RESEARCH ARTICLE

A longitudinal study of educational needs among patients with inflammatory arthritis

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Abstract

Introduction: Patient education is important in the follow-up and disease management for patients with chronic inflammatory arthritis. Patients' needs for education and information varies, and it is important that the education is tailored to the individual patient. Hence, the aim of this study is to investigate whether patients' educational needs change over time, and which demographic, disease-related or self-management characteristics that are associated with patients' educational needs.

Methods: The Mann–Whitney U-test was used to study patients' longitudinal educational needs and whether their needs change over time, while multivariable linear regression analyses were used to investigate associations between patients' educational needs and demographic variables, disease-related and self-management characteristics.

Results: There were no changes in patients' educational needs in the domains of managing pain, movement, feelings, arthritis process and treatment from health professionals during the study period of seven years. A small decrease in educational needs in the domains self-help measures (p-value 0.047) and support from others (p-value 0.010) was detected. The regression analyses showed that higher educational needs were associated with being female, lower educational level, shorter disease duration, and a lower level of patient activation.

Conclusions: Patients with chronic inflammatory arthritis have continual needs for patient education throughout their disease trajectory. Nurses and health care professionals must therefore ask their patients what kind of education they need at every follow-up throughout the disease course.

KEYWORDS
chronic diseases, inflammatory arthritis, nurses, patient education

1 | INTRODUCTION

Patients with chronic inflammatory arthritis have to cope with fluctuations of joint swelling, pain, tenderness, stiffness and fatigue (Ledingham et al., 2017). These patients need support and patient education to improve disease knowledge and how to manage their disease (Bech et al., 2020). According to the European League Against Rheumatism recommendations for the role of the nurses in the management of chronic inflammatory arthritis, patients should have access to a nurse for needs-based education and self-management support, including tele-health throughout the course of their disease (Bech et al., 2020). Nurses are trained to recognize what is important and necessary for patients in different situations, and act with and on behalf of their patients (Henry, 2018). Recognising what patients with chronic inflammatory arthritis need to learn when living with a chronic disease (Grønning et al., 2017), is necessary to provide patients with person-centred care (McCormack B, 2015; McCormack & McCance, 2016). Person-centred care in the field of rheumatology (Bala et al., 2018), includes activities involving the patient in making decisions about what kind of information, education or support the patient need at different times in the disease course.

Patients seek different kinds of health information to gain ownership over their condition, to facilitate self-management (Connelly et al., 2018) and to cope with the disease (Sierakowska et al., 2016). Patient education is shown to be effective in strengthening patients' abilities to cope well with the consequences and symptoms of their rheumatic diseases (Grønning et al., 2012; Vermaak et al., 2015) and across different chronic conditions (Stenberg et al., 2016).

Patients' educational needs varies and are depended on the individual patient's situation (des Bordes et al., 2018). It has been shown that patients need knowledge to engage in behaviours and practices to manage their symptoms and complaints associated with their disease (des Bordes et al., 2018). The information that patients are searching for relates to pharmacological and non-pharmacological treatment options, how to deal with pain, disability, emotional and psychosocial impacts of the disease, diet, exercise, pain control, and how to lead a stress-free life (des Bordes et al., 2018). Studies also show that patients' educational needs are depended on the characteristics of their disease complaints (Bremander et al., 2018), and gender and age (Sierakowska et al., 2016). For instance, patients that struggle with morning stiffness need more knowledge about mobility, methods of self-care, and support services (Sierakowska et al., 2016).

Patient education can be provided in different formats such as individually, to patients in groups, in written materials, videos (des Bordes et al., 2018; Lopez-Olivo et al., 2020; Stenberg et al., 2016) or as avatar-based technology (Wonggom et al., 2019). Studies show that self-administered educational materials in clinical settings improve patients' disease knowledge (Lopez-Olivo et al., 2020) and that the Internet is widely used to search for health information (des Bordes et al., 2018; Lopez-Olivo et al., 2020). However, the Internet does not comprehensively address all educational needs of patients with arthritis (Siddhanamatha et al., 2017) but the use of technology in patient education has a potential to enhance traditional patient education and reach more patients.

Since patients' needs for patient education is individual and varies, there is a need for developing and offering different kinds of patient education (Stenberg et al., 2016) that can be tailored to the individual patients' situation (Haglund et al., 2017). Some patients are also shown to be more vulnerable with a higher risk of suboptimal self-management (Bartlett et al., 2020). These risk factors include unemployment, disability, multimorbidity, and low self-efficacy (Bartlett et al., 2020), and must be considered when deciding how, when and what kind of patient education to offer.

Patients with chronic inflammatory arthritis have also different educational needs depended on their rheumatic diagnosis (Hirsch et al., 2020), gender, age (Dragoi et al., 2013; Kars Fertelli, 2019; Sierakowska et al., 2016), educational background and disease duration (Dragoi et al., 2013; Kars Fertelli, 2019). Patients newly diagnosed may be in a denial phase with limited knowledge to successfully manage their situation (Farley et al., 2019), while patients with longer disease duration have more experience in living with disease and have other needs (Grønning et al., 2011; Ndosi & Adebajo, 2015). The individual timing and readiness for education (Kristiansen & Antoft, 2016) in addition to demographic and disease-related factors (Bremander et al., 2018; Meesters et al., 2009; Ndosi et al., 2013; Sierakowska et al., 2016; Zangi et al., 2008) is also necessary to take into account when planning life-long care and support for patients with chronic inflammatory arthritis. It is therefore needed to study how patients' educational needs develop and change over time.

1.1 | Aim

The aim of this study is to investigate whether patients' educational needs change over time, and which demographic, disease-related or self-management characteristics that are associated with patients' educational needs.

2 | METHODS

2.1 | Study design and setting

This is a longitudinal observational study, following a cohort of patients with inflammatory arthritis that had participated in an open, pragmatic, parallel-group randomised controlled trial (RCT) on the effects of nurse-led patient education (Grønning et al., 2013; Grønning et al., 2012). The only inclusion criterion for this study was that the participants had taken part in the RCT.

2.2 | Data collection and measurements

One hundred and thirty-two patients completed the RCT (Grønning et al., 2013). When the invitation letter for this follow-up study was sent 5 years later, only 127 patients were eligible, five patients had died. The response rate was 101 (80%).

The data consist of demographic information (age, gender, education), disease -related information (diagnose, disease duration, use of disease-modifying anti-rheumatic drugs [DMARDS]), comorbidity, self-management, and patients' educational needs. Self-management was measured using the Patient activation measure (PAM-13) which captures the participants' knowledge, skills, beliefs, and behaviours in managing the chronic condition (Hibbard et al., 2005; Steins-bekk, 2008). Patients' educational needs were measured by the validated Norwegian version of the Educational Needs Assessment Tool 2 (ENAT-2) (Hardware et al., 2004; Hill et al., 2008; Zangi et al., 2008). The ENAT-2 contains an introduction question; 'how much information in general do you want about your disease' with the response alternatives 'I do not want to know anything', 'I want to know something', 'I want to know pretty much' and, 'I want to know as much as possible' (Hardware et al., 2004). It allows the patients to prioritise their educational needs and contains 39 items grouped into seven domains. These domains are managing pain, movement, feelings, arthritis process, treatments, self-help measures and support. The ENAT can be used as a clinical tool to guide patient education or as an outcome measure in research. The scoring range for each domain in ENAT-2 is 0 (no needs) to 3 (highest need). The total educational needs score ranges from 0 (no needs) to 21 (highest needs) (Hill et al., 2008; Zangi et al., 2008). The ENAT-2 is further developed into ENAT, translated and validated for patients with RA in several European countries (Meesters et al., 2009; Ndosi et al., 2011) and in different rheumatic diseases (Bremander et al., 2018; Ndosi et al., 2013; Sierakowska et al., 2016).

The participants were also invited to answer an open-ended question if they have experienced any changes in themselves after participating in patient education: 'Our experience is that people with chronic diseases might experience changes in themselves after they have participated in organized patient education. We wonder if you could describe whether you have experienced any changes in yourself. Feel free to write down whatever comes to your mind, even though you think it does not matter'.

2.3 | Analyses

The Mann–Whitney U-test was used to study changes in ENAT-2 since ENAT-2 is considered as nonparametric data, while associations between educational needs and demographic, disease-related and self-management characteristics were analysed with multivariable linear regression. In multivariable regression analyses, the standardized beta coefficient (Beta) compares the strength of the association between the independent and dependent variable when controlling for other independent variables in the model. The level of

significance was set to $p < 0.05$. The assumptions of linear regression analyses were checked, the Durbin-Watson and Variance Inflation Factor were satisfactory. Contribution of the independent variables in the model is expressed as explained variance (adjusted R^2). We used IBM SPSS Statistics (version 25) to analyse the data (SPSS, 2016).

2.4 | Ethical approval

The patients received written information about the purpose of the study and returned a signed written consent to participate in the study. The regional committee for medical and health research ethics in South East Norway approved the observational study (2014/196/REK sør-øst A).

3 | RESULTS

The characteristics of the study sample is presented in Table 1, showing that the majority were female participants, the mean age was 58.7 years, and 34% had a university level of education or more. Most of the participants had RA, the majority used one or several DMARDS, and more than half had several diagnoses in addition to their rheumatic disease.

The responses to the ENAT's introduction question: «how much information in general, do you want about your disease? » showed that approximately 85% wanted to know as much as possible in 2008-2009 (baseline) compared to 75% in 2015-2016 (last follow-up). Further analyses showed that the participants' educational needs were almost unchanged from baseline to the last follow-up in (Table 2), except from a statistically significant decrease in the two domains 'self-help measures' (p-value = 0.047) and 'support from others' (p-value = 0.010).

The regression analyses (Table 3), showed statistically significant associations between patients' total educational needs and being

TABLE 1 Participant characteristics at baseline, 2008–2009 (N = 101)

Characteristics	N (%)	Mean (SD)
Men	29 (28.7)	
Females	72 (71.3)	
Age, mean (SD)		58.7 (9.9)
Education (university level or more)	34 (33.7)	
RA	63 (62.4)	
PsA	20 (19.8)	
UA	15 (14.9)	
Disease duration, mean (SD)		11.5 (9.3)
Comorbidities	56 (55.4)	
Using DMARDs	82 (83)	

ENAT-2 Domains	T1	T2	T3	T1—T2	T2—T3	T1—T3
	Median (Mean, SD)			p-value		
Managing pain	2.5 (2.3, 0.6)	2.3 (2.2, 0.7)	2.2 (2.2, 0.6)	0.138	0.824	0.086
Movement	2.0 (2.0, 0.7)	2.0 (1.9, 0.9)	2.2 (2.0, 0.8)	0.576	0.728	0.963
Feelings	1.8 (1.8, 0.9)	2.0 (1.8, 1.0)	2.0 (1.8, 0.9)	0.790	0.867	0.917
Arthritis process	2.4 (2.3, 0.7)	2.2 (2.1, 0.8)	2.1 (2.1, 0.7)	0.265	0.518	0.054
Treatment from HP	2.1 (2.1, 0.7)	2.0 (2.0, 0.8)	2.0 (1.9, 0.8)	0.503	0.539	0.195
Self-help measures	2.3 (2.2, 0.6)	2.2 (2.1, 0.7)	2.0 (2.0, 0.7)	0.445	0.261	**0.047***
Support from others	2.0 (1.8, 0.7)	2.0 (1.7, 0.8)	1.8 (1.6, 0.8)	0.366	0.124	**0.010***
Total score	15.2 (14.7, 3.8)	14.6 (13.8, 5.0)	13.8 (13.6, 4.5)	0.385	0.457	0.092

TABLE 2 Changes in educational needs over time

$T1$ = Baseline (2008–2009), $T2$ = after 12 months (2009–2010), $T3$ = 6 years later (2015–2016). Mann–Whitney test (non-parametric data). *Level of significance, $p < 0.05$.

TABLE 3 Explained variance in patients' total educational needs (total ENAT-2)

	Total Educational Needs (ENAT-2)			
	B	Std. Error	Beta	p-value
Constant	19.098	3.530		0.000
Female	2.381	0.971	0.247	**0.016***
Age	0.029	0.043	0.066	0.499
University education	−2.327	0.886	−0.248	**0.010***
RA	−0.699	0.922	−0.076	0.451
Disease duration (years)	−0.111	0.043	−0.233	**0.012***
DMARDS	0.635	1.153	0.051	0.583
Comorbidities	0.860	0.834	0.096	0.306
PAM-13	−0.106	0.028	−0.353	**0.000***
Adjusted R^2				25.6

Multiple linear regression analyses, B = unstandardized coefficients, Std. Error = standard error, Beta = standardized coefficients.
Level of significance, $p < 0.05$*. PAM-13 = Patient activation measure-13.

female, having a university level of education or more, disease duration, and patient activation. Being female was associated with statistically significant larger educational needs while controlling for other sociodemographic and disease-related variables. Having a university education or more, higher patient activation, and longer disease duration were all statically significantly associated with less educational needs while controlling for sociodemographic and disease-related variables. There were no statistically significant associations between patients' total educational needs at the final follow-up and age, diagnose (RA), using DMARDS or comorbidity. The regression model accounted for 25.6% of the explained variance (R^2) in patients' total educational needs.

The responses to the open-ended question were placed into four main categories, 'coping', 'knowledge', 'healthy life' and 'challenges'. The categories are further elaborated and presented in Table 4. A

few participants ($N = 8$) wrote that they educational needs had not altered in the period, and a handful ($N = 5$) wrote that they never participated in the patient education program. Furthermore, several participants ($N = 24$) stated that they had made changes, and learned important things in other patient educational, self-management or rehabilitation programs that they had attended after the RCT additionally, and some ($N = 7$) wrote that their life was very good if the medications were effective.

4 | DISCUSSION

The aim of this study was to investigate whether patients' educational needs change over time, and which demographic, disease-related or self-management characteristics are associated with patients' educational needs. At the final follow-up in 2015–2016, 74% of the patients wanted as much information as possible about their disease compared to 84% at baseline (2008–2009). The analyses also showed that there was a small statistically significant decrease in patients' need for education in the domains 'self-help measures' and 'support from others'. The regression analyses further showed that less educational needs were associated with being male, having a university level of education or more, longer disease duration, and a higher level of patient activation.

To the best of our knowledge, no other studies on patient education in the field of rheumatology have investigated whether patients' educational needs change over time. Other studies have mainly focused on whether patients have different needs depended on diagnosis (Hirsch et al., 2020), disease activity or demographic characteristics (Bremander et al., 2018; Haglund et al., 2017). This study did not detect any associations between patients' total educational needs and diagnosis, but other studies have shown that patients with Spondyloarthritis report higher needs for education on pain and movement (Bremander et al., 2018), patients with Rheumatoid Arthritis want more education on treatments, and patients with fibromyalgia have higher needs for education about feelings (Hirsch et al., 2020). We did not investigate associations between

TABLE 4 Overview of the responses to the open-ended question (N = 46)

Coping	Knowledge	Healthy Life	Challenges
Avoided stressful situations Balanced the energy with daily breaks	Had learned about effects and side-effects of medications	Were physical active spent time outside/in the nature	Struggled with anxiety
Prioritized what was most important Focused on positive aspects	Knew more about how to deal with the disease complaints	Conscious about eating healthy (less fat and sugar)	Had a lot of pain due to unsuccessful surgery or medical treatment
Asked for help Took responsibility for the disease	Had learned about the disease	Had good experience with high intensity training	The hospital did not care, had lost the follow-up controls
Accepted the disease made necessary adjustments	Had learned to better communicate with HP	Exercised regularly (fitness, strength, pool/swimming)	Had not accepted the disease

diagnoses and different educational domains, but we found that females have larger total educational needs than men, which was supported by the systemic review by Connelly and co-workers (Connelly et al., 2018).

Nonetheless, this study shows that patients with chronic inflammatory arthritis have a continuous need for patient education which emphasise the importance of asking patients about their educational needs at every visit at the hospital (Bech et al., 2020). Ndosi and colleagues have shown that need-based patient education is effective (Ndosi & Adebajo, 2015; Ndosi et al., 2016) indicating that screening patients for educational needs may be a way to better target patient education to patients' individual needs. Certain patient characteristics such as low level of self-efficacy, less education, employment disability, and multimorbidity are all indicators for higher needs for self-management support (Bartlett et al., 2020). These characteristics must be taken into account when asking patients about their educational needs.

This study shows that higher needs for patient education are associated with less education, being female, shorter disease duration, and a lower level of self-management, confirming the importance of keeping these characteristics in mind when targeting those with greater needs for self-management support that match their preferences (Bartlett et al., 2020). There are however some inconsistencies whether education, employment status, disease duration and disease severity are associated with higher information needs or not (Connelly et al., 2018), and further studies are warranted.

Furthermore, the open-ended responses in this study confirm findings from other studies showing that patients learn a lot by participating in patient education, but many patients need life-long education to adjust to the disease and develop coping strategies that can address the disease fluctuations (Connelly et al., 2018; Grønning et al., 2016). It is therefore important to deliver patient education in different ways such as one-to-one education, group-based (Connelly et al., 2018; Grønning et al., 2012, 2013; Ndosi et al., 2016), by written materials, educational CDs, video, or through

the Internet (Connelly et al., 2018). Knowing that targeting patients' individual educational needs can be challenging, the ENAT should be used to detect need-based patient education since the questionnaire was found to be a valuable and effective clinical tool (Ndosi et al., 2016). This study shows that patients need education throughout the whole disease trajectory, which is logical due the fluctuating nature of chronic inflammatory arthritis (Connelly et al., 2018; Ledingham et al., 2017). The life situation of this group of patients is unpredictable (Toye et al., 2019). The patients must have access to nurses for need-based education throughout the disease trajectory (Bech et al., 2020) since managing a life with chronic inflammatory arthritis is challenging even though the patients have participated in patient education (Grønning et al., 2016, 2017). The continual need for knowledge may be a reason for the active engagement among patients that seek information on their own (Connelly et al., 2018; des Bordes et al., 2018; Sierakowska et al., 2016). Finally, this study shows that patients with higher levels of self-management, measured by PAM, have less educational needs. The benefits of more activated patients are substantial, and the benefits can last for several years (Hibbard et al., 2015). It is therefore important to integrate information about patients' knowledge, skill, and confidence for self-management (Hibbard et al., 2015) in the follow-up of patients in rheumatology care (Lopez-Olivo et al., 2020).

4.1 | Strengths and limitations

A major strength of this study is the longitudinal design, and that this is the first study investigating longitudinal changes in educational needs among this group of patients. A noteworthy limitation is the risk of selection bias because the participants were originally included in an RCT studying the effect of nurse-led patient education (Grønning et al., 2012, 2013). Patients enrolled in the RCT may differ from the patient population, that is, some patients might have declined participation because they did not perceive any needs for patient education. Nevertheless, the data indicate that the sample

were heterogeneous and representative for the patient population in Norway (Zangi et al., 2008).

5 | CONCLUSION

Patients with chronic inflammatory arthritis need patient education throughout their whole disease trajectory to manage their unpredictable and fluctuating diseases. Demographic factors, self-management skills and disease duration have influence on patients' needs for education. Lower level of education, lower level of patient activation, shorter disease duration and being female are all factors associated with higher educational needs. To provide high-quality person-centred care in the field of Rheumatology, nurses must ask their patients at every visit what kind of patient education they need, and keep in mind the factors that may influence patients' educational needs.

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