

BARRIERS TO AND FACILITATORS OF RHEUMATOLOGY NURSES IN THEIR SUPPORT OF PATIENTS TO USE A SELF- MANAGEMENT PROGRAM: A QUALITATIVE STUDY

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ENGLISH ABSTRACT

Title: Investigating the barriers to and facilitators of rheumatology nurses in their support of patients to use the self-management program 'Challenge Your Arthritis'.

Background: 'Challenge Your Arthritis' is a peer-guided program to enhance patients' self-management in coping with their rheumatic disease. Although rheumatology nurses are seen as important suppliers of the program, only a few patients are referred to this program by them. Moreover, a limited number of patients participate in it. To date, nurses' perspectives on the program have remained underexposed. Insight into the barriers to and facilitators of rheumatology nurses in their support of patients to use the program is needed.

Aim: To investigate the barriers to and facilitators of rheumatology nurses in daily care practice with respect to their support of patients to use the self-management program 'Challenge Your Arthritis', in order to provide information that may be used to optimize its implementation.

Methods: A qualitative generic descriptive design was chosen, using semi-structured interviews with Dutch rheumatology nurses. Theoretical thematic analysis with constant comparison was applied, using a deductive approach in which analysis was directed by the concepts of theoretical frameworks.

Results: Data collected from fourteen participants yielded fourteen barriers and twelve facilitators, within sixteen subthemes at six overarching levels: professional, innovation, patient, social context, organizational context and external context.

Conclusion and recommendations: Regarding the identified barriers to and facilitators of rheumatology nurses, it was found that whereas rheumatology nurses reported facilitators on the levels of professional, innovation and social context, they indicated many barriers on the levels of professional and organizational context. For 'Challenge Your Arthritis' to be more widely supported by nurses, barriers should be overcome. Notably the lack of work structure and of resources, time, knowledge and skills, and an undue attitude of care. It is recommended to explore the use of a tool to guide the work structure and of a multifaceted training for nurses.

Keywords: rheumatic care, nurses' perspective, self-management program, self-management support, implementation science

NEDERLANDSE SAMENVATTING

Titel: Onderzoek naar de factoren die reumatologieverpleegkundigen belemmeren en faciliteren bij hun ondersteuning van patiënten om het zelfmanagement programma ReumaUitgedaagd! te gebruiken.

Achtergrond: ReumaUitgedaagd! is een door lotgenoten geleid programma om het zelfmanagement van patiënten te verbeteren bij het omgaan met hun reumatische aandoening. Hoewel reumatologieverpleegkundigen worden gezien als belangrijke aanbieders van het programma, worden maar enkele patiënten door hen verwezen naar het programma. Bovendien neemt een beperkt aantal patiënten eraan deel. Het verpleegkundig perspectief op het programma is tot dusver onderbelicht gebleven. Er is inzicht nodig in de factoren die reumatologieverpleegkundigen faciliteren en belemmeren bij hun ondersteuning van patiënten om ReumaUitgedaagd! te gebruiken.

Doelstelling: Het onderzoeken van factoren die reumatologieverpleegkundigen belemmeren en faciliteren bij het ondersteunen van patiënten om ReumaUitgedaagd! te gebruiken, om informatie te vergaren die kan worden gebruikt om de implementatie ervan te optimaliseren.

Methode: Een generieke, beschrijvende, kwalitatieve onderzoek is gekozen, met gebruik van semigestructureerde interviews onder reumatologieverpleegkundigen. Theoretische thematische analyse met constante vergelijking is gehanteerd, met gebruikmaking van een deductieve werkwijze, waarbij de analyse werd gestuurd door de concepten van theoretische raamwerken.

Resultaten: Gegevens van veertien verpleegkundigen leverden twaalf facilitators en veertien belemmeringen op, binnen zestien sub thema's op zes overkoepelende niveaus; professional, innovatie, patiënt, sociale context, organisatorische context en externe context

Conclusie: Met betrekking tot de factoren die reumatologieverpleegkundigen belemmeren en faciliteren kan worden geconcludeerd dat, terwijl verpleegkundigen faciliterende factoren rapporteerden op het niveau van de innovatie, sociale context en professional, zij veel belemmeringen indiceerden op het niveau van de organisatorische context en professional.

Aanbevelingen: Voor bredere ondersteuning van het programma door verpleegkundigen, is het nodig om de belemmeringen te overwinnen. Met name het gebrek aan werkstructuur en aan middelen, tijd, kennis en vaardigheden en een overmatige zorghouding. Het wordt aanbevolen om het gebruik van een tool om de werkstructuur te begeleiden en een veelzijdige training voor verpleegkundigen te verkennen.

Sleutelwoorden: reumatologische zorg, verpleegkundig perspectief, zelfmanagement programma, zelfmanagement ondersteuning, implementatie wetenschap

INTRODUCTION

Every year, one in 66 people in the Netherlands is diagnosed with a rheumatic disease, which occupies the seventh place among the most burdensome disorders(1). The term 'rheumatism' covers more than 200 different types of diseases, a substantial proportion of which is considered to be chronic and typically has no prospect of full recovery(2-4). Rheumatism is characterized by pain and a consequent reduction of the range of motion and function of the musculoskeletal system, not caused by trauma(4,5). The psycho-social impact of rheumatism may include feelings of depression and low self-esteem(1,6,7). Rheumatic diseases significantly limit the performance of daily life functions and require behavioral changes and psychological adjustments to manage their impact(1,8). Patients' ability to meet these challenges and take an active role in their own care requires support from professionals and peers(1,8,9).

Within the broad range of multidisciplinary professional rheumatic care, self-management has become increasingly common in the management of chronic conditions(10-12). It is often described as the individual's ability to cope with symptoms, treatment, physical and psychological consequences and changes in life style inherent with living with a chronic disease(13). Supporting self-management is a challenge for the professional involved in patient care, and includes all actions that enable patients to cope with their own disease(14). In recent decades, numerous self-management interventions have been established in healthcare settings(15). These interventions include educational, behavioral, and cognitive approaches to influence health knowledge, attitudes, beliefs, and behavior(15). Stanford University's Arthritis Self-Management Program (ASMP) is the best known and most widely studied self-management intervention for people with a rheumatic disease(12,16).

In 2001, a self-management intervention, called 'Challenge Your Arthritis', (in Dutch *ReumaUitgedaagd!*), was introduced in the Netherlands(17). This peer-guided self-management program, based on the successful ASMP, aims to enhance patients' self-management in coping with their rheumatic disease(18-20). This program was originally developed as a face-to-face training for adults and has evolved on a scientific basis(16,18,19), with online and face-to-face version for young adults, and an online version for adults. In order to develop these training variants, the Medical Research Council guidance was followed(21). The program is based on Bandura's self-efficacy theory(18,22) and on the self-determination theory of Ryan and Deci(12,18,23). As for the effectiveness of the program, no significant effect has been found for the online version for young adults, but qualitative results have indicated a positive appreciation of the program(19). Currently, the

effectiveness of the online adult version is still under investigation, and results have not been published yet.

The program can be found via social media and in rheumatology healthcare settings(24). In these settings, rheumatology nurses can be seen as important suppliers of the program. Although nurses fulfil different roles, depending on their level of education or work setting, all nurses working with patients with rheumatic diseases may fulfil these supportive role(25). Their support of patients to use the program includes counselling patients on their self-management needs and referring them to the program. However, the number of referrals to the program by nurses is low, according to the program's internal report(26,27). Less than 10% of participants who follow the program were referred to it by nurses. Moreover, a limited number of patients actually use the program, as only 95 of the 1.95 million people coping with a rheumatic disease in the Netherlands participated in 2018(28).

New insights from research investigating effective, efficient and patient-friendly care, frequently find their way slowly to daily practice(29,30). This may be due to the difficulty of changing well-established patterns of care(30). The translation into daily practice necessarily involves behavioral change by health professionals amongst other factors, and these have proven to be a challenge(31). With regard to providing self-management support by nurses, recent publications state that this support may be difficult to realize(9,32). An explanation can be found in the ethical dilemmas nurses are facing, based on different views about what constitutes good care and good self-management(32). It has furthermore been suggested that nurses may lack sufficient training to provide self-management support to meet patients' needs(9).

Despite the program's extensive development, it may not yet be utilized optimally. During the development and evaluation of the program(21), the patients' perspectives were well exposed, whereas the nurses' perspective has have to date remained underexposed. Insight is required into the barriers to and facilitators of rheumatology nurses with respect to their support of patients to use the program.

AIM

The aim of this study is to investigate barriers to and facilitators of rheumatology nurses in daily care practice with respect to their support of patients to use the self-management program 'Challenge Your Arthritis', in order to provide information that may be used to optimize the implementation of the program.

METHODS

Design

A qualitative, generic, descriptive design was chosen for this research study, because, to date, little is known about barriers to and facilitators of rheumatology nurses' experience and beliefs regarding their support of patients to use 'Challenge Your Arthritis'(33,34). This design aims to provide a rich descriptions of these nurses' views. A generic approach is most suitable, as it seeks to describe the actual content of participants' reports on their experiences(35). The study was conducted from January 2020 to June 2020. The study meets the COREQ criteria for conducting qualitative research(36).

Population and domain

The population consists of Dutch rheumatology nurses working with patients with a rheumatic disease. As for their education, there are two occupational positions: master trained nurses (MTNs) who are advanced nurse practitioners, and specialized nurses (SNs). Both groups are specialized in rheumatology and mainly work in outpatient clinics(5).

Procedures

A purposive maximum variation sampling strategy was used to select a diverse group of participants with variation in perspectives and backgrounds. Characteristics of rheumatology nurses were defined in a pre-specified profile sketch based on the literature(5) and on a consensus meeting of the research team. This was done to obtain optimal variance in terms of the demographic characteristics. Eligible criteria for the current study included registered rheumatology nurses, aged over 18 years old, working with patients with a rheumatic disease, who are fluent in Dutch. Nurses were invited to participate at a Rheumatology Congress in the Netherlands in November 2019 and through the network of the Dutch Nurse Association, unit Rheumatology. After information was provided by the principal researcher (MdV), interested nurses were able to submit their personal details. Subsequently, participants were selected on the basis of the pre-developed profile sketch.

Data collection

Demographic data were collected by means of a questionnaire, including questions about participants' age, gender, working position, organization, work setting, hours of working and years of work experiences. These data were used to clarify the representativeness of the participants. Semi-structured interviews were conducted to collect barriers to and facilitators of influencing their support of patients to use the program. The interview started with a general question about self-management support in daily practice and subsequently

questions were guided by the concepts of the theoretical framework of the multilevel approach of Grol and Wensing(30). This approach examines barriers and facilitators influencing implementation at six levels of healthcare: the professional (i.e. the rheumatology nurse), innovation (i.e. the program), patient, social context, organizational context and external context(30). In addition, the Theoretical Domains Framework (TDF) was used to further explore influences on health professionals' behavior(37). Box 1 shows an overview of both theoretical frameworks. A test interview was conducted with a rheumatology nurse in order to refine the interview guide. The first four interview were conducted face-to-face, and the following by telephone, one of which was held with two participants simultaneously. Each interview lasted, on average, 55 minutes (range: 43–66 minutes).. Member check took place during the interviews by restating and paraphrasing the information provided, to determine whether it was understood correctly, which contributes to the credibility of the data(33,38). The interviews were audio-taped, transcribed verbatim and rendered anonymous. The interview guide was adapted several times due to new insights gained from previous data, and changes were documented. The interviews were held by MdV, a registered nurse and master student, trained in interviewing prior to the data collection. The aim was to achieve data saturation(33). However, confirmation of the planned data saturation by conducting two additional interviews was not achieved.

Insert Box 1. [Overview of the framework of the multilevel approach of Grol and Wensing and of the Theoretical Domains Framework]

Data analysis

Theoretical thematic analysis – with constant comparison – according to Braun and Clarke(39) was used to analyze the interviews. This method offers an iterative, flexible and reflexive process of data analysis(34,35,39). The analysis started during the data collection and constantly moved back and forth between current and previously analyzed data(31,32). A deductive approach was used, where coding and theme development were directed by pre-existing concepts within the six levels influencing implementation of the framework of Grol and Wensing, with additional input from domains of the TDF(29,30,37,40). During the execution of the study, observational, methodological, and theoretical notes were made to monitor the process in order to stay embedded in the empirical reality, and to contribute to the trustworthiness of the findings(41,42). The analysis was conducted by the research team (MdV, YvE-H, JA, LG). MdV had previously followed a workshop about coding data and the use of NVivo. The other researchers are experts in qualitative data analysis. The first three interviews were analyzed individually by MdV and YvE-H and discussed to achieve consensus. The subsequent interviews were analyzed by MdV alone and discussed with the

other researchers during all phases of the analysis(38,39). The researchers became familiar with the data by (re)reading the first interview and noting down initial ideas for coding(34,39). Meaningful segments were marked and initially coded. Subsequently, codes were combined to discover patterns. Patterns were combined and discussed with the research team(38,39). Then, clustering and the assignment of patterns to overarching subthemes took place, and related to pre-existing concepts, distinguishing between the facilitators and barriers(35,38). Finally, the main thematic map and table were established. Computer software NVivo, version 12 (ORS international, Australia) was used to organize the data(43).

Ethical considerations

This study was conducted according to the ethical principles of the Declaration of Helsinki(44) and the Dutch law General Protection Regulation(45). After consultation with the University Medical Center Utrecht, the study was not submitted to the Medical Research Ethics Committee (MREC), since it is not a medical study and participants are not subject to acts or the imposition of certain behaviors(46). All participants provided written informed consent.

RESULTS

Fourteen rheumatology nurses participated in this study. Table 1 lists the characteristics of the participants. All participants are female, and the mean age is 46 years (range: 28–62 years). Four participants work as MTNs and ten as SNs. The mean work experience in current position is eight years (range: 1–23 years).

Insert Table 1. [Demographic Characteristics of the participants]

Findings

Fourteen barriers and twelve facilitators emerged from the data and were assigned to sixteen subthemes on the six overarching levels, that is, the levels of the framework of the multilevel approach of Grol and Wensing. See Appendix 1 for a thematic map of the levels and subthemes. Table 2 shows an overview of the findings, including the barriers and facilitators. Most barriers were identified on the levels of the organization and professional, and most facilitators on the levels of the professional, innovation and social context.

Insert Table 2. [Overview of the barriers and facilitators, subthemes and levels]

Organizational context

On the level of the organization mainly barriers were identified. A lack of structure, which would enable discussion of topics concerning self-management and the program, was found to be a frequently mentioned barrier. The utility of a guiding tool to overcome this barrier was mentioned by several participants.

“People do experience problems in everyday life that are not discussed during the consultation. Therefore, a tool like ‘the self-management-web’ should be recommended during the consultation, or at least mentioned.” (P4)

Another example of lack of structure was the period of time to submit the program with patients: several participants declared that the timing of the program was inappropriate, since

“It [time for the consultation] is regularly too short. We have fifteen minutes per patient for a follow-up consultation. If it is a regular check-up and everything is going well, then there is enough time, but when something comes up during the consultation – especially on a psychosocial level or indeed with regard to self-management – it usually turns out that there is lack of time, when you also have to examine the joints, check the blood results and discuss the medication. When this happens, well, then consultation time is running out. Sometimes I happened to have some extra time, but most of the time I don't.” (P7)

A lack of informative material about the program was often mentioned as a barrier by participants, both for nurses and for patients. As for patients' materials, participants mentioned providing information prior to the consultation may lead to a better reception of support of the program, illustrated by a participant who said the following:

"We also have a digital board in the waiting room where people can see a variety of information, for instance about the patients' association. In addition, we could also mention it [the program], so that people, after having read about 'Challenge Your Arthritis', come to us and ask questions such as: 'Gosh, I have read about this and that.'" (P11)

Another barrier is the use of alternatives for the program, as evidenced by comparable trainings or internal self-management support within the institution. As for facilitating factors in the organizational context, the current informative material rated as user-friendly and accessible. Besides, the positive policy and vision of the institution on support of self-management and the program were deemed a facilitator.

Professional

All participants mentioned they were aware of the existence of the program. Some of them frequently support patients in need of self-management to use this program, others do so only occasionally and a minority never does. A motivated attitude towards supporting the program often came up as a facilitator. A participant reported as follows:

"We inform them [patients] in a very enthusiastic way about the program. We ourselves are enthusiastic about it. So you always try to convey this enthusiasm to patients, I guess. And it is very important to do so, in my opinion." (P12)

A lack of knowledge about the content of the program among participants was a frequently mentioned barrier. Participants regularly stated that they had inadequate knowledge of it, did not know its contents precisely, or how it works for patients, or that they did not know what actually to do in their support role as a nurse. Several participants expressed their need for more knowledge and a wish to follow the program with other rheumatology colleagues:

"In my opinion, nurses should follow the training themselves, so you would know what it actually is you're offering to patients. Then you would be able to convey the importance of this training with more persuasion." (P2)

An undue attitude of taking care of patients was found to be a frequent barrier. This attitude was described as being solution-orientated, which may prevent from giving patients self-management support.

“Sometimes I have the urge to keep the patients to myself too much because I want to solve it for them, while what you actually want is to stimulate self-management.” (P6)

Conveying self-management support to patients was frequently mentioned by participants as both a facilitator and a barrier: the facilitator related to participants’ general conversational skills, with an additional input from techniques, for example motivational interviewing. The barrier turned out to be the actual apply of the support, especially in situations where patients demonstrated resistance or lack of motivation. Furthermore, insecurity about the decision-making process, whether to support the program to patients or not, turned out to be another barrier. This was expressed as follows by a participant:

“You can have a day at your consultations, seeing, for instance, eight patients in the morning and thinking to yourself ‘To this person I will mention the program, but to that person I will not’ [...] ‘But that might also be a pitfall. That you decide for someone that it [the program] is not suitable, whereas it might work out perfectly.’ (P2)

A lack of actual awareness of the program during consultations was a barrier. The participants who raised this, attributed this mostly to their tendency to follow the conversational flow. A facilitating factor was the establishment of a good relationship with the patient prior to the support of the program. Greater trust between the professional and the patient was mentioned as helpful in addressing topics of self-management.

Innovation

With regards to the innovation, belief in the effectiveness of the program was a repeatedly mentioned facilitator. Another facilitator was found in the perspective that the program is – a sometimes additional – part of the treatment, and in the multiple surplus values of the program that were attribute to it: Its main surplus value was seen to the fellowship between patients, while the guidance by experts was also mentioned in this context.

“I really believe it contributes to self-management from what I know about it [the program], and from what I hear from patients.” (P7)

“I think that it can be very helpful [for patients] to be in contact with other patients suffering from a similar illness.” (P1)

Social context

The team’s positive view of support of the program was found to be a facilitator often mentioned by participants. In this context, participants also declared an open, innovative culture in their team, with freedom for self-development, as well as the absence of obstacles to support the program.

“We actually do everything together and we are an enthusiastic team, I should say. This does give us the chance to develop self-management support further and to offer it [the program] to our patients.” (P11)

Mutual communication and encouragement within the team with respect to support of the program were also seen as a facilitator. While a few participants mentioned their willingness to have more of this, the majority expressed the positive mutual communication and encouragement. Another facilitator is that support of the program is regarded as an important task of SNs. For the supporting task of MTNs, a lack of a clear vision on these tasks was found to be barrier: some participants indicated that SNs should mainly support the program. Others pointed out that there are no differences between the tasks of both nurses kinds of nurses.

The patient

Participants raised various patient characteristics that pose a barrier to their support of the program. A frequently mentioned characteristic was patients’ negative attitudes and motivation towards self-management and the program, the more so since patients’ compliance with the program is seen as a prerequisite by participants.

“When I think of ‘Challenge Your Arthritis’ – and that’s a criterion for us – I only recommend it to those patients who are willing to change and to learn.” (P10)

External context

The location – and geographic distance – of the program’s training may negatively or positively influence patients’ decision to go there, along with participants’ support for it, which makes it both a barrier and a facilitator. Furthermore, another barrier is the costs of training and additional circumstances, such as the administration needed for reimbursement by the health insurer, because these may negatively influence patients’ use of the program, as well the support by the participants.

DISCUSSION

This study identified a variety of barriers and facilitators reported by rheumatology nurses with respect to their support of patients to use the self-management program 'Challenge Your Arthritis'. The central facilitators were the motivated attitude of nurses to this support, their belief in the effectiveness of the program, and their team's positive view of it. Key barriers were the lack of work structure and of resources, of time, of nurses' knowledge and skills, as well as nurses' undue attitude of care and patients' negative attitudes regarding self-management support.

To our knowledge, no study on factors influencing the support of self-management by rheumatology nurses has been conducted before. However, previous studies have been published on factors influencing the self-management support offered by care professionals to chronic patients in general and to patients with long-term lung conditions, which may be compared with the key findings of this study(47-52). The following findings of this study correspond with those of the previous studies: a motivated attitude of nurses as facilitator as well as the barriers of lack of structure(47) and of resources(47-50), of time(47-50), of nurses' knowledge(47,52) and skills(47,51) and patients' negative attitude(47). Although the type of the chronic disease and of care professional may differ, this correspondence underlines the importance of these factors. However, some contrasts were also found in the previous studies. Van Hooft et al. (2016) reported that patients' characteristics are an impediment, but do not in fact negatively influence nurses' actions regarding self-management support(47), which may cast doubt about the finding that patients' negative attitude is a key barrier. As for lack of knowledge of nurses, the same authors reported this lack for only 18% of them, whereas Feiring et al. (2020) – similar to this study – report it as a central barrier. If there is a discrepancy in this respect, this may be due to the type of support, namely: support in general compared to support of a specific program. This highlights its supposed importance for a specific programs. An undue attitude of care – i.e. the attitude of nurses to solve problem for patients, which hinders self-management support –, is reported as a key barrier in this study, is not confirmed by previous studies.

A strength of this study is the purposive sampling with use of a pre-specified profile sketch for recruitment, resulting in the maximized representative variety of the sample, which contributed to the obtainment of rich data and to the transferability of the findings(33,34). Second, member check was used to further deepen the discussion of the topics during the interviews, which established the credibility of the data(33,38). In addition, the trustworthiness was strengthened by investigators' triangulation(34) within research team

meetings and by peer debriefing with student researchers. This strategy reduces the risk of biased decisions with a view to quality enhancement(34).

This study has certain limitations which have to be considered. The aforementioned transferability of the findings may have reduced by the fact that the nurses who participate signed up on the basis of their own interest(33): their motivation to participate may have influence on the findings. Due to the COVID-19 pandemic, confirmation of data saturation could not be accomplished as planned and also the planned iterative process of data-analysis could not be followed strictly, due to the disruption of recruitment and time-management. Despite the fact that this may have affected the quality of the data, a relevant range of findings was collected. Moreover, most interviews had to be conducted by telephone, while they were intended to be face-to-face interviews. This may have led to missing out on more in-depth interaction, since the social cues of facial expression were absent(33). Still, both interview styles have their pros and cons(33,56,57). Furthermore, two participants were interviewed simultaneously, which may have led to unequal opportunity to express themselves(58). Another limitation, but also a strength, was the use of theoretical frameworks as a guide. This frameworks may have led to miss out on barriers and facilitators not falling under the pre-existing concepts. On the other hand, a systematic identification of potential factors is provided by it and it may support the transferability of the findings.

The findings of this study have implications for clinical practice. First, the variety of barriers and facilitators underlines the complex reality of the implementation of healthcare interventions and the accompanying behavioral change of the professionals(31,59-61).Therefore, a comprehensive effort at different levels is needed to address the findings, especially the levels of the organization and professional most key barriers were found. Secondly, the key barriers on knowledge, attitude and skills call for the exploration of a multifaceted training directed at nurses' support of patients' self-management and the program. The more so, as such a training is recommended by the systematic review of Duprez et al. (2017) on effective interventions to enhance nurses' competencies in self-management support(62). Thirdly, the study shows a need for a work structure to discuss self-management with patients. Use of a guiding tool to structure this may be of added value.

Since this is a detailed study, future large-scale research is needed to strengthen the findings and assess its transferability. Furthermore, research on the lack of a work structure, with exploration of the abovementioned guiding tool, is recommended. In addition, patients' perspective should be incorporated in future research with a view to improve the implementation of the program.

With regard to the identified barriers to and facilitators of rheumatology nurses, the overall conclusion is that, whereas all participants report being motivated to use the program, appreciate the innovation itself, and report support for it in their social context, participants

indicated many barriers at the levels of the organizational context and the professional. For 'Challenge Your Arthritis' to be more widely supported by nurses, policymakers and future research should build on the findings of this study. Notably the barriers lack of work structure and of, resources, time and of nurses' knowledge and skills and the undue attitude of care should be overcome. To this end, it is specially recommended to explore a tool to guide nurses' work structure, and a training to enhance nurses' knowledge, skills and attitudes to supporting patients in their self-management and their use of the program.

REFERENCE LIST

- (1) Sloot R, Flinterman L, Heins M, Lafeber M, Boeije H, Poos R, et al. Reumatische aandoeningen in Nederland: ervaringen en kengetallen. NIVEL report 2016 Nov,;1-133.(in Dutch)
- (2) Chorus AMJ, van Overbeek K, Hopman-Rock M. Reumatische klachten in Nederland: resultaten Nationale Peiling van het Bewegingsapparaat 2006. TNO 2007 Jan 1,;1-54.(in Dutch)
- (3) Nielen M, Poos M, Gommer AM. Aantal mensen met chronische aandoening bekend bij de huisarts. 2019; Available at: <https://www.volksgezondheidenzorg.info/onderwerp/chronische-ziekten-en-multimorbiditeit/cijfers-context/huidige-situatie#node-aantal-mensen-met-chronische-aandoening-zorg-bij-de-huisarts>. Accessed , May 28, 2020.(in Dutch)
- (4) European League Against Rheumatism, (EULAR). 10 things you should know about rheumatic diseases. unknown; Available at: <https://www.eular.org/myUploadData/files/10%20things%20on%20RD.pdf>. Accessed May 28, 2020.(in Dutch)
- (5) van Eijk-Hustings Y. Eindrapport Reumaverpleegkundigen in actie. Onderzoek naar de rol en positionering van gespecialiseerde verpleegkundigen en verpleegkundig specialisten in reumatologie in Nederland. V&VN afd Reumatologie 2017 Jan,;1-31(in Dutch).
- (6) Vriezekolk J, Eijsbouts A, Evers A, Stenger A, Van Den Hoogen F, van Lankveld W. Poor psychological health status among patients with inflammatory rheumatic diseases and osteoarthritis in multidisciplinary rehabilitation: Need for a routine psychological assessment. Disabil. Rehabil. 2010;32(10):836-844.(in Dutch)
- (7) Gettings L. Psychological well-being in rheumatoid arthritis: a review of the literature. Musculoskelet. Care 2010 Jun;8(2):99-106.
- (8) Dures E, Hewlett S, Ambler N, Jenkins R, Clarke J, Gooberman-Hill R. Rheumatology clinicians' experiences of brief training and implementation of skills to support patient self-management. BMC Musculoskelet Disord 2014 Mar 28,;129(17): doi 10.1186/s12891-016-0984-0.
- (9) Been-Dahmen J, Walter M, Dwarswaard J, Hazes M, Staa A, Ista E. What support is needed to self-manage a rheumatic disorder: a qualitative study. BMC Musculoskelet Disord 2017 Feb 16,;18(1):84.
- (10) Heijmans M, Lemmens L, Otten W, Havers J, Baan C, Rijken M. Zelfmanagement door mensen met chronische ziekten: kennissynthese van onderzoek en implementatie in Nederland. NIVEL report 2015 Dec,;1-55(in Dutch).
- (11) Trappenburg JCA, Jonkman N, Jaarsma T, van Os-Medendorp H, Kort H, de Wit N, et al. Self-management: One size does not fit all. Patient Educ Couns. 2013 Jul;92(1):134-137.
- (12) Lorig K, Holman H. Self-management education: History, definition, outcomes, and mechanisms. ann behav med 2003 Aug;26(1):1-7.

- (13) Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*. 2002 Jan 6;48:177-187.
- (14) Bech B, Primdahl J, van Tubergen A, Voshaar M, Zangi HA, Barbosa L, et al. 2018 update of the EULAR recommendations for the role of the nurse in the management of chronic inflammatory arthritis. *Ann Rheum Dis* . 2020 Jan;79(1):61-68.
- (15) Iversen MD, Hammond A, Betteridge N. Self-management of rheumatic diseases: state of the art and future perspectives. *Ann Rheum Dis* 2010 Jun;69(6):955-963.
- (16) Kate R. Lorig, David S. Sobel, Anita L. Stewart, Byron William Brown, Albert Bandura, Philip Ritter, et al. Evidence Suggesting That a Chronic Disease Self-Management Program Can Improve Health Status While Reducing Hospitalization: A Randomized Trial. *Medical Care* 1999 Jan 1;37(1):5-14.
- (17) ReumaUitgedaagd R. Informatie voor zorgverleners. 2020; Available at: <https://www.reumautgedaagd.nl/zorgverlener/>. Accessed Apr 13, 2020.(in Dutch)
- (18) Ammerlaan JJW, van Os-Medendorp H, Scholtus L, de Vos A, Zwier M, Bijlsma H, et al. Feasibility of an online and a face-to-face version of a self-management program for young adults with a rheumatic disease: experiences of young adults and peer leaders. *Pediatr Rheumatol Online J* 2014 Mar 25;12(1):doi:10.1186/1546-10.
- (19) Ammerlaan JJW, Os-Medendorp H, de Boer-Nijhof N, Scholtus L, Kruize A, Pelt P, et al. Short term effectiveness and experiences of a peer guided web-based self-management intervention for young adults with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2017 Oct 13;15(1): doi:10.1186/s12969-017-0201-1
- (20) Ammerlaan JJW, Mulder OK, de Boer-Nijhof NC, Maat B, Kruize AA, van Laar J, et al. Building a Tailored, Patient-Guided, Web-Based Self-Management Intervention 'ReumaUitgedaagd!' for Adults With a Rheumatic Disease : Results of a Usability Study and Design for a Randomized Control Trail. *JMIR Research Protocols* 2016;5(2): doi: 10.2196/resprot.5735
- (21) Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 2008;337:979-983.
- (22) Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychological review* 1977 Mar;84(2):191-215.
- (23) Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis & Rheumatism* 1993 Apr;36(4):439-446.
- (24) Ammerlaan J. Implementatie ReumaUitgedaagd! 2016:1-3 (in Dutch, internal report).
- (25) Ammerlaan JJW, de Vos A. Eindrapport project ReumaUitgedaagd!: zelfmanagementtraining ReumaUitgedaagd! voor jongeren met reuma. UMC Utrecht, afd. Reumat Reumapatiëntenbond 2011:0-45(in Dutch).
- (26) ReumaNederland. Evaluatieformulieren participanten training ReumaUitgedaagd! 2019:(in Dutch, internal report).

- (27) Vos M, Ammerlaan JJW. Evaluatie van de cursus ReumaUitgedaagd! voor volwassenen. 2013:1-42(in Dutch, internal report).
- (28) ReumaNederland. Jaarverslag 2018 ReumaNederland. ReumaNederland 2019:1-57(in Dutch).
- (29) Wensing M, Grol R. Implementatie. Effectieve verbetering van de patiëntenzorg. zevende ed. Houten: Bohn Stafleu van Loghum; 2017.(in Dutch)
- (30) Grol R, Wensing M. What drives change? Barriers to and incentives for achieving evidence-based practice. Medical Journal of Australia 2004;180(S6):57-60.
- (31) Potthoff S, Rasul O, Sniehotta FF, Marques M, Beyer F, Thomson R, et al. The relationship between habit and healthcare professional behaviour in clinical practice: a systematic review and meta-analysis. Health Psychology Review 2019 , Jan 2;13(1):73-90.
- (32) Dwarswaard J, Bovenkamp vd, H. Self-management support: A qualitative study of ethical dilemmas experienced by nurses. Patient Educ Couns. 2015 May 23;;98:1131-1136.
- (33) Holloway I, Galvin K. Qualitative Research in Nursing and Healthcare. fourth ed. Chichester, West Sussex, UK: John Wiley & Sons, Ltd.; 2017.
- (34) Polit DF, Beck CT. Nursing research. Generating and Assessing Evidence for Nursing Practice. tenth ed. Philadelphia: Wolters Kluwer; 2017.
- (35) Percy WH, Kostere K, Kostere S. Generic qualitative research in psychology. The Qualitative Report 2015 , Feb 1;20(2):76-85.
- (36) Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care 2007 Dec;19(6):349-357.
- (37) Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, et al. A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. Implement Sci: IS 2017 , Jun 21;12(1).
- (38) Creswell JW, Poth CN. Qualitative Inquiry and research design. Choosing among five approaches. fourth ed. California: SAGE Publications Inc.; 2018.
- (39) Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006 , Jan 1;3(2):77-101.
- (40) The University of Auckland. Thematic analysis | a reflexive approach. 2019; Available at: <https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html>. Accessed May 28, 2020.
- (41) Boeije H. Analysis in qualitative research . third ed. London: SAGE Publications Ltd; 2012.(in Dutch)
- (42) Edmonds WA, Kennedy TD. An Applied Guide to Research Designs: Quantitative, Qualitative, and Mixed Methods. second edition ed. Nova Southeastern University, USA: SAGE Publications, Inc; 2016.
- (43) QSR International Pty Ltd. NVivo quality data analysis. 2018;12.

- (44) World Medical Association. World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. *JAMA* 2013;310(20):2191-2194.
- (45) Schermer BW, Hagenauw D, Falot N. Handleiding Algemene verordening gegevensbescherming (AVG). 2018; Available at: <https://www.rijksoverheid.nl/onderwerpen/privacy-en-persoonsgegevens/documenten/rapporten/2018/01/22/handleiding-algemene-verordening-gegevensbescherming>. Accessed May 28, 2020.(in Dutch)
- (46) Centrale Commissie Mensgebonden Onderzoek, (CCMO). Uw onderzoek: WMO-plichtig of niet? 2019; Available at: <https://www.ccmo.nl/onderzoekers/wet-en-regelgeving-voor-medisch-wetenschappelijk-onderzoek/uw-onderzoek-wmo-plichtig-of-niet>. Accessed May 28, 2020.(in Dutch)
- (47) van Hooft S, Dwarswaard J, Bal R, Strating M, van Staa A. What factors influence nurses' behavior in supporting patient self-management? An explorative questionnaire study. *Int J Nurs*. 2016;63:65-72.
- (48) Kennedy A, Rogers A, Bowen R, Lee V, Blakeman T, Gardner C, et al. Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: A qualitative study. *Int J Nurs*. 2014 Aug;51(8):1103-1113.
- (49) Roberts NJ, Younis I, Kidd L, Partridge MR. Barriers to the implementation of self management support in long term lung conditions. *London J Prim Care* 2013 Apr 7,;5(1):35-47.
- (50) Feiring E, Friis T. Facilitators and barriers to clinicians' use of COPD action plans in self-management support: A qualitative study. *Patient Educ Couns*. 2020 Apr;103(4):693-701.
- (51) Bos-Touwen ID, Trappenburg JCA, Van Der Wulp I, Schuurmans MJ, De Wit NJ. Patient factors that influence clinicians' decision making in self-management support : A clinical vignette study. *PLoS ONE*. 2017 Feb,;12(2):1-14.
- (52) Battersby M, Lindner H, Litt J, Lawn S, Mathews R, Morris S, et al. What skills do primary health care professionals need to provide effective self-management support? Seeking consumer perspectives. *Aust. J. Prim. Health* 2009;15(1):37-44.
- (53) Irvine A, Drew P, Sainsbury R. 'Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews. *Qual Res*. 2013 Feb;13(1):87-106.
- (54) Irvine A. Duration, Dominance and Depth in Telephone and Face-to-Face Interviews: A Comparative Exploration. *Int J Qual Methods* 2011 Sep;10(3):202-220.
- (55) Wilson AD, Onwuegbuzie AJ, Manning LP. Using paired depth interviews to collect qualitative data. *The Qualitative Report* 2016 Sep 1,;21(9):1549-1573.
- (56) Woolf SH. The Meaning of Translational Research and Why It Matters. *JAMA* 2008 Jan 9,;299(2):211-213.
- (57) Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. *Implementation Sci* 2012 May 31,;50(7):1-17.

(58) Tombor I, Michie S, (in press). *Methods of Health Behavior Change*. Oxford Research Encyclopedia of Psychology 2017:1-43.

(59) Duprez V, Vandecasteele T, Verhaeghe S, Beeckman D, Van Hecke A. The effectiveness of interventions to enhance self-management support competencies in the nursing profession: a systematic review. *J Adv Nurs*. 2017 Aug;73(8):1807-1824.

BOX AND TABLES

Box 1

Overview of the framework of the multilevel approach of Grol and Wensing and of the Theoretical Domains Framework

See overview 1 for a summary of the level factors and content of the framework of the multilevel approach of Grol and Wensing(30). See overview 2 for a summary of the domains and content of the Theoretical Domains Framework(37). The concepts of those theoretical frameworks guided the methodological processes of this study; i.e. the interview guide and the analysis process.

Overview 1 – Summary of the level factors and content of the framework of the multilevel approach of Grol and Wensing¹

Level factor	Content
Professional	Awareness, knowledge, attitude, motivation to change, behavioural routines
Innovation	Advantages in practice, feasibility, credibility, attractiveness, accessibility
Patient	Knowledge, skills, attitude, compliance
Social context	Opinion of colleagues, culture of the network, collaboration, leadership
Organizational context	Organization of care processes, staff, capacities, resources, structures
External context	Financial arrangements, regulations, policies

¹ Taken from "What drives change? Barriers to and incentives for achieving evidence-based practice" by RPTM Grol and M Wensing, 2004, Medical Journal of Australia 180, p. 59. Copyright 2004 by the Authors(30).

Overview 1 – Summary of the domains and content of the Theoretical Domains Framework²

Domain	Content
Knowledge	An awareness of the existence of something
Skills	An ability or proficiency acquired through practice
Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting
Beliefs about capabilities	Acceptance of the truth, reality, or validity about an ability, talent, or facility that a person can put to constructive use
Optimism	The confidence that things will happen for the best or that desired goals will be attained
Belief about consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way
(motivation and) Goals	Mental representations of outcomes or end states that an individual wants to achieve
Memory, attention and decision processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives
Environmental context and resources	Any circumstances of a persons' situation or environment that discourage or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour

Domain	Content
Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviour
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
Behavioural regulations	Anything aimed at managing or changing objectively observed or measured actions

2 Adapted taken from "A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems". By Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, R Foy, EM Duncan, H Coquhoun, JM Grimshaw, R Lawton, S Michie, 2017, Implementation Science 12, p. 4-5. Copyright 2017 by the Authors(37).

Table 1

Demographic Characteristics of participants

Characteristic (n=14)		
Sex, n (ratio)	Female	14
Age, mean (range)		46 (28 - 62)
Working position, n	Specialized nurse ¹	10
	Master trained nurse ¹	4
Years of working in current position, mean (range)		8 (1 - 23)
Hours of working in current position, mean (range)		28 (23 – 36)
Organization, n	Academic hospital	2
	General hospital	8
	Categorical treatment center	2
Work setting	Outpatient clinic	10
	Independent clinic	1
	Combination of settings ²	2
Years of work experiences within rheumatology setting, mean (range)		11 (1 – 30)

1 Specialized in rheumatology

2 One participant is working both at an outpatient clinic and a day care setting. One participant is working both at an outpatient clinic and an inpatients' clinic setting.

Table 2

Overview of the barriers and facilitators, subthemes and levels

Level	Subtheme	Barrier	Facilitator
Organizational context	Work structure	Lack of work structure	
	Consultation time	Lack of consultation time	
	Resources	Lack of informative material for patients	User-friendly and accessible of current resources
		Lack of informative material for nurses	
	Care processes	Use of alternatives for the program	
	Policy and vision of the institution		Positive policy and vision of the institution towards the program
Professional	Knowledge	Lack of knowledge about the program	
	Awareness	Lack of awareness of the program	
	Attitude	Undue attitude of taking care	Motivation to support the program
	Skills	Difficulties conveying self-management support	Ability to convey self-management support
		Insecurity within the decision-making process	Establishment of a good patient-professional relationship
Innovation	Advantages in practice		Belief in effectiveness of the program View the program as an – additional - part of the treatment The multiple surplus values of the program
Social context	View of the team		Team's positive view towards the program
	Collaboration within the team		Positive mutual collaboration communication and encouragement
	View on tasks	Lack of clear vision on tasks of the MTN ¹	Support of the program is seen as an important task of the SN ²
Patient	Attitude and motivation	Patients' negative attitude and motivation	
External context	Facilities the program	Location of a training far away	Location of a training nearby
	Financial aspects	Costs of the program trainings and its additional circumstances	

1 MTN = Master trained nurse

2 SN = specialized nurse

APPENDIX

Appendix 1

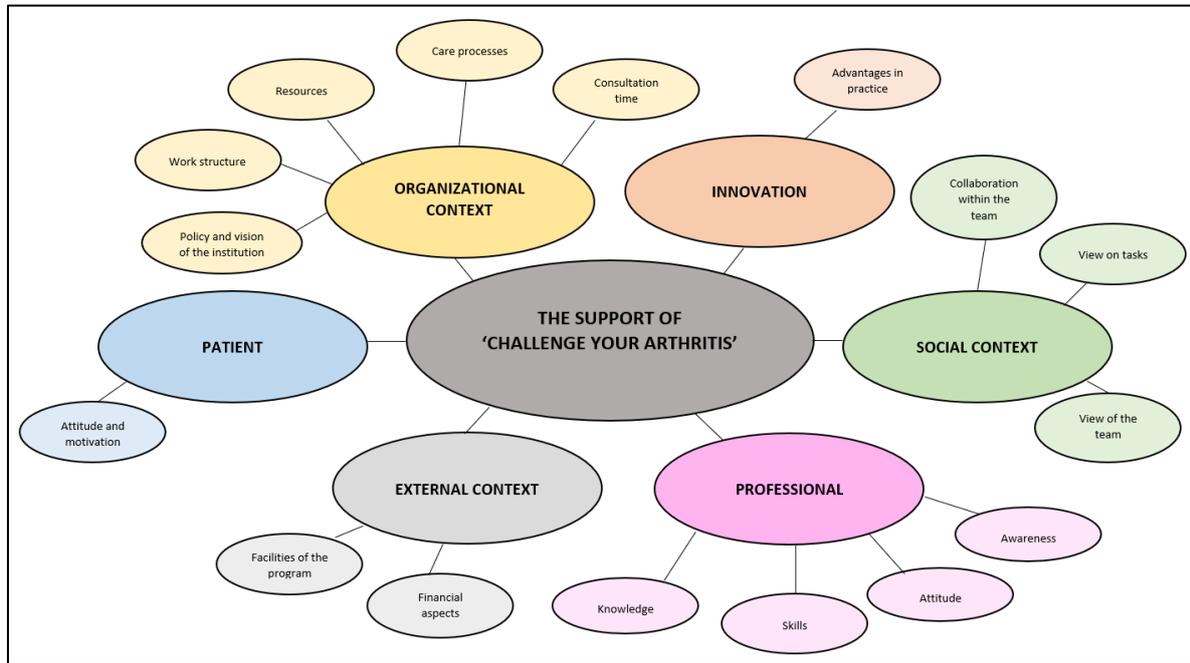


Figure 1. The thematic map of the six levels and sixteen subthemes

Note. This figure demonstrates the thematic map of the six levels and sixteen subthemes; which are findings from the study which investigates the barriers and facilitators of rheumatology nurses in their support of patients to use the self-management program 'Challenge Your Arthritis'.