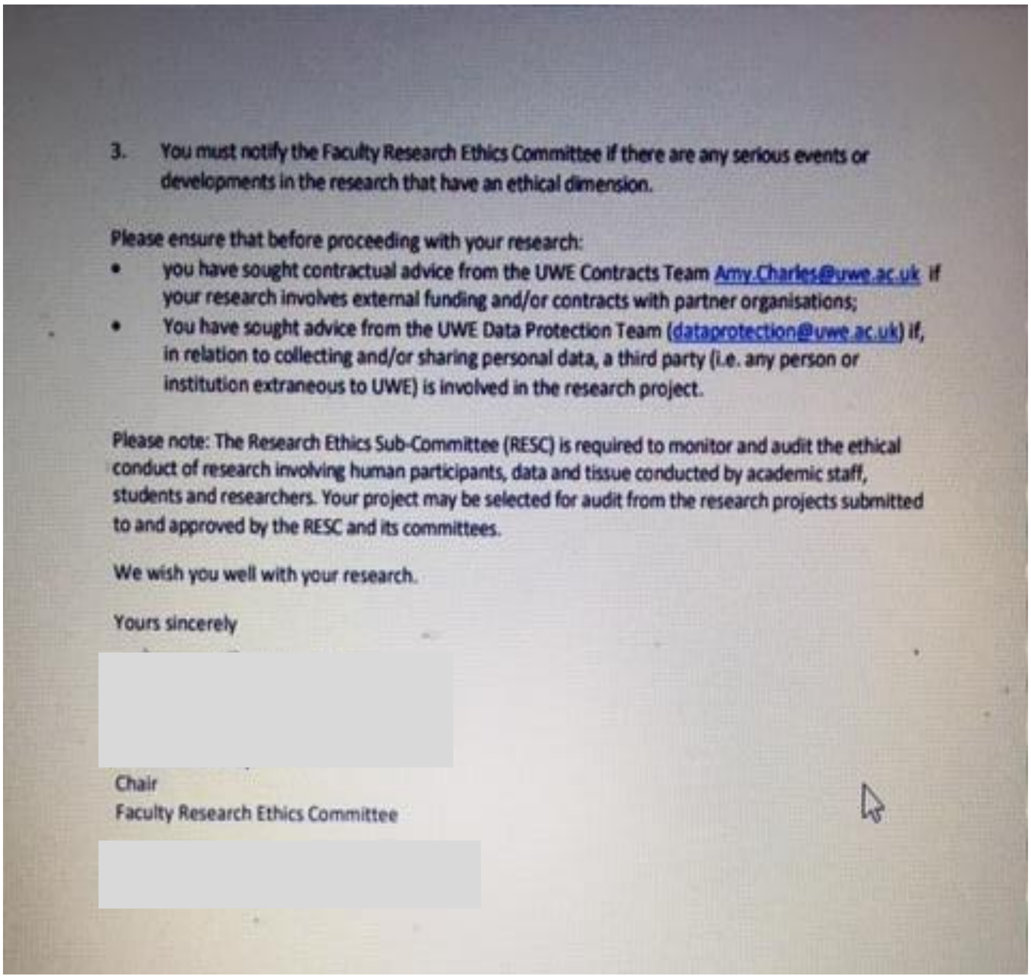
Final ethics approval letter page 2.



3. You must notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please ensure that before proceeding with your research:

- you have sought contractual advice from the UWE Contracts Team Amy.Charles@uwe.ac.uk if your research involves external funding and/or contracts with partner organisations;
- You have sought advice from the UWE Data Protection Team (dataprotection@uwe.ac.uk) if, in relation to collecting and/or sharing personal data, a third party (i.e. any person or institution extraneous to UWE) is involved in the research project.

Please note: The Research Ethics Sub-Committee (RESC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research.

Yours sincerely

[redacted]

Chair
Faculty Research Ethics Committee

[redacted]

Appendix O. Participant information and questionnaire

A) Ethics approved version of participant information and questionnaire: V2.23.11.2021. Questionnaire Patient Perspective

The patient perspective of early RA nurse-led care and satisfaction with care in early RA.

Survey – Patients, Version 1. 10th October 2021.

We invite you to take part in our research about nurse-led care in early rheumatoid arthritis.

The survey is only for people diagnosed with RA in the last two years, who live in England and have attended a consultation with a rheumatology nurse specialist within that time.

What is the purpose of the study?

People with early rheumatoid arthritis often attend nurse-led care for management of the disease. The purpose of this study is to get the patient perspective of rheumatology nurse-led care and assess how patient care needs are met by nurse specialists.

Why have I been invited to take part?

We are inviting participants with early rheumatoid arthritis (0-24 months' disease duration) who attend consultations with nurse specialists for management of the disease in England.

Do I have to take part?

No, taking part is voluntary. If you decide not to take part, you do not have to give a reason, nobody will be upset, and the standard of care you receive will not be affected.

Please note that by ticking the box below you indicate that you have read this information sheet, you are 18 years old or over, and agree to take part in this research.

What will I be asked to do if I take part?

If you wish to take part, please click on the link to the online survey and continue to read and fill out the questionnaire, we estimate this will take approximately 15 minutes.

Questions about yourself.

This survey contains questions about the type of rheumatology consultations you attend with a rheumatology nurse specialist at the hospital rheumatology clinic. There are also questions about the information you have received about your diagnosis, the duration of your RA, and the medication you may take. We also have some questions about you, such as your age, sex.

Questions about satisfaction with care.

These questions are statements about your care, and you can choose responses ranging from 'strongly disagree' to 'strongly agree'.

Questions about items for a model of care in early rheumatoid arthritis.

These questions are statements about items for a model of care in early rheumatoid arthritis, and you can choose responses ranging from 'I do not agree' to 'I agree completely'

If there is an item, you think should be added, you may want to write down your opinion in the space provided.

Once completed, please click the 'Submit' button at the end of the questionnaire.
You are not required to do anything once this is done

How can I withdraw from this study?

If you decide to withdraw from the study, you may exit the survey at any point before submitting the survey. If you wish, you may delete your responses by backtracking through the survey before the exit point. ***Please note that withdrawal of responses is not possible once the survey has been submitted as the responses will not contain identifiable information.***

What are the possible disadvantages of taking part?

There are no disadvantages to taking part. This questionnaire should not cause any harm, but if you are distressed by any of the topics it raises then please seek advice from your usual rheumatology team. Please note we will not be routinely informing your rheumatology team of your responses as this questionnaire is anonymous.

What are the possible benefits of taking part?

You may not have direct benefit from taking part in this study. We hope that the results will help us implement a model of care in early rheumatoid arthritis.

Will my taking part in this study be kept confidential?

Yes. This survey is anonymous. Your questionnaire will be marked with a number, not your name. No contact information will be obtained, and no contact information will be passed on to the research team from patient organisations. All information which is collected about you during the research will be kept strictly confidential and will not be disclosed outside of the project team.

What will happen to the results of the research study?

This research is part of a PhD project. The results of this research will be used in a PhD thesis and will likely be used in scientific journal articles, poster presentations and oral presentations to publicise the results and better improve care. No identifiable information will be shared.

Who is organising, funding and reviewing the research?

The University of the West of England (UWE) Bristol is the official sponsor of this research. This study has been approved by the Faculty Research Ethics Committee (FREC) at the University of the West of England Bristol. ***(Please note, that this statement will be added after approval)***

Thank you for taking part in this study

Anne-Marie Tetsche Sweeney,

PhD researcher in rheumatology Nursing

University of the West of England

[redacted]

Dr Mwidimi Ndosi, Director of studies (Principal Investigator)

Senior Lecturer in Rheumatology Nursing

University of the West of England

[redacted]

Participant consent

(Please tick '**Yes**' in the box to indicate that you have read this information sheet, you are 18 years old or over, and agree to take part in this research)

○ **Yes**

Section 1: Questions about you

Demographics

1) How old are you? (With text box)

2) **What is your sex?**
   - ○ **Male**
   - ○ **Female**
   - ○ **Prefer not to say**

3) **Do you live in England?**
   - ○ **Yes**

Clinical data

1. **Have you been diagnosed with rheumatoid arthritis?**
   - ○ **Yes**

2. How long have you had a diagnosis of rheumatoid arthritis?
   - ○ Number of months (0-24) (Text box)

3. Which medication do you take to manage your rheumatoid arthritis? *(Tick all that apply)*
   - ○ Steroids
   - ○ DMARDs (Methotrexate, Hydroxychloroquine, Sulfasalazine, Leflunomide)
   - ○ Biologics (injection, infusion)
   - ○ JAK Inhibitors (Baricitinib, Tofacitinib)
   - ○ Other (text box)

4. Which medication do you take to manage pain? *(Tick all that apply)*
   - ○ Paracetamol
   - ○ Nonsteroidal anti-inflammatory drugs (Ibuprofen, Naproxen)
   - ○ Other (text box)

Nurse-led care attendance

1. Have you attended a consultation with a nurse specialist at a hospital rheumatology clinic for management of your rheumatoid arthritis?
    - ○ Yes

2. How did you last attend rheumatology nurse-led care?
    - ○ Face-to-face appointment
    - ○ Telephone appointment
    - ○ Video appointment
    - ○ Telephone combined with digital solution
    - ○ Telephone combined with posted material
    - ○ Other (text box)

3. **When did you last attend the consultation with a rheumatology nurse specialist?**
    - ○ Month of attendance/contact (mm) (text box)
    - ○ Year (yyyy) (text box)

Section 2: Questions about satisfaction with care

This questionnaire has been devised to tell us about your overall opinion of your care in the rheumatology out-patients clinic. It is not a test and there are no right or wrong answers. We are interested in your opinions and impressions, whether they are **GOOD** or **BAD.**

The questionnaire consists of a number of statements about your care in the clinic. Some statements may look the same but they are different so please read each one very carefully before filling it in.

Please place a tick in the column which resembles your opinions most closely.

ONLY TICK ONE BOX FOR EACH STATEMENT

Please keep in mind that what we are trying to find out are **YOUR** opinions and not those of your husband, wife or neighbour, so please complete the questionnaire by yourself.

Please try to think about the care that you are receiving at the **PRESENT TIME** and give us your opinions about that.

THANK YOU FOR YOUR HELP

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1. They don’t seem to listen to anything I tell them during my consultation					
2. I feel that I’m in good hands when I come to the clinic					
3. The person I see in clinic takes an interest in my family					
4. I’m always given a clear explanation of why I am having tests done.					
5. There are some things about my care in the clinic which could be improved.					
6. I’m told everything I want to know about my arthritis drugs.					
7. During my consultation I’m given little or no medical explanation about my arthritis.					
8. Side effects of tablets are rarely discussed during my consultation.					
9. The person I see in clinic really knows what he/she is talking about.					
10. Visiting the clinic is not a stressful occasion.					
11. I am given good advice on how to cope with my arthritis.					
12. No matter how long you have to wait in clinic, it’s worth it.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
13. I’m satisfied with the care I receive in the clinic.					
14. There’s no one to get in touch with at the clinic if I have a problem.					
15. I’m rarely told why I need tests such as bloods and x-rays.					
16. My questions are answered in words that I find hard to understand.					
17. I find it difficult to talk about things that concern me when I’m in the clinic.					
18. The person I see in clinic has no interest in the effect my disease has on my family.					
19. It’s easy to get an appointment if I need to come back to the clinic.					
20. I’m given as much time as I need for my consultation.					
21. The person I see in clinic sometimes appears uncertain about what they are doing.					
22. The person I see in the clinic is not as thorough as he/she should be.					
23. I am given very little information on how to cope with my arthritis.					
24. The person I see in clinic doesn’t understand what it’s like to have arthritis.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
25. The person I see in clinic seems to know how it feels to have arthritis.					
26. I feel that I'm treated as a person rather than a disease.					
27. I've no confidence in the person who is treating me.					
28. I am encouraged to ask questions about my arthritis.					
29. If I had a problem it would be difficult to get someone to speak to over the phone.					
30. I'm rarely asked which treatments I would prefer.					
31. If I had a problem with my arthritis I would find it easy to get advice over the phone.					
32. My feelings about my treatment are taken into consideration.					
33. If I had a medical problem I feel sure it would be checked out when I came to the clinic.					
34. Prescriptions for new medications are given without any explanation.					
35. I'm usually told what the possible side effects of the tablets could be.					
36. I'm encouraged to contact the person I see in clinic if I have a problem with my arthritis.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
37. The care I receive in the clinic is just about perfect.					
38. I hardly ever see the same person when I come for my appointment.					
39. The person I see in clinic appears skilful at their job.					
40. The person I see in clinic does not always talk sense.					
41. Sometimes the person I see in clinic is too busy to spend enough time with me.					
42. When I attend the clinic I'm told everything I want to know about my arthritis.					
43. It's hard to get an appointment if I need it quickly.					
44. I see the same person nearly every time I come to clinic.					
45. I'm usually kept waiting a long time in the waiting area.					

Section 3: Questions about items for a model of care in early rheumatoid arthritis

3A. Please consider each statement and indicate if it reflected the care you received from the nurse-led consultation

(0= I do not agree at all. 10=I agree completely)

1. I received specialist rheumatology care

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

2. Care was provided with compassion

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

3. Care was provided with a person-centered approach

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

4. Care was provided with a holistic approach

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

5. Care was provided with an empathic approach

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

6. My disease was controlled well

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

7. My psychological needs were addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

8. My social needs were addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

9. My treatment was monitored to evaluate its effectiveness

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

10. I was asked about the side-effects of medication

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

11. I was followed up to see the impact of arthritis on my life

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

12. The nurse coordinated my care with doctors, GPs and other health professionals

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

13. The nurse referred me to other health professionals (such as physiotherapist, *occupational therapist, podiatrists or psychologist) according to my needs*

(Tick not applicable if you did not need referral to other health professionals)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

þ Not applicable (I did not need referral to health professionals)

14. The nurse signposted me to relevant agencies, charities or patient organisations

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

þ Not applicable (I did not need signposting to other services)

15. I was provided easy access to the nurse via a telephone helpline

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

16. The nurse checked that my questions had been addressed in the consultation

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

17. My opinion about my care was considered important

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

18. Innovation and service improvement was part of my care.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

3B: Please consider each statement and indicate how important it is for your care in early rheumatoid arthritis

(0= not at all important, 10=extremely important)

1. **I receive specialist rheumatology care**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

2. **Care is provided with compassion**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

3. **Care is provided with a person-centred approach**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

4. **Care is provided with a holistic approach**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

5. Care is provided with an emphatic approach

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

6. My disease is controlled well

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

7. My psychological needs are addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

8. My social needs are addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

9. My treatment is monitored to evaluate its effectiveness

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

10. I am asked about the side-effects of medication

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

11. I am followed up to see the impact of arthritis on my life

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

12. The nurse coordinates my care with hospital doctors, GPs and other health professionals

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

13. The nurse refers me to other health professionals according to my needs

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

14. The nurse signposts me to relevant agencies, charities and patient organisations

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

15. I am provided easy access to the nurse via a telephone helpline

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

16. The nurse checks that my questions are addressed in the consultation

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

17. My opinion about my care is considered important

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important									Extremely important	

18. Innovation and service improvement is part of my care

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important									Extremely important	

Your opinion

Please add any aspect of care that you feel is important to you and is missing from the above statements (Free Text)

This is the end of the survey.

Thank you for your time and your valuable contribution

B) Final minor revision of patient information and questionnaire before publication. V2.23.11 Rev Dec 2021.

The patient perspective of early RA nurse-led care and satisfaction with care in early RA.

Survey – Patients, Version 1. 10th October 2021.

We invite you to take part in our research about nurse-led care in early rheumatoid arthritis.

The survey is only for people diagnosed with RA in the last two years, who live in England and have attended a consultation with a rheumatology nurse specialist within that time.

What is the purpose of the study?

People with early rheumatoid arthritis often attend nurse-led care for management of the disease. The purpose of this study is to get the patient perspective of rheumatology nurse-led care and assess how patient care needs are met by nurse specialists.

Why have I been invited to take part?

We are inviting participants with early rheumatoid arthritis (0-24 months' disease duration) who attend consultations with nurse specialists for management of the disease in England.

Do I have to take part?

No, taking part is voluntary. If you decide not to take part, you do not have to give a reason, nobody will be upset, and the standard of care you receive will not be affected.

Please note that by ticking the box below you indicate that you have read this information sheet, you are 18 years old or over, and agree to take part in this research.

What will I be asked to do if I take part?

If you wish to take part, please click on the link to the online survey and continue to read and fill out the questionnaire, we estimate this will take approximately 15 minutes.

Questions about yourself.

This survey contains questions about the type of rheumatology consultations you attend with a rheumatology nurse specialist at the hospital rheumatology clinic. There are also questions about the information you have received about your diagnosis, the duration of your RA, and the medication you may take. We also have some questions about you, such as your age, sex.

Questions about satisfaction with care.
These questions are statements about your care, and you can choose responses ranging from 'strongly disagree' to 'strongly agree'.

Questions about items for a model of care in early rheumatoid arthritis.
These questions are statements about items for a model of care in early rheumatoid arthritis, and you can choose responses ranging from 'I do not agree' to 'I agree completely'

If there is an item, you think should be added, you may want to write down your opinion in the space provided.

Once completed, please click the 'Submit' button at the end of the questionnaire.
You are not required to do anything once this is done

How can I withdraw from this study?
If you decide to withdraw from the study, you may exit the survey at any point before submitting the survey. If you wish, you may delete your responses by backtracking through the survey before the exit point. ***Please note that withdrawal of responses is not possible once the survey has been submitted as the responses will not contain identifiable information.***

What are the possible disadvantages of taking part?
There are no disadvantages to taking part. This questionnaire should not cause any harm, but if you are distressed by any of the topics it raises then please seek advice from your usual rheumatology team. Please note we will not be routinely informing your rheumatology team of your responses as this questionnaire is anonymous.

What are the possible benefits of taking part?
You may not have direct benefit from taking part in this study. We hope that the results will help us implement a model of care in early rheumatoid arthritis.

Will my taking part in this study be kept confidential?
Yes. This survey is anonymous. Your questionnaire will be marked with a number, not your name. No contact information will be obtained, and no contact information will be passed on to the research team from patient organisations. All information which is collected about you during the research will be kept strictly confidential and will not be disclosed outside of the project team.

What will happen to the results of the research study?

This research is part of a PhD project. The results of this research will be used in a PhD thesis and will likely be used in scientific journal articles, poster presentations and oral presentations to publicise the results and better improve care. No identifiable information will be shared.

Who is organising, funding and reviewing the research?

The University of the West of England (UWE) Bristol is the official sponsor of this research. This study has been approved by the Faculty Research Ethics Committee (FREC) at the University of the West of England Bristol. ***(Please note, that this statement will be added after approval)***

Thank you for taking part in this study

Anne-Marie Tetsche Sweeney,

PhD researcher in rheumatology Nursing

University of the West of England

[redacted]

Dr Mwidimi Ndosi, Director of studies (Principal Investigator)

Senior Lecturer in Rheumatology Nursing

University of the West of England

[redacted]

Participant consent

(Please tick '**Yes**' in the box to indicate that you have read this information sheet, you are 18 years old or over, and agree to take part in this research)

○ **Yes**

Section 1: Questions about you

Demographics

4) How old are you? (With text box)

5) **What is your sex?**
   - ○ **Male**
   - ○ **Female**
   - ○ **Prefer not to say**

6) **Do you live in England?**
   - ○ **Yes**

Clinical data

5. **Have you been diagnosed with rheumatoid arthritis?**
   - ○ **Yes**

6. How long have you had a diagnosis of rheumatoid arthritis?
   - ○ Number of months (0-24) (Text box)

7. Which medication do you take to manage your rheumatoid arthritis? *(Tick all that apply)*
   - ○ Steroids
   - ○ DMARDs (Methotrexate, Hydroxychloroquine, Sulfasalazine, Leflunomide)
   - ○ Biologics (injection, infusion)
   - ○ JAK Inhibitors (Baricitinib, Tofacitinib)
   - ○ Other (text box)

8. Which medication do you take to manage pain? *(Tick all that apply)*
   - ○ Paracetamol
   - ○ Nonsteroidal anti-inflammatory drugs (Ibuprofen, Naproxen)
   - ○ Other (text box)

Nurse-led care attendance

4. Have you attended a consultation with a nurse specialist at a hospital rheumatology clinic for management of your rheumatoid arthritis?
    - ○ Yes

5. How did you last attend rheumatology nurse-led care?
    - ○ Face-to-face appointment
    - ○ Telephone appointment
    - ○ Video appointment
    - ○ Telephone combined with digital solution
    - ○ Telephone combined with posted material
    - ○ Other (text box)

6. **When did you last attend the consultation with a rheumatology nurse specialist?**
    - ○ Month of attendance/contact (mm) (text box)
    - ○ Year (yyyy) (text box)

Section 2: Questions about satisfaction with care

This questionnaire has been devised to tell us about your overall opinion of your care in the rheumatology out-patients clinic. It is not a test and there are no right or wrong answers. We are interested in your opinions and impressions, whether they are **GOOD** or **BAD.**

The questionnaire consists of a number of statements about your care in the clinic. Some statements may look the same but they are different so please read each one very carefully before filling it in.

Please place a tick in the column which resembles your opinions most closely.

ONLY TICK ONE BOX FOR EACH STATEMENT

Please keep in mind that what we are trying to find out are **YOUR** opinions and not those of your husband, wife or neighbour, so please complete the questionnaire by yourself.

Please try to think about the care that you are receiving at the **PRESENT TIME** and give us your opinions about that.

THANK YOU FOR YOUR HELP

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1. They don’t seem to listen to anything I tell them during my consultation					
2. I feel that I’m in good hands when I come to the clinic					
3. The person I see in clinic takes an interest in my family					
4. I’m always given a clear explanation of why I am having tests done.					
5. There are some things about my care in the clinic which could be improved.					
6. I’m told everything I want to know about my arthritis drugs.					
7. During my consultation I’m given little or no medical explanation about my arthritis.					
8. Side effects of tablets are rarely discussed during my consultation.					
9. The person I see in clinic really knows what he/she is talking about.					
10. Visiting the clinic is not a stressful occasion.					
11. I am given good advice on how to cope with my arthritis.					
12. No matter how long you have to wait in clinic, it’s worth it.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
13. I’m satisfied with the care I receive in the clinic.					
14. There’s no one to get in touch with at the clinic if I have a problem.					
15. I’m rarely told why I need tests such as bloods and x-rays.					
16. My questions are answered in words that I find hard to understand.					
17. I find it difficult to talk about things that concern me when I’m in the clinic.					
18. The person I see in clinic has no interest in the effect my disease has on my family.					
19. It’s easy to get an appointment if I need to come back to the clinic.					
20. I’m given as much time as I need for my consultation.					
21. The person I see in clinic sometimes appears uncertain about what they are doing.					
22. The person I see in the clinic is not as thorough as he/she should be.					
23. I am given very little information on how to cope with my arthritis.					
24. The person I see in clinic doesn’t understand what it’s like to have arthritis.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
25. The person I see in clinic seems to know how it feels to have arthritis.					
26. I feel that I'm treated as a person rather than a disease.					
27. I've no confidence in the person who is treating me.					
28. I am encouraged to ask questions about my arthritis.					
29. If I had a problem it would be difficult to get someone to speak to over the phone.					
30. I'm rarely asked which treatments I would prefer.					
31. If I had a problem with my arthritis I would find it easy to get advice over the phone.					
32. My feelings about my treatment are taken into consideration.					
33. If I had a medical problem I feel sure it would be checked out when I came to the clinic.					
34. Prescriptions for new medications are given without any explanation.					
35. I'm usually told what the possible side effects of the tablets could be.					
36. I'm encouraged to contact the person I see in clinic if I have a problem with my arthritis.					

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
37. The care I receive in the clinic is just about perfect.					
38. I hardly ever see the same person when I come for my appointment.					
39. The person I see in clinic appears skilful at their job.					
40. The person I see in clinic does not always talk sense.					
41. Sometimes the person I see in clinic is too busy to spend enough time with me.					
42. When I attend the clinic I’m told everything I want to know about my arthritis.					
43. It’s hard to get an appointment if I need it quickly.					
44. I see the same person nearly every time I come to clinic.					
45. I’m usually kept waiting a long time in the waiting area.					

Section 3: Questions about items for a model of care in early rheumatoid arthritis

3A. Please consider each statement and indicate if it reflected the care you received from the nurse-led consultation

(0= I do not agree at all. 10=I agree completely)

1. I believe that received specialist rheumatology care

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

2. Care was provided with compassion

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

3. Care was provided with a person-centred approach (The care was tailored to my individual needs)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

4. Care was provided with a holistic approach (I was treated as a whole person, not just as a disease)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

5. Care was provided with an empathic approach (The nurse specialist was kind and understanding)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

6. My disease was controlled well

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

7. My psychological needs were addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

8. My social needs were addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

9. My treatment was monitored to evaluate its effectiveness

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

10. I was asked about the side-effects of medication

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

11. I was followed up to see the impact of arthritis on my life

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

12. **The nurse coordinated my care with hospital doctors, GPs and other health professionals**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

13. **The nurse referred me to other health professionals (such as rheumatologist, physiotherapist, *occupational therapist, podiatrists or psychologist) according to my needs***

(Tick not applicable if you did not need referral to other health professionals)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

þ Not applicable (I did not need referral to health professionals)

14. **The nurse signposted me to relevant agencies, charities or patient organisations**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

þ Not applicable (I did not need signposting to other services)

15. **I was provided easy access to the rheumatology nurse specialist via a telephone advice line**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

16. The nurse checked that my questions had been addressed in the consultation

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

17. My opinion about my care was considered important

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

18. Innovation and service improvement were part of my care.

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
I do not agree at all										I agree completely

3B: Please consider each statement and indicate how important it is for your care in early rheumatoid arthritis

(0= not at all important, 10=extremely important)

1. I receive specialist rheumatology care

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

2. Care is provided with compassion

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

3. Care is provided with a person-centred approach (The care is tailored to my individual needs)

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

4. **Care is provided with a holistic approach (I am treated as a whole person, not just as a disease)**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

5. **Care is provided with an emphatic approach (The nurse specialist is kind and understanding)**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

6. **My disease is controlled well**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

7. **My psychological needs are addressed**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

8. My social needs are addressed

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

9. My treatment is monitored to evaluate its effectiveness

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

10. I am asked about the side-effects of medication

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

11. I am followed up to see the impact of arthritis on my life

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

12. **The nurse coordinates my care with hospital doctors, GPs and other health professionals**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

13. **The nurse refers me to other health professionals (such as rheumatologist, physiotherapist, occupational therapist, podiatrist or psychologist) according to my needs**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

14. **The nurse signposts me to relevant agencies, charities and patient organisations**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

15. **I am provided easy access to the rheumatology nurse specialist via a telephone advice line**

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

16. The nurse checks that my questions are addressed in the consultation

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

17. My opinion about my care is considered important

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

18. Innovation and service improvement are part of my care

0	1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Not at all important										Extremely important

Your opinion

Please add any aspect of care that you feel is important to you and is missing from the above statements (Free Text)

This is the end of the survey.

Thank you for your time and your valuable contribution

Appendix P. Process of developing themes from free text box data

Themes	Candidate themes	Codes	Participant comments 1 to 12 (P1 to P12)
Information	More practical information	Information lacking (practical info about clinic/contact)	P1. Explanation of how the rheumatology clinic works, who does what, who to contact was absent for me.
Listening	They are not listening	Not listened to (concerns about side effects/new drugs) ‘They don’t want to hear’ /‘focusing on the negative’/’do as told’)	P2. I feel as though if I talk about my concerns of side effects when starting new drugs they don't want to hear and think I'm just focusing on the negative. They think I should just do as I'm told.
Information	Information about work and benefits is lacking Information about impact on daily life and ability to work	Information lacking (work/benefits)	P3. How RA impacts on my daily life and how it has affected my ability to work and hold down a job. No advice on any benefits given which would be really helpful
Consultations Information	Regular follow up at change of drugs or other issues Impact on work and intimate life	More regular follow up (at change of drug/added issues) Impact on working and intimate life	P4. More regular follow ups when drugs are changed/added or you have phoned with an issue Impact on my working life and my intimate life with my husband
Patient involvement Telephone service –	Discussion of RA management	Discussion of day-to-day management (vitamin/holistic med)	P5. Discussion about day to management, vitamins abs holistic meds phone service is difficult as could be different person abs I’ve felt dismissed at

Listening Consultations Continuity	Telephone service not optimal Feeling dismissed Not being listened to Face-to-face consultation with nurse is appreciated Physio	Have felt dismissed when calling the clinic Phone service not optimal (different people answer) Face-to-face with same nurse excellent Physio amazing	times. face to face with same nurse excellent. Physio amazing!
Information Patient involvement	Information about MTX Information about drugs pros and cons Patient involvement is wanted	Lacking information (Automatically put on MTX) More information about drugs (pros/cons) Want to be part of the decision process (drugs)	P6. I was automatically put on methotrexate rather than another drug recommended by NICE for palindromic rheumatism. I would love to understand how the drugs work and pros and cons so I could be part of the decision process.
Telephone service Listening	Telephone and email access with generic answers not optimal Not being listened to Made feel a burden Made feel alone and scared	Telephone and email available, but with generic replies Not being listened to Made feel a burden Made feel alone and scared Everything is rushed	P7. Telephone and email contact are made available but generic replies are sent, you aren't listened to and made to feel a burden. Everything is rushed, makes you feel very alone as a patient. Before I had RA i never imagined healthcare professionals would leave you to cope in pain alone for so long. Makes you feel scared

	Left to cope in pain	Left to cope in pain by healthcare professionals	
Information	Explanation about monitoring tests wanted	Detailed explanation (monitoring tests/bloods)	P8. Detailed explanation regarding monitoring tests i.e. bloods
Consultations	Enduring long waiting times before consultation	Long waiting times (over 2 hours delay) Only seen the nurse once (due to waiting time)	P9. My appointments have all been over 2 hrs late and i have only managed to see the nurse once as I couldn't wait any longer.
Continuity Listening	Happy with care Worries about MTX and side effects Listening to the patient (worries about medication)	Happy with care Nurse advice to start MTX Worried about MTX and work (no regular days off/know of side-effects from relative)	P10. I feel very happy with my care, the only thing I think rheumatology nurse would like me to do is take methotrexate which I am reluctant to do as I don't have regular days off and the damage it has caused my mum who all so has RA
Listening Patient involvement	Wanting to feel able to speak up Listening to the patient	Feeling able to speak up about everyday life	P11. Feeling able to speak up about what is going on for me
Continuity	Continuity in care wanted	Continuity in care (seeing/talking to the same – don't have to keep explaining issues)	P12. Continuity with seeing or talking to the same person so I don't have to keep explaining my issues

Appendix Q. Themes developed from free text box data

Themes	**Illustrative quotations**
Need of information	**Explanation of how the rheumatology clinic works**, **who does what**, **who to contact** was **absent for me** (P1) **How RA impacts on my daily life** and **how it has affected my ability to work and hold down a job**. **No advice on any benefits** given which **would be really helpful** (P3) **Impact on my working life** and **my intimate life with my husband** (P4) I was **automatically put on methotrexate rather than another drug recommended by NICE** for palindromic rheumatism. I would love **to understand how the drugs work** and **pros and cons** so I could **be part of the decision process** (P6) **Detailed explanation** regarding **monitoring tests i.e. bloods** (P8)
Being listened to	I feel as though **if I talk about my concerns of side effects** when **starting new drugs** they **don't want to hear** and think I'm just focusing on the negative. **They think I should just do as I'm told** (P2) **Phone service is difficult** as **could be different person** and **I've felt dismissed at times** (P5) **Telephone and email contact are made available** but **generic replies are sent**, you **aren't listened to** and **made to feel a burden**. **Everything is rushed**, **makes you feel very alone** as a patient. Before I had RA I **never imagined healthcare professionals would leave you to cope in pain alone for so long**. **Makes you feel scared** (P7) I feel **very happy with my care**, **the only thing** I think **rheumatology nurse would like me to do is take methotrexate** which **I am reluctant to do** as **I don't have regular days off** and **the damage it has caused my mum** who all so **has RA** (P10) **Feeling able to speak up** about **what is going on for me** (P11)
Wanting to be involved	**Discussion about day to management**, **vitamins and holistic meds phone service is difficult** as **could be different person** and **I've felt dismissed** at times (P5)

	I was **automatically put on methotrexate rather than another drug recommended by NICE** for palindromic rheumatism. I **would love to understand how the drugs work** and **pros and cons so I could be part of the decision process** (P6) **Feeling able to speak up** about **what is going on for m**e (P11)
Appreciation of timely follow-up and face-to-face consultations	**More regular follow ups when drugs are changed/added** or **you have phoned with an issue** (P4) **Face to face with same nurse excellent**. **Physio amazing**! (P5) **My appointments have all been over 2 hrs late** and I **have only managed to see the nurse once** as I **couldn't wait any longer** (P9)
Access to a supportive telephone service	**Phone service is difficult** as **could be different person** and **I've felt dismissed at times** (P5) **Telephone and email contact are made available but generic replies are sent, you aren't listened to** and **made to feel a burden**. **Everything is rushed, makes you feel very alone** as a patient. Before I had RA I **never imagined healthcare professionals would leave you to cope in pain alone for so** long. **Makes you feel scared** P7.
Continuity in care and contacts	**Face to face with same nurse excellent**. **Physio amazing!** (P5) I feel very **happy with my care**, the only thing **I think rheumatology nurse would like me to do is take methotrexate** which I am reluctant to do as I don't have regular days off and the damage it has caused my mum who all so has RA (P10) **Continuity with seeing or talking to the same person so I don't have to keep explaining my issues** (P12)