

Educational Needs of Patients with Rheumatic and Musculoskeletal Diseases Attending a
Large Health Facility in Austria

J.K. Hirsch¹
L. Toussaint²
M. Offenbacher³
N. Kohls⁴
C. Hanshans⁵
M. Vallejo⁶
J. Rivera⁷
F. Sirois⁸
J. Untner³
B. Hölzl⁹
M. Gaisberger¹⁰
M. Ndosi¹¹

¹Department of Psychology, East Tennessee State University, Johnson City, USA

²Department of Psychology, Luther College, Decorah, USA

³Gastein Healing Gallery, Bad Gastein-Böckstein, Austria

⁴Department of Integrative Health Promotion, University of Applied Science, Coburg,
Germany

⁵Department of Applied Sciences and Mechatronics, University of Applied Science, Munich,
Germany

⁶Department of Psychology, National Distance Education University, Madrid, Spain

⁷Hospital General Universitario Gregorio Marañón, Madrid, Spain

⁸Department of Psychology, University of Sheffield, Sheffield, UK

⁹St. Veit Hospital, St. Veit, Austria

¹⁰Paracelsus Medical University, Salzburg, Austria

¹¹Department of Nursing and Midwifery, University of the West of England, Bristol, UK

Corresponding Author: Jameson K. Hirsch, Ph.D., Department of Psychology, 420 Rogers Stout Hall, East Tennessee State University, Johnson City, TN 37614; Telephone: 423-439-4463; Email: hirsch@etsu.edu

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ABSTRACT

Introduction. Patient education is an important part of the management of rheumatic and musculoskeletal diseases. Given that patients with diverse diseases do not have the same needs, it is crucial to assess the educational requirements of targeted groups to provide tailored educational interventions. The aim of our study was to assess educational needs of a large cohort of patients with different rheumatic and musculoskeletal diseases attending a health facility in Austria.

Methods. We assessed educational needs, via an online survey of patients with fibromyalgia (FMS), rheumatoid arthritis (RA) and ankylosing spondylitis (AS) recruited from an Austrian healthcare facility, using the Austrian version of the Educational Needs Assessment Tool (OENAT).

Results. For our sample of 603 patients, AS (62%), RA (15%) and FMS (24%), there were no educational need differences for the domains of movements, disease process, and self-help measures. Patients with FMS had less need for pain management education and greater need for education about feelings, than other disease groups. Patients with RA had a greater need for education related to treatments than other groups, and patients with AS had a greater need for treatment education than patients with FMS. Patients with AS reported greater need for support system education than other patient groups.

Conclusion. Educational needs vary by disease groups, suggesting that healthcare professionals should assess disease-specific needs for education to provide optimal assistance in disease management for patients.

Keywords: Educational Needs; Rheumatic and Musculoskeletal Diseases; Fibromyalgia; Rheumatoid Arthritis; Ankylosing Spondylitis

Educational Needs of Patients with Rheumatic and Musculoskeletal Diseases Attending a Large Health Facility in Austria

According to the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR), rheumatic and musculoskeletal diseases (RMDs) are a heterogeneous group of conditions that affect the joints, muscles and other tissues including internal organs. Left untreated they result in pain and functional impairment, and a negative impact on both quality of life and life expectancy (Blyth, Briggs, Schneider, Hoy, & March, 2019; Branco et al., 2016). RMDs are caused by an array of factors including infections, inflammation, immunological dysfunction, and joint, muscle or bone deterioration (Van Der Heijde et al., 2018). According to an international study of adults, the prevalence of musculoskeletal pain in the general population is approximately 30% and, for chronic widespread pain, is approximately 18% (Cimmino, Ferrone, & Cutolo, 2011). In Europe, approximately one-quarter of adults endorse symptoms of arthritis or rheumatism and, pertinent to our sample, 15% of Austrians report symptoms of osteoarthritis (Dorner & Stein, 2013).

From a patient-centered and empowerment-based perspective, effective intervention for RMDs requires shared decision making and patient involvement. This includes active self-management of disease, which are processes predicated on having a disease-specific understanding of the educational needs of patients (Voshaar, Nota, Van De Laar, & Van Den Bemt, 2015). Such assessments may also be idiographic, warranting assessment across cultures, type of patient and clinical settings (Ndosi & Adebajo, 2015).

Broadly, patient education typically focuses on parameters (e.g., information about symptoms), consequences (e.g., illness trajectory) and management of the disease (e.g., physical activity, treatment adherence), and support during the illness (e.g., promoting emotional and social support) (Haglund, Bremander, Bergman, & Larsson, 2017). Concerns

about service delivery, including autonomy of choice for treatment and satisfaction with treatment (e.g., patient-provider working relationship), have also been identified as targets for education, for patients with rheumatoid arthritis (Radford et al., 2008). Yet, there is a need for individualised assessment and delivery of educational information to patients, based on their personality and demographic characteristics, and on their unique manifestation of disease (e.g., stage of disease, impairment) (Drăgoi et al., 2013).

The aim of our study was to assess the educational needs of a large sample of patients, with three types of RMDs, to inform the development of needs-based educational materials. Although exploratory, we hypothesized that educational needs would differ across the diagnostic groups of fibromyalgia, rheumatoid arthritis and ankylosing spondylitis.

METHOD

Study Design

Respondents were recruited from a health center for radon therapy, the Gasteiner Heilstollen (“healing gallery”), located in Bad Gastein-Böckstein, Austria, which exposes patients to hyperthermia, humidity and radon, resulting in pain alleviation and immune stabilization. In our cross-sectional study, regular clinic attendees, originating from Austria, Germany and Switzerland, were invited via email to anonymously participate in an online survey.

Measures

In addition to assessment of demographic characteristics, including age, sex and education levels, we measured the educational needs of our patients using the Austrian version of the Educational Needs Assessment Tool (OENAT) (Drăgoi et al., 2013). The OENAT, which is adapted from the English ENAT (Hardware, Lacey, & Shewan, 2004), consists of 39 items assessing seven domains of patient educational needs, including: pain management (6 items), movement (5 items), feelings (4 items), arthritis process (7 items), treatment (7 items), self-help measures (6 items) and support systems (4 items). Items are

rated on a Likert-type scale ranging from 0 (not important at all) to 4 (extremely important), yielding summed subscale scores and a total score (range = 0-156), with higher scores indicating greater need for education. Thus, scores ranging from 0-39 indicate lack of acknowledgment of educational need, whereas scores of 40 and above indicate at least some identified need for education. OENAT scores are Rasch-transformed to facilitate use in parametric analyses (Ndosi et al., 2014; Sierakowska, Sierakowski, Sierakowska, Horton, & Ndosi, 2015). The original ENAT has evidenced excellent psychometric properties, including construct validity and test-retest reliability, in international samples of persons with a variety of RMDs (e.g., arthritis, ankylosing spondylitis) (Ndosi et al., 2014, 2011).

Data Collection Procedure

Potential respondents were invited via email to complete a battery of surveys, which were administered online via a secure server. Respondents provided informed consent prior to survey completion.

Statistical Analyses

Prior to analyses, OENAT scores were Rasch transformed and data were descriptively analysed. One-way analyses of variance (ANOVA) were utilized to assess differences between patient groups. Pairwise comparisons were made with Fisher's Least Significant Difference tests, a technique which also protects against Type I error when used with three groups (Meier, 2006). Data met assumptions of the statistical tests, and statistical significance was set at $p < 0.05$.

RESULTS

In total, 603 questionnaires were returned, consisting of patients with fibromyalgia (n = 144; 24%), rheumatoid arthritis (n = 88; 15%) and ankylosing spondylitis (n = 371; 62%). Our sample was mostly male (n = 325; 54%) and had a mean and median age of 56 (SD = 11). Regarding education, 32% (n = 190) reported completing elementary school, 23% (n =

141) completed junior high school, 20% (n = 119) high school, 12% (n = 73) college and 13% (n = 80) university.

Separate ANOVAs were conducted for each of the ENAT domains, examining differences across the samples of fibromyalgia, rheumatoid arthritis, and ankylosing spondylitis patients (see Table 1). Group differences were observed on ENAT subscales of managing pain, $F(2,518) = 33.22, p < .001$, managing feelings, $F(2,518) = 3.27, p = .039$, treatments, $F(2,516) = 10.34, p < .001$, and support systems, $F(2,513) = 4.91, p = .008$. No group differences were observed on movements, $F(2,518) = .84, p = .432$, disease process, $F(2,518) = 1.43, p = .239$, or self-help, $F(2,515) = 2.31, p = .100$, subscales.

In pairwise comparisons (see Table 1), FMS patients had a significantly lower need for education about managing pain and a higher need for education about managing feelings, as compared to both AS and RA groups which did not significantly differ from each other for either need. RA patients had significantly higher need for education about treatments, compared to both FMS and AS patients, and AS patients had a higher need for treatment education than FMS patients. Finally, AS patients had significantly higher need for education about support systems, as compared to both FMS and RA patient groups which did not differ from each other on this need.

DISCUSSION

We assessed the educational needs of patients with RMDs from an Austrian health care facility. Our findings will be used to inform the development of educational material based on disease-specific areas of priority. We found similarities between disease groups for several OENAT domains, including movements, disease process and self-help measures. In contrast, we found differences between disease groups for the domains of managing pain, feelings, treatments and support systems. Patients with fibromyalgia had significantly lower needs for education regarding pain management and a higher need for education about feelings, compared to patients with ankylosing spondylitis and rheumatoid arthritis. Patients

with rheumatoid arthritis had a greater need for education about treatments than the other disease groups, and patients with ankylosing spondylitis desired treatment education more than those with fibromyalgia. Finally, patients with ankylosing spondylitis reported a greater need for education about support systems than those with fibromyalgia and rheumatoid arthritis. Our findings imply that some educational materials, such as those focused on disease processes, movement and self-help measures, may be commonly developed across disease groups, whereas educational materials for other OENAT domains must be disease specific.

For patients with fibromyalgia, there may be several reasons why they desire less education about pain management. To begin, given their often-negative experiences with treatment and health care providers, persons with FMS may feel they have exhausted all avenues for pain relief (Colmenares-Roa et al., 2016). As a result of such delegitimization, FMS patients may perceive a sense of hopelessness about the potential for successful pain management, thereby negating the need for education on this topic (Armentor, 2017). It may also be that, given their regular attendance at our health facility, pain levels for FMS patients have been reduced to a manageable level, thereby negating need for additional education regarding pain management, although this premise requires further investigation. However, patients with FMS may report a greater need for education about feelings as a result of the emotional distress that often accompanies the disease (Lumley et al., 2017). Our pattern of associations is supported by the extant literature. For example, in a comparative study of pain in persons with fibromyalgia and rheumatoid arthritis, persons with RA reported greater pain (Ulus et al., 2011) and, across studies, patients with fibromyalgia reported greater levels of psychological symptoms and neuroticism than patients with rheumatoid arthritis (Bucourt et al., 2017; Medina, Hirshberg, Taylor, Gilbert, & Heaton, 2019).

We also found that patients with rheumatoid arthritis desired education about treatments more than patients with other RMDs, and patients with AS desired treatment education more than those with fibromyalgia. A high level of need for treatment education has

been previously reported in patients with rheumatoid arthritis (Pérez et al., 2019). Further, this pattern of effects may reflect the severity of disease or pain, or deleterious impact to quality of life, of RA and AS, compared to FMS (Ataoglu, Ankaralı, Ankaralı, Ataoglu, & Ölmez, 2018), although conflicting findings exist (e.g., that persons with FMS are more impaired than patients with RA and AS) (Tander et al., 2008). On the other hand, a focus on treatments may reflect a sense of hopefulness, or comparative lack of psychological distress, in patients with RA and AS compared to FMS (Birtane, Uzunca, Taştekin, & Tuna, 2007; Hellou et al., 2017).

Finally, patients with ankylosing spondylitis reported a greater need for education about support systems than those with fibromyalgia and rheumatoid arthritis. Our findings parallel past research indicating that persons with AS are less likely to be married and more likely to be divorced than expected (Ward, Reveille, Learch, Davis, & Weisman, 2008), perhaps due to lifelong pain or poor body image (Packham & Hall, 2002), and identify support of family and health professionals as among the most important facilitators of quality of life (Van Echteld et al., 2006). Such results suggest significant impairment to the relationships of persons with AS, but also the beneficial impact of social support on the health of persons with this disease.

Limitations

Our findings must be understood within the context of potential limitations. For instance, although our study was intended to be a snapshot of the educational needs of our sample, the cross-sectional nature of our data does not allow for examination of changes in educational needs over time or with progression of disease (Zangi et al., 2015). Further, additional disease-related factors, such as severity of disease, comorbid conditions and level of disability, were unable to be accounted for. Generalizability is also limited to the culture, medical setting and disease groups represented in our study, and future cross-cultural research with diverse patient groups and in additional types of health care facilities is necessary to substantiate our findings. Our sample was also primarily of older age and, given the

homogenous ethnic makeup of the clinic attendees, we did not assess race/ethnicity; thus, future research is needed to verify our findings in younger adults and racial/ethnic minorities.

Implications

Despite the limitations of our study, our findings may have implications for future clinical intervention and research. To begin, the differences in educational needs between our subgroups of patients suggest a need for disease-specific tailoring of interventions, for persons with differing diagnoses. For the purposes of dissemination and implementation, the ENAT has shown acceptability and ease of usage for both patients and providers, and the ability to focus and enhance patient-provider educational interactions, in past international studies of RMD patients (Hardware, Johnson, Hale, Ndosu, & Adebajo, 2015). We expand support for its usage, via the OENAT, to our sample of RMD patients attending an Austrian radon healing gallery clinic, including its ability to differentiate between the educational needs of patients with fibromyalgia, rheumatoid arthritis and ankylosing spondylitis. Such differences suggest that the impact of rheumatic and musculoskeletal diseases should not be viewed homogeneously, and require that health care professionals assess, and direct attention toward, the unique educational needs of their patients and patient subgroups. Doing so will require additional future research on the educational needs of diverse disease groups, including across cultures and medical settings (Cañizares, Power, Perruccio, & Badley, 2008; Ruiz-Montero, Van Wilgen, Segura-Jiménez, Carbonell-Baeza, & Delgado-Fernández, 2015; Yazici, Kautiainen, & Sokka, 2007; Zangi et al., 2015).

Conclusions

In a large sample of patients recruited from a healthcare facility in Austria, we found significant differences in educational needs between patients with fibromyalgia, rheumatoid arthritis and ankylosing spondylitis, and our results will inform the development of disease-specific patient education modules. Our findings highlight the unique educational needs of patients across disease groups, suggesting that differences in the manifestation and trajectory

of symptoms for different rheumatic and musculoskeletal diseases will require that healthcare providers offer individualized approaches to patient education depending on disease diagnosis.

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Table 1

Differences in Educational Needs Across Ankylosing Spondylitis, Fibromyalgia Syndrome, and Rheumatoid Arthritis Groups

OENAT Subscale	Ankylosing Spondylitis		Fibromyalgia Syndrome		Rheumatoid Arthritis		<i>F</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Managing Pain	14.54 _a	5.41	9.98 _b	6.49	15.30 _a	5.07	33.22***
Movements	10.20	4.86	9.53	5.13	10.07	4.64	.84
Managing Feelings	8.33 _a	4.39	9.39 _b	4.53	7.94 _a	4.41	3.27*
Disease Process	16.74	6.29	16.87	6.37	18.15	6.71	1.43
Treatments	13.98 _a	7.26	11.91 _b	7.57	16.85 _c	6.76	10.34***
Self-Help	15.07	5.45	14.09	6.36	15.82	5.31	2.31
Support Systems	7.85 _a	4.18	6.80 _b	4.54	6.41 _b	4.04	4.91**

* $p < .05$, ** $p < .01$, *** $p < .001$; Mean scores in each row that share subscripts do not differ significantly at the $p < .05$ level of statistical significance.