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HPR Interdisciplinary research

AB0912-HPR

AMIGOS DE FIBRO (FIBRO FRIENDS): EDUCATIONAL PROGRAM TO PROMOTE THE HEALTH OF PEOPLE WITH FIBROMYALGIA IN BRAZIL

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Background: Health education is pointed out as the front line in non-pharmacological approaches in fibromyalgia.

Objectives: To develop an interdisciplinary educational program to promote the health of individuals with fibromyalgia in Brazil.

Methods: This is a qualitative study, through a focus group, carried out in a Basic Health Unit in the city of São Paulo, SP. The guiding questions were about the needs and demands exposed by patients with fibromyalgia and health professionals who work in primary health care. 12 individuals with fibromyalgia and 10 health professionals participated. The data were analyzed using the content analysis method proposed by Bardin, specifically the thematic content analysis.

Results: Amigos de Fibro (Fibro Friends) should be conducted through lectures, dynamics and conversation circles. The educational program must include 15 meetings with weekly frequency. The meetings are: 1st to present the program and socialization activities. 2nd: Doctor presents the concepts of fibromyalgia. 3rd: Nurse informs about practices and environments that favor self-care. 4th: Social Worker shows the importance of support. 5th: Physiotherapist shows the main body practices and physical activity. 6th: Nutritionist presents an adequate and healthy diet. 7: Psychologist shows mental health practices. 8th: Pharmacist informs about medicines. 9, 11 and 13: participants perform activities at home. 10: Naturologist presents integrative and complementary practices. 12th: Occupational Therapist encourages methods to save energy. Day 14: Speech therapist helps in the quality of sleep. 15: closing activity.

Conclusion: Amigos de Fibro is a program that presents interdisciplinary educational information for individuals with fibromyalgia, being considered a trend of care for the future. The next step is to conduct a clinical trial to verify the effect of this intervention and then implement it in the health service in Brazil. Fibro Friends was created from the conjoint action of patients and healthcare professionals, it can be an effective educational tool to be implemented at primary health attention centers, promoting the self-care, life quality and the promotion of health in individuals with Fibromyalgia. Fibro Friends is an excellent tool for patient education and counseling in Brazil.

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Patient information and education

AB0913-PARE

METHOTREXATE FOR RHEUMATOID ARTHRITIS: PATIENT PERSPECTIVES ON MONITORING IN PRIMARY CARE

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Background: Monotherapy with methotrexate (MTX) is one first-line option for newly diagnosed Rheumatoid Arthritis (RA)¹. Although treatment is usually commenced by a specialist, repeat prescribing and monitoring responsibilities often lie with primary care. While inadequate monitoring is a safety concern, unnecessary duplication of monitoring invariably has cost implications for General Practice (GP).

Objectives: To ensure that patients in one South-West GP practice who are taking oral MTX for RA are appropriately monitored in line with current guidance from the British Society of Rheumatology (BSR). Current guidance recommends that once a stable MTX dose is maintained for six weeks, followed by monthly bloods for the next three months, that at least twelve weekly blood monitoring is sufficient from then on¹.

Methods: A randomised sample of 50 patients registered in one South-West GP practice that were taking a stable dose oral MTX for RA; for at least 6 months; was collected. The length of time between the patient's two most recent blood tests was recorded. A random selection of ten patients with more frequent monitoring than BSR guidance suggest were asked a series of questions to determine patient perspectives on reasons for monitoring frequency.

Results: 58% of patients had more frequent monitoring bloods than current BSR guidelines recommend. Within this group, the mode frequency of monitoring was four weeks, in line with the previous National guidance which was superseded in 2017². The most common themes in patient's perspectives on monitoring frequency were:

- a. Previous abnormal blood results requiring close monitoring
- b. Multiple disease modifying anti-rheumatoid drug (DMARD) regimes that included MTX
- c. Patient preference
- d. Unclear or unknown reason

The purported increased monitoring for multiple DMARD regimes were not in line with current national guidelines¹.

Conclusion: This audit demonstrates that over half of patients taking MTX for RA in one GP practice are having more frequent blood monitoring than BSR guidance suggests is necessary. Furthermore, it demonstrates that patient's understanding of their perceived need for increased monitoring is largely inaccurate or unclear to them. There is a clear deficit in patient education surrounding monitoring frequency which must be addressed in order to empower patients, as well as reducing unnecessary duplication of blood tests. As a result of this audit, patient education on MTX monitoring frequency was formally introduced as part of the RA annual patient review. An information sheet with these monitoring requirements was produced to aid practitioners in the education process.

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AB0914-PARE

INFORMATION PREFERENCES ABOUT TREATMENT OPTIONS IN DIFFUSE CUTANEOUS SYSTEMIC SCLEROSIS: A DELPHI CONSENSUS STUDY

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Background: Diffuse cutaneous systemic sclerosis (dcSSc) has a high impact on quality of life and is associated with increased mortality. Several treatment options are available in dcSSc, including immunosuppressives, chemotherapy and hematopoietic stem cell transplantation. Shared decision making is key in choosing the appropriate treatment strategy. In earlier studies however, patients reported that the lack of accessible and reliable patient information about treatment options complicates decision making. In order to provide information that meets the needs of patients and addresses relevant benefits and harms, more insight in the preferences of patients is needed.

Objectives: The aim of this study was to identify and prioritize aspects that should be addressed when informing patients with dcSSc about treatment options, from a patient's perspective.

Methods: A three-round Delphi study was conducted with a panel of patients with dcSSc. The first questionnaire was based on a systematic literature search regarding benefits and harms of the four main treatments in dcSSc: methotrexate,

mycophenolate mofetil, cyclophosphamide, and stem cell transplantation. In the first round, patients were asked to indicate which information on the benefits and harms is essential for making a treatment decision; they could also add new items. In the second and third rounds, patients were asked to prioritize the items. After the third round, a live, online panel discussion was held in order to reach consensus. Consensus was defined as $\geq 75\%$ agreement among panel members.

Results: Of the 36 patients invited, 67% (n=24) completed the first, 69% (n=25) the second and 75% (n=27) the third round. In the third round, median age of participants was 51 years (IQR 18), median disease duration was 4 years (IQR 5), 52% was female. Most patients had completed either an intermediate education level (59%) or high level of education (30%). Patients were or had been treated with mycophenolate mofetil (67%), methotrexate (44%), cyclophosphamide (41%), autologous stem cell transplantation (26%), rituximab (4%). Seven percent of patients were treatment-naïve. After the third round, eight patients joined the online panel discussion to reach final consensus. The panel reached consensus on seven benefits (prolonged progression-free survival, improved quality of life, improved daily functioning, improved pulmonary function, improved skin thickness, improved mobility and reduced fatigue) and four adverse events (treatment-related mortality, viral infections, cardiac damage, increased risk of cancer) as key themes for the decision making process (Table 1).

Conclusion: This study identified essential aspects of the four main treatment options for dcSSc. Our results can be used to develop effective patient information.

Table 1. Agreement on benefits and harms that should be addressed

Benefits	Agreement	Harms	Agreement
Improved pulmonary function	100%	Viral infections	88%
Improved skin thickness	100%	Cardiac damage	88%
Improved mobility	100%	Increased risk of cancer	88%
Prolonged progression-free survival	95%*	Treatment-related mortality	79%*
Improved quality of life	77%*	Flare or relapse of disease	63%
Improved daily functioning	77%*	Temporary increase in fatigue	25%
Reduced fatigue	75%	Temporary negative impact	25%
		on social activities	
Improved hand function	25%	Nausea	25%
Improved mood	25%	Other autoimmune disease	13%
Improved cardiac function	13%	Hormonal imbalance	13%
Improved oesophageal function	7%	Concentration difficulty	13%
		Diarrhea	13%
		Erectile dysfunction	13%
		Depression	13%
		Infertility	13%
		Hair loss	13%

*Items on which consensus was reached in round 3

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AB0915-PARE DEVELOPMENT AND USABILITY OF A WEB-BASED PATIENT-TAILORED TOOL TO SUPPORT ADHERENCE TO URATE-LOWERING THERAPY IN GOUT PATIENTS

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Background: Adherence to prescribed urate-lowering therapy (ULT) among gout patients is considered to be among the poorest of all chronic conditions. eHealth programs can be a possible opportunity to foster ULT adherence.

Objectives: This study describes the development and usability evaluation of a web-based tool to support ULT adherence among gout patients, specifically designed for a complement to usual care.

Methods: The Integrated Change (I-Change) model was used as theoretical basis for the development. The model combines various socio-cognitive theories and differentiates between three phases: a pre-motivational, a motivational, and a post-motivational phase. In practice, the I-Change gout tool contains three sessions, following the three phases of the I-Change model. Patients receive tailored feedback based on their answers in the form of animated videos and text messages after each session, and are prompted to set specific goals and action plans for their ULT adherence. The content and development of the I-Change gout tool was determined along an iterative process within a steering group of clinicians and researchers, supported by patient interviews and gout specific literature related to key aspects of medication adherence behavior. A cross-sectional

mixed methods design was used to test usability of the support tool consisting of a think aloud method and a usability questionnaire.

Results: The steering group decided on the content of the three sessions of the I-Change gout tool. Depending on the intention to change ULT adherence behavior patients were navigated through the I-Change gout tool, patients with a low intention go through all 3 sessions and patients with a high intention go through the pre- and post-motivational session (figure 1). In total, the I-Change gout tool contains three sessions with 80 questions, 66 tailored textual feedback messages, and 40 tailored animated videos.

Figure 1. Flowchart of the computer-tailored I-Change gout tool for urate-lowering therapy adherence.

Twenty gout patients and seven healthcare professionals participated in the usability tests. The program end score rating for the gout tool was on average 8.4 ± 0.9 (range 6-10) for patients and 7.7 ± 1.0 (range 6-9) for healthcare professionals. Furthermore, participants reported a high intention to use and/or recommend the program in the future. Yet, participants identified some issues for further improvement of the systems user-friendliness by addressing barriers (e.g. more explicitly navigation) and weaknesses (e.g. technical and health literacy). The I-Change gout tool was updated according suggestions of improvements of the participants.

Conclusion: This study provides initial support for the usability by patients and healthcare professionals of a ULT adherence I-Change gout tool. Further studies need to be conducted to assess its efficacy and (cost-) effectiveness in daily practice.

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AB0916-PARE KNOWLEDGE OF DISEASE, DIAGNOSIS, ADHERENCE AND IMPACT OF RESEARCH IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: The diagnosis and treatment of inflammatory arthritis has been transformed largely by the development of drugs that target specific molecules of the immune system. However, these changes have increased the complexity of the mechanisms of disease, its treatment and patients understanding. Patient education is needed in this area to facilitate decision making and to facilitate strong patient-partnerships in research.

Objectives: The aim of this study was to examine the level of understanding of inflammatory arthritis patients and the need for strong patient-partnership in research.

Methods: An online anonymous survey addressed questions about diagnosis, routine tests, medications and how they work, medication adherence, disease flare, heredity, pregnancy, and patient involvement in research.

Results: There were 1,873 respondents, 1416 of which had inflammatory arthritis (IA)-RA (65.8%) and PsA (34.2%). They were predominantly female (RA 86%,