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Original article

The perception of stakeholders on the applicability of nurse-led clinics in the management of rheumatoid arthritis

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Abstract

Objectives RA should be treated to target in a process of shared decision-making with patients. Person-centred care is essential to meeting specific patient needs. Nurse-led clinics, where a nurse is responsible for care, have demonstrated added value in some countries but are still not implemented widely. This study aimed to explore stakeholders' perceptions of advantages, disadvantages and conditions for the implementation of nurse-led clinics for RA in Belgium.

Methods We performed a cross-sectional qualitative study consisting of five semi-structured focus group interviews. Rheumatology nurses, patients with RA and rheumatologists were interviewed as stakeholders. The analysis was carried out by three researchers according to the Qualitative Analysis Guide of Leuven (QUAGOL), formulating a conceptual framework of overarching themes and deconstructing this into perceived advantages, disadvantages and conditions.

Results Two focus groups with nurses (total $n = 16$), two with patients ($n = 17$) and one with rheumatologists ($n = 9$) were conducted. The interview synthesis resulted in five overarching themes across stakeholders: efficiency of care, disease management, legal and organizational requirements, the conventional role of the nurse and the extended role of the nurse. All stakeholders perceived additional education for nurses as essential, but rheumatologists debated nurses' abilities to lead a rheumatology clinic. Furthermore, patients preferred care protocols to guide nurses, and care providers approached this reluctantly. Generally, patients with a well-controlled disease were perceived as the ideal candidates for nurse-led care.

Conclusion Nurse-led clinics could provide many benefits but require additional nurse education and a legal and organizational framework before being implemented widely and successfully.

Key words: rheumatoid arthritis, nurse-led clinics, nurse specialists, care models, care innovation, stakeholders, perceptions, qualitative, focus groups

Key messages

- All stakeholders expect nurse-led clinics to improve care efficiency, patient education and psychosocial support.
- Extending nurses' responsibilities requires a legal and organizational framework, including specialized nursing education.
- Patients with a well-controlled disease are perceived as the ideal candidates for nurse-led care.

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CLINICAL SCIENCE

Introduction

Current guidelines for the management of RA recommend starting treatment early and intensively to a target of remission or low disease activity [1]. However, it is essential not only to treat RA early, but also to address specific patient needs [2, 3]. Worryingly, however, early access to specialist rheumatological care is under increasing pressure [4]. Many countries are confronted with a relative shortage of practising rheumatologists [5], while shifts to a treat-to-target strategy and person-centred care have made ambulatory care for RA more labour intensive. These developments prompt the exploration of innovative care models, including nurse-led clinics (NLCs).

Across Europe, rheumatology is increasingly recognized as a dedicated nursing specialty, with rheumatology nurses fulfilling multiple roles ranging from complementary to more extended responsibilities [6]. NLCs are an ambulatory care model where specialized nurses provide care with greater autonomy, for instance monitoring specific conditions, prescribing or adapting medication and referring when necessary, in addition to their roles in education and psychosocial support [7]. This model has shown promise in the management of chronic conditions, including diabetes and heart disease. In some European countries, including the UK, Sweden and The Netherlands, NLCs have also been implemented in the management of rheumatic diseases. These NLC models range from consultations with an autonomous nurse specialist to nurse consultations supervised by a rheumatologist.

In RA, several trials comparing nurse-led care with the standard of care have shown improved patient satisfaction and an appealing cost-effectiveness profile, without compromising clinical disease control [8–11]. Contributors to the satisfaction of patients with nurse-led care appear to include positive communication and empathy, continuity of care, the time spent on the consultation, the information provided and the nurse's degree of specialism [12].

Although NLCs show definite promise in the management of rheumatic diseases, these care models have, to date, been introduced in only a few countries. The Belgian setting is particularly interesting to study because it stands in stark contrast to neighbouring countries, such as The Netherlands and the UK, where NLCs have been firmly established in daily care for patients with chronic inflammatory arthritis. Although courses for health professionals were organized by the Belgian rheumatology society in the past, an officially recognized training programme for rheumatology nursing is not currently available in Belgium, and opportunities for additional nursing education remain largely optional. In fact, any licensed Belgian nurse experienced in rheumatic diseases can assume the role of rheumatology nurse. Additionally, there is no legal framework to support the extended roles generally performed by nurses in NLCs. Lack of knowledge and education for nurses, reluctance among rheumatologists and legal constraints have previously been suggested as possible barriers to creating an extended role for rheumatology nurses [13]. However, there is little evidence about the perceptions of all relevant stakeholders, including patients and rheumatologists, on nurse-led care for rheumatic diseases. In view of a potential implementation of NLCs in RA care, the aim of this study was to gain more insight into possible advantages and disadvantages of this care model and conditions for its implementation, as perceived by patients, nurses and rheumatologists.

Methods

We conducted a cross-sectional qualitative study to assess perceptions of relevant stakeholders on NLCs for RA in Belgium. Patients with RA, rheumatologists and rheumatology nurses were interviewed as stakeholders in semi-structured focus group interviews. The University Hospitals Leuven Ethics Committee approved the study protocol. All participants provided written informed consent before participation.

Patients were either recruited from the Rheumatology outpatient clinic at the University Hospitals Leuven, Belgium, or via representatives of RA patient associations who were contacted via email. Consequently, we included both patients in follow-up at an academic hospital and patients in non-academic or private practice care. Practising rheumatologists were invited for group interviews through local peer quality groups, which are mandatory for accreditation in Belgium. Rheumatology nurses were contacted through the Flemish working group on rheumatology nursing and the Belgian Health Professionals association.

A total of five focus groups were conducted: two patient groups, two nurse groups and one rheumatologist group. The focus groups took place in four different municipalities across Flanders, Belgium, between January and March 2020. All interviews were semi-structured and coordinated by the same interviewer (M.V.) and two observers (R.V.M. and D.D.C.).

The interview guide was constructed in agreement with rheumatologists, rheumatology nurses and two patient partners (Supplementary Data S1, available at *Rheumatology Advances in Practice* online). The interviews started with open-ended exploratory queries before proceeding to more specific follow-up questions. During the interview, notes were taken by the observers to record participant body language and behavioural cues. All interviews were audio-recorded, transcribed and anonymized for analysis.

Transcripts were analysed by two independent investigators (M.D. and D.D.C.), guided by an experienced researcher (R.W.) and compared in accordance with the Qualitative Analysis Guide of Leuven (QUAGOL), which is based on the constant comparative method of grounded theory [14]. A first draft of the manuscript was reviewed by three patient partners to assess the credibility of our findings. Guided by the QUAGOL, a

conceptual framework of overarching themes was formulated and validated alongside all individual transcripts.

Results

Seventeen patients, sixteen nurses and nine rheumatologists participated in a total of five focus groups (two patient groups, two nurse groups and one rheumatologist group). The conceptual synthesis of these focus groups resulted in five overarching themes: efficiency of care, disease management, legal and organizational requirements, the conventional role of the nurse and the extended role of the nurse (Fig. 1). These themes and their subthemes were divided into perceived advantages, disadvantages and conditions for each stakeholder group (Table 1).

Efficiency of care

Efficient time management

Patients, nurses and rheumatologists assumed that NLCs could reduce rheumatologists' workload, providing more time to spend on patients needing urgent medical care. Generally, all stakeholders believed that this approach could make nurse-led care more time efficient than the current standard of practice. Patients specifically mentioned reduced waiting times for clinic appointments as a possible advantage.

> Shorter waiting times [could be an advantage]. Otherwise, as a new patient, you have to wait half a year, so to speak. (Patient 10, patient group 2)

This assessment was underlined by nurses, who expected NLCs to facilitate early diagnosis by providing rheumatologists with more time to see new patients early.

The nurse as the first line of care

Some patients proposed that NLCs could facilitate access to care. They felt that it was often difficult to contact their rheumatologist directly, whereas nurses were perceived as more accessible than physicians. This aspect was more explicitly stated by patients in follow-up at non-academic centres, where there are no trainee physicians who can act as an intermediary.

> I once lost a certificate. If you then need to get hold of the rheumatologist.... So, I contacted the nurse and was able to arrange it. I thought, 'Good thing these people are there'. (Patient 9, patient group 2)

Rheumatology nurses recognized that they often form a central point of communication for the patient. Although this perception was widely shared by

Fig. 1 Conceptual framework of overarching themes and subthemes

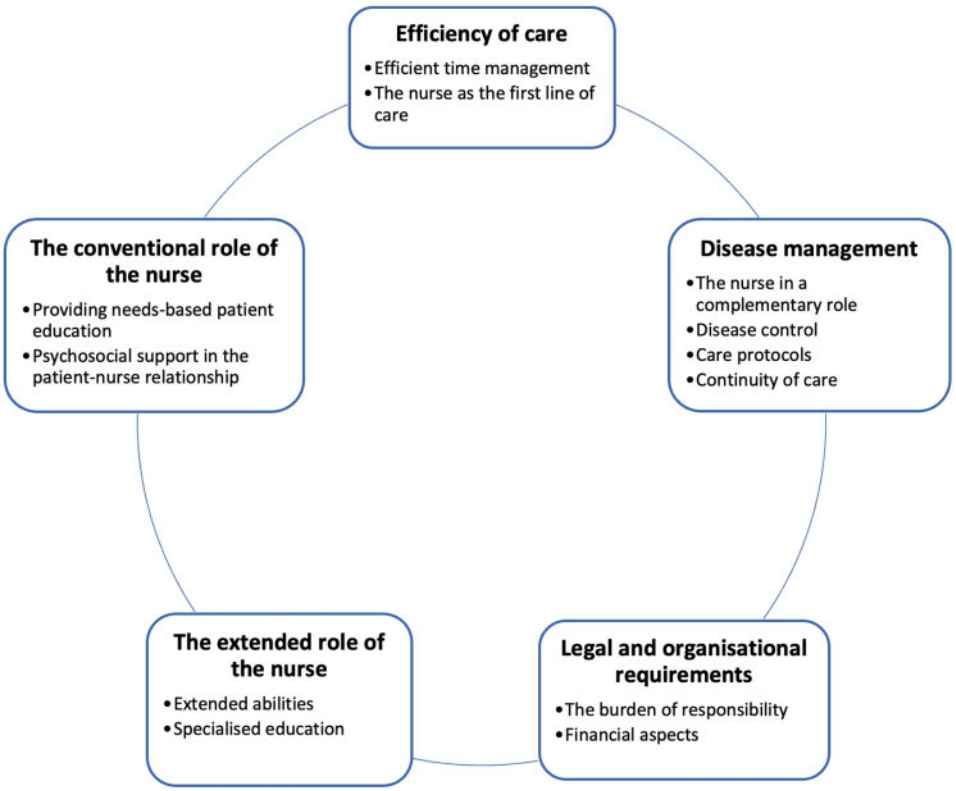

Table 1 Advantages, disadvantages and conditions for the implementation of nurse-led clinics, as perceived by stakeholders

Parameter	Advantages			Disadvantages			Conditions		
	Patients	Nurses	Rheumatologists	Patients	Nurses	Rheumatologists	Patients	Nurses	Rheumatologists
Efficiency of care									
Efficient time management	◆	◆	◆						
The nurse as the first line of care	◆	◆	◆						
Disease management									
The nurse in a complementary role							◆	◆	◆
Disease control							◆	◆	◆
Care protocols					◆	◆	◆		
Continuity of care	◆						◆		
Legal and organizational requirements									
The burden of responsibility					◆	◆		◆	
Financial aspects		◆						◆	◆
The conventional role of the nurse									
Providing needs-based patient education	◆	◆	◆		◆				
Psychosocial support in the patient–nurse relationship	◆	◆	◆						
The extended role of the nurse									
Extended abilities				◆		◆			
Specialized education						◆	◆	◆	◆

Some aspects were identified univocally as (dis)advantages or conditions, whereas others differed between stakeholder groups. For instance, patients identified continuity of care as a condition for nurse-led clinics (NLCs), but also NLCs to improve care continuity. Moreover, providing needs-based patient education was widely perceived as an advantage of NLCs, but nurses feared that extended roles would not leave enough time to provide this education. Finally, additional responsibilities for nurses and the need for specialized education were perceived as disadvantages of NLCs, but nurses approached these challenges more positively and emphasized corresponding legal and organizational changes and conditions for this care model.

rheumatologists, this nursing role was not regarded as unique to an NLC model.

> For calls, they are the first buffer. Same thing for emails; that's all very useful. And a nurse is much better equipped to sense a problem than a secretary. (Rheumatologist 1)

Aside from providing a buffer for communication, rheumatologists also highlighted nurses' ability to screen patients. They saw a particular benefit in an NLC model where nurses could triage patients requiring urgent clinic visits.

Disease management

The nurse in a complementary role

Both nurses and rheumatologists felt that NLCs would be feasible only if the nurse functioned in cooperation with a rheumatologist, in some capacity. Most nurses were reluctant to assume full responsibility and expressed a need to feel 'backed up' by a physician at all times.

> Having the final say; I don't think I would be confident enough to handle that. (Nurse 8, nurse group 1)

This need for a rheumatologist to be available to consult was also of concern to patients. Some patients did not feel comfortable with the idea of leaving their care completely in the hands of a nurse.

> That they can go and ask for advice. That there's a plan B available behind the scenes. I think that would be necessary. (Patient 6, patient group 1)
> I would still prefer to see the rheumatologist every once in a while, and not always go to the nurse. Maybe sometimes you think everything is okay, but it isn't? (Patient 1, patient group 2)

The concerns expressed in the latter quote were also voiced by rheumatologists, who expected nurses to be less prone to screen for certain disease aspects, such as cardiopulmonary involvement or co-morbidities. These concerns also relate to the need for a well-controlled disease.

Disease control

Patients strongly emphasized a stable, well-controlled disease as a requirement for nurse-led care.

> It might be advantageous if you're in remission and there are no problems. If there are, I would still prefer to see a rheumatologist. (Patient 1, patient group 2)

As another expression of this need for stability, some patients indicated they would not prefer nurse-led follow-up to be 'that first step', in the early stages of treatment. Both nurses and rheumatologists also identified well-controlled patients in a more established stage of the disease as the ideal candidates for nurse-led care.

> Most RA patients, we treat to target and then they do well for 10 years. In that phase, the rheumatology nurse could be useful. (Rheumatologist 1)

Care protocols

Some patients indicated they would feel more comfortable with nurse-led care if nurses had access to a prespecified protocol in case of problems.

> Would these nurses get a list of standard questions from the doctors, to help them decide when it's necessary to refer someone? (Patient 6, patient group 1)

However, contrary to patients, both nurses and rheumatologists feared that NLCs would result in a practice excessively guided by protocols. Nurses, in particular, worried that this would shift their focus away from the person-centred aspects of care.

> Then we're no longer working with a patient, but with a skeleton. You're more likely going to say, 'Give me your hand so I can look at it' than ask, 'How are you doing?'. (Nurse 3, nurse group 2)

Continuity of care

Patients valued continuity of care as a prerequisite for any care model. Particularly, patients under care at an academic hospital were more accustomed to seeing various physicians in the clinic. These patients felt that NLCs could improve upon this, as long as continuity of care was ensured.

> That would be a must for me, that you would always see the same nurse. (Patient 10, patient group 2)

Legal and organizational requirements

The burden of responsibility

Nurses expressed particular concern about the increased level of responsibility the NLC model would entail. They felt that this responsibility would need to be supported by a legal framework as a prerequisite for nurse-led care.

> There needs to be someone to take final responsibility. I wouldn't know how a framework for that could be created. (Nurse 1, nurse group 2)

In contrast, rheumatologists felt reluctant to give up the final responsibility for their patients and preferred to retain the expert role.

Financial aspects

Although rheumatology nurses expected NLCs to be more cost-effective than usual care, this was not expressed as a priority by patients or rheumatologists.

> It's not all that expensive now, right? Travelling to the clinic costs more than the consultation. (Patient 3, patient group 2)

However, both nurses and rheumatologists did indicate the need for an adapted remuneration system to support the extended responsibilities that NLCs would imply.

The conventional role of the nurse

Providing needs-based patient education

Patients, nurses and rheumatologists identified the provision of education to patients about their condition,

medication adherence and adverse effects as a crucial nursing role. They also experienced that patients often have a need for more clarification after a rheumatologist consultation.

> Sometimes people don't expect to get this diagnosis. It regularly happens that people then get emotional. Often, a lot of what is said after that is lost. (Nurse 4, nurse group 2)

Although both patients and nurses considered nurses' educational abilities to be a possible advantage of NLCs, some nurses feared that extending their current roles would conflict with their educational duties.

Psychosocial support in the patient–nurse relationship

Some patients felt that there is often still a barrier to open communication with their doctor, because the nurse was usually perceived as more accessible than the rheumatologist.

> For some people, it's still a barrier. This is the doctor and I'm just.... (Patient 9, patient group 2)

Nurses considered a more open patient–caregiver relationship as one of the most important advantages of nurse-led care. Both nurses and rheumatologists experienced that patients often gave more or different information to nurses than to a physician.

> I have the impression that they'll sooner tell that to me, as a nurse, than to our doctor. There is less reluctance to talk about self-management, being able to pick up your kid.... That's something that isn't discussed with the doctor, but in a nurse consultation, there is a place for that. (Nurse 2, nurse group 1)
>
> There are patients that I've known for 10 years, then go to the nurse and tell her that they've been having relationship problems for 5 years.... And then I think, why didn't they tell me that? (Rheumatologist 1)

The extended role of the nurse

Extended abilities

Some patients, in addition to rheumatologists, were concerned about nurses' abilities to perform the additional roles required in the NLC model.

> A doctor has studied for so many years and might notice things that nurses can't. (Patient 5, patient group 1)

Specialized education

Nurses were equally insecure about their ability to ensure comprehensive care for a patient with RA, but specifically addressed this as a result of insufficient training.

> I think we haven't had the right education. What if a patient asks me about lab results, how should I interpret that? (Nurse 1, nurse group 2)

Patients, nurses and rheumatologists identified a specialized education as a crucial requirement for NLCs to be feasible. However, rheumatologists generally assumed that having medical intuition is crucial in caring for patients with RA, which cannot be taught without attending proper medical training.

Discussion

This study investigated the perceptions of three stakeholder groups on the feasibility of NLCs in the care for patients with RA in Belgium. Through semi-structured focus group interviews, we identified five principal topics: efficiency of care, disease management, legal and organizational requirements, the conventional role of the nurse and the extended role of the nurse.

The most recent EULAR recommendations for the role of the nurse identified three overarching principles to which any rheumatology nurse should adhere: the nurse as part of a health-care team, the nurse as a provider of evidence-based care and the principle of shared decision-making [6]. NLCs extend the conventional roles of rheumatology nurses and require nurses to assume additional responsibilities, which can include more independent patient follow-up, treatment decisions or ordering diagnostic tests, in addition to autonomous nurse consultations without physician supervision [15]. An important finding of our study is that the conventional role of a nurse, complementary to the rheumatologist, is seen by all stakeholders as a significant added value in rheumatology care. Patients clearly appreciated the general approachability of nurses, an aspect nurses themselves were well aware of, while rheumatologists saw the nurses' roles as highly compatible with their own role as expert. All stakeholders identified nurses' generally more person-centred approach as a particular advantage, in line with previous research [16].

In addition to the benefits provided by conventional nursing roles, all stakeholders in our study agreed on the potential added value of extending these roles to nurse-led care in specific scenarios. Specifically, all groups placed an emphasis on efficiency gains in the care for patients with a stable, controlled disease state. In previous studies from other countries, the use of protocols and guidelines was perceived as a promoter of such efficient care [17, 18]. Patients in our study clearly valued care protocols as contributors to an overall sense of safety and a more transparent, consistent care among different care providers. In contrast, nurses and rheumatologists were generally more reluctant to rely heavily on protocols, worrying that turning to care protocols would steer them away from the person-centred approach they valued so highly.

Although all stakeholders agreed on the potential benefits of the NLC model, the transition of nurses from more classical roles to the extended roles in NLCs was widely perceived as a challenge. Illustrating this, nurse education was an important theme for all stakeholders in our study. Although access to continuous and specialized nursing education was put forward by EULAR recommendations, tailored training for rheumatology nurses is not readily available in every country [19, 20]. Although all stakeholders in our study considered additional education for nurses to be essential, we noticed a contrast between stakeholder groups in how they approached this specific theme. Rheumatologists heavily debated nurses' abilities

to lead a rheumatology clinic independently, without a comprehensive medical education. Such scepticism by physicians has also been reported in previous research from The Netherlands on the implementation of extended nursing roles [21]. However, in the case of Dutch rheumatology care, this initial scepticism seemed to decrease when theory was put to practice [20]. In our study, patients also underlined the need for additional education for nurses to work independently. Nonetheless, both patients and nurses were generally more positive towards nurse-led care than rheumatologists and tended to perceive additional education more as a prerequisite than as a barrier for the implementation of NLCs. Finally, because nurses perceived their current roles as complementary to the tasks usually performed by physicians, another barrier consistently underlined in the nurse groups was the fear that an extended role would hamper their usual roles and decrease the quality of care instead of raising it.

Implementing an NLC model also poses several organizational challenges. It was clear to both nurses and rheumatologists in our study that a legal and financial framework should be in place before NLCs can be implemented widely. Nurses were reluctant to take up more responsibility without legal protection or financial compensation. Rheumatologists were also more hesitant to share the expert role in the care for patients and the corresponding remuneration. Finally, nurses worried that a general lack of nursing staff would be a hurdle for the applicability of NLCs in practice, a concern previously described in international studies [20]. Therefore, a legal basis together with financial investments are required, yet the evidence for justification of such investments is not supported by all stakeholders.

Our study has some limitations. First, although focus groups are an efficient way to ask several individuals about a specific topic, participants sometimes do not feel able to speak as freely as in individual interviews. However, for patients and nurses, results per individual focus group were comparable, underlining the robustness of our findings. Moreover, our results were validated by three patient partners, revealing no missing or additional themes.

Second, multiple rheumatologists in our focus group worked in a private practice. Therefore, we cannot rule out the possibility that rheumatologists' practice settings might influence their perception of NLCs. We had planned a second rheumatologist focus group, but this group was cancelled in the context of the coronavirus disease 2019 pandemic. However, efforts were made to make the groups as heterogeneous as possible. Rheumatologists were recruited from general and academic hospitals, while patients were recruited directly from an academic rheumatology practice and via patient organizations. Rheumatology nurses were included from two distinct regions.

Third, it can be debated whether all important stakeholders have been involved. In addition to patients' relatives, governmental representatives could have been valuable to discuss the legal and financial framework in more detail. Fourth, given that NLCs are not formally practised in Belgium, stakeholders expressed difficulties in imagining what NLCs consist of and in describing their perceptions of it. The results might therefore not be generalizable to countries where NLCs have already been implemented or to countries where a legal or financial framework does exist. Finally, detailed demographic characteristics of participants could not be provided, because the collection of these data was not included in the study protocol.

A strength of our study is the use of the QUAGOL as a framework to guide analyses by an interdisciplinary research team. The team was involved in a structured way in analysing the results, but also in testing the interview guide and concepts after each interview. Additionally, the involvement of patient partners in every stage of this study is an important strength. Their personal experience with the disease of interest significantly complemented the scientific perspective of the researchers.

In conclusion, our study explored the perceptions of patients, nurses and rheumatologists on the feasibility of NLCs in Belgium. Many advantages were specified, such as increased efficiency of care and improved general disease management. A disadvantage could be the challenging step from the general nursing role towards extended roles in an NLC. This challenge requires some conditions to be met, including tailored nurse education and a clear legal and organizational framework, before NLCs can be implemented widely. Our findings can provide guidance for policymakers to avoid specific pitfalls in the future implementation of this care model in rheumatology practice.

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Data availability statement

The original transcripts (in Dutch) used and analysed during the current study are available from the corresponding author on reasonable request.

Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

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