

Educational groups for ankylosing spondylitis patients: systematic review*

Grupos educacionais para pacientes com espondilite anquilosante: revisão sistemática

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SUMMARY

BACKGROUND AND OBJECTIVES: Ankylosing spondylitis (AS) is a chronic inflammatory disease affecting sacroiliac joints, the spine in different degrees and in lesser extension peripheral joints. Among non-pharmacological treatments, educational groups have been recommended as major coadjuvants to treat this disease. This study aimed at reviewing the literature on scientific evidences of educational groups for AS patients.

METHOD: The following databases were reviewed: LILACS, Medline, Web of Science and PEDro. Words for systematic search were extracted from Health Sciences Keywords (HSC).

RESULTS: Nine scientific articles were found between

1990 and 2012. Inclusion and exclusion criteria were used to select and analyze studies, including scientific articles especially addressing educational groups as treatment approaches for AS patients.

CONCLUSION: Literature on educational groups as coadjuvant to treat such patients is scarce. Further studies are needed to show group formats, number and content of classes, in addition to evaluating their effectiveness.

Keywords: Ankylosing spondylitis, Health education, Patients' education as subject, Spondylitis.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A espondilite anquilosante (EA) é uma doença inflamatória, crônica, que acomete as articulações sacroilíacas, em graus variáveis a coluna vertebral e, em menor extensão as articulações periféricas. Dentre as formas de tratamento não medicamentoso, os grupos educacionais têm sido recomendados como importante coadjuvante no tratamento da doença. O objetivo deste estudo foi rever na literatura as evidências científicas sobre grupos educacionais para pacientes com EA.

MÉTODO: A revisão foi realizada nas Bases de dados LILACS, Medline, Web of Science e PEDro. Os termos para busca sistemática foram extraídos dos Descritores em Ciências da Saúde (DeCS).

RESULTADOS: Foram localizados nove artigos científicos no período de 1990 a 2012. Na seleção e análise dos estudos foram utilizados critérios de inclusão e exclusão, incluído artigos científicos que abordassem principalmente os grupos educacionais como forma de tratamento para os pacientes com EA.

CONCLUSÃO: A literatura a respeito dos grupos educacionais como coadjuvante no tratamento desses pacientes é escassa. Futuros estudos mostrando os formatos dos grupos, duração, quantidade e conteúdos das

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aulas devem ser realizados, bem como a avaliação de sua efetividade.

Descritores: Educação de pacientes como assunto, Educação em saúde, Espondilite, Espondilite anquilosante.

INTRODUCTION

Ankylosing spondylitis (AS) may be defined as chronic inflammatory disease affecting sacroiliac joints, the spine in variable degrees and, in a lesser extension, peripheral joints. It is more prevalent in males, in the ratio of 2-4:1 and most symptoms are developed between 20 and 35 years of age. AS causes pain in entheses, joints and spine, which may lead to physical changes such as decreased spinal mobility, fatigue, sleep disorders, and psychological consequences such as depression, anxiety and stress¹. Due to major physical and functional changes, many patients go on medical leave, which may lead to poor quality of life (QL)². In addition, the inactivity caused by inflammation and pain leads to a higher risk of losing muscle mass. In chronic diseases, the loss of muscle mass may be considered a complication, leading to major muscle strength decrease and consequent less independence of such individuals, further cooperating for their poorer QL³.

AS may determine extra-joint manifestations such as anterior uveitis, inflammatory bowel disease, pulmonary and cardiac impairment⁴.

The management of such disease may be divided into therapeutic, surgical and rehabilitation. Among different rehabilitation modalities there are physical therapy, occupation therapy, psychological support and patients' education.

Patients' education involves any planned activity to improve the behavior with regard to health, improving health status with long term results. It is an adjuvant for the standard management and consists of persuading patients to improve their adherence to the standard management and of encouraging self-efficacy, adopting attitudes which will benefit their condition. Educational groups are the most common and less expensive means to educate patients⁵.

Education may help improving the incapacity of such patients. Education would allow patients to control daily pain, fatigue and physical function, with an important role to adapt patients to their disease. Patients' education improves self-efficacy, generating psychological well being and healthy behaviors with regard to the disease, such as exercising⁶.

Together with physical therapy and exercises, education

has been recommended as non pharmacological treatment of the disease, according EULAR (European League Against Rheumatism) guideline – 2006⁷.

According to the Brazilian consensus to treat spondyloarthropathies, physician-patient relationship is critical for the therapeutic success.

“Patients should be fully aware that their participation – especially by being well with themselves in spite of the disease – will be a critical starting point for the therapeutic success⁸.”

A way to evaluate the effectiveness of an education program is by evaluating patients' knowledge after attending the program⁹. Several investigators and educators have recognized the importance of evaluating patients' knowledge of the specific disease. This is the reason for several studies which developed tools to evaluate the knowledge of chronic diseases, such as rheumatoid arthritis⁹⁻¹¹, fibromyalgia¹² and low back pain¹³.

The concept of health education is superimposed to the concept of health promotion, as a broader definition of a process involving the participation of the whole population in the context of their daily lives and not only of people at risk of falling ill. This notion is based on an enhanced concept of health, considered as a positive and dynamic state in search for well being, which integrates physical and mental (lack of disease), environmental (adjustment to the environment), personal/emotional (personal and affective self-realization) and socioecologic aspects (commitment with social equality and with nature preservation).

As from this enhanced notion of health, it is also observed in practice that there are still different health education models or paradigms, which condition different practices, several of them reductionists, which requires questionings and the reach of more integrated and participative perspectives¹⁴.

Enhanced health education includes public policies, adequate environments and re-orientation of health services to beyond clinical and healing treatments; as well as liberating pedagogic proposals committed to the development of solidarity and citizenship, oriented toward actions the essence of which is to improve QL and ‘promote men’¹⁴. This concept may also be applied to patients' education, generating learning not only for the educator but also for patients, so that they may keep and use information to improve their well being. So, learning implies networks of knowledge and experiences which are adequate and enhanced by individuals in their relationships with different types of information.

This study aimed at reviewing in the literature scientific evidences about educational groups for AS patients.

METHOD

This was a systematic review of scientific papers and their identification was done via queries in four internationally recognized databases, with Health Science contents. Initially, LILACS, Medline, Web of Science and PEDro were systematically and sequentially queried. PEDro is a database with physical therapy evidences, free, with more than 22 thousand randomized clinical trials, systematic reviews and clinical practice guidelines in physical therapy, from 1990 to July 2012.

There has been no geographic boundary or language limitation. Keywords used were extracted from Health Sciences Keywords (DeCs). LILACS and MEDLINE were accessed via Virtual Health Library (VHL)/BIREME/OPS/OMS, using the following query expressions: (Spondylitis or Espondilits or (Spondylitis and Ankylosing) or (Espondilits and Anquilosante) or “Ankylosing Spondylitis” or “Bechterew Disease” or “Rheumatoid Spondylitis” or “Spondylarthritis Ankylopoietica”) and (“Patient Education as Topic” or “Educación del Paciente como Asunto” or “Educação de Pacientes como Asunto” or (educs and group)).

Keywords used for Web of Science and PEDro were: ankylosing spondylitis, education, education group.

Inclusion criteria were articles addressing educational groups to treat AS patients. Exclusion criteria were articles addressing education of physicians about genetic factors of the disease to obtain early diagnosis, and articles published in more than one selected database. Results found and analyzed in this study were 9 scientific articles, being 6 in English and 3 in German.

RESULTS

In a study, 53 patients were randomized in two groups: one receiving education and physical therapy and the other with no intervention¹⁵. Patients were individually educated with information about joint pain, better spinal mobility, peripheral and costovertebral joints, postural improvement, increased pulmonary capacity, stretching, resistance and physical function improvement, understanding of exercises and psychosocial adjustments. Authors have concluded that physical therapy associated to an educational program is effective to treat AS patients. A different study used different patients' education tools, such information about exercises via videos and leaflets within a package with AS exercises. Authors discuss the importance of education specifically aimed at exercises as adjuvants to improve pain, self-efficacy and other AS-related symptoms¹⁶.

In Germany, patients' education programs in diseases such as rheumatoid arthritis, AS and other spondyloarthritis, systemic lupus erythematosus, vasculitis, fibromyalgia and chronic juvenile arthritis were developed by a multidisciplinary team of the German Society of Rheumatology (Deutsche Gesellschaft für Rheumatologie). Until 2003, approximately 500 people were trained to be group leaders. In 1999, the Society published preliminary guidelines for patients' education in rheumatology. Prospective randomized studies have shown that patients' education has led to further knowledge, self-efficacy and self-aid in addition to improving arthritis related to impotency and pain, and a decrease in temporary and permanent incapacity¹⁷.

A different German study, also published in 2003, has evaluated the cost of education programs by a multicenter study. Cost per patient was approximately 117 Euros in a program with a group of 10 patients, and 186 Euros per patient in a group of 6 patients. The effects of educational programs have determined savings of approximately 2500 Euros in indirect costs, which by itself justifies the programs¹⁸.

Another study used education in two groups of AS patients. One group would perform supervised exercises and the other home based exercises. The study reports that the program consisted of information about the disease and physical exercises, for one hour. Conclusion was that supervised exercises are more effective than home exercises, and nothing was said about patients' education¹⁹.

An important research has shown that the knowledge of the disease by French patients was lower than what has been previously described for a British population. And it has also stressed that although education may be offered to every AS patient, there might be a higher need for people with limited education. Leaflets about the disease and contact with groups of patients seem to be useful tools to improve the knowledge about the disease²⁰.

In 2008, another German study stated that spondyloarthritis patients very often are uncertain about the disease and its prognosis. They also stated that rheumatic disease patients need an encompassing and multidisciplinary management. Patients' education leads to a better self-management. The study also points that the objective of patients' education are: to improve understanding and interoception to influence attitudes and self-efficacy, in addition to improving the disease or the health behavior. The German Society of Rheumatology (DGRh) has a “patient education” group and has developed several

education programs where methods and themes are based on behavioral science. The program for AS patients was multidisciplinary, carried out by a qualified education team with 6 modules and duration of 90 minutes. Efficacy was proved in different levels, as well as return to work and economic advantages²¹.

A study has randomized 62 patients in three groups, being one group with exercises and education, one with education only and one control group. In comparing groups in time 1, the group with exercises and education has shown significant improvement in BASMI and BASDAI, chest expansion and spinal mobility. BASFI and visual analog cervical pain scale have improved both for the group with exercises and education and the group with education only. Positive results obtained by the group with exercises and education were maintained during six-month follow up. The combination of education and exercises has promoted promising results in patients with clinically stable AS being treated with drugs⁶. Another research has shown the impact of an education program for AS patients, evaluating the effect of such intervention on patients' satisfaction, knowledge of the disease and spinal mobility. A four-day program was carried out with information about the disease and its management, the use of biological and rehabilitation, including home exercises. Patients were evaluated before the program, in the fourth day and three months after the intervention. Authors have concluded that at the end of three months, there was a high level of patients' satisfaction and that the program had improved patients' knowledge and the practice of self-care. Authors have also stated that an educational program should also be developed for rheumatic inflammatory diseases and should be considered an additional treatment, and that better consensual tools should be used to evaluate the effectiveness of such programs²².

The classic editorial by Calin, published in 1994, already questioned the importance of showing physical therapy results by well validated tools. It already mentioned AS patients education within a package of interventions. However, to date there is no consensus about educational programs for AS patients, although knowing the importance of this tool to manage such disease²³.

CONCLUSION

Although the theme is of major importance within a context of enhanced health education, few studies were found about AS patients' education. Formats of education programs are still not well established in the literature, although such programs are recommended and

their effectiveness have been already shown as coadjutant to treat AS patients.

REFERENCES

1. Baysal O, Durmus B, Ersoy Y, et al. Relationship between psychological status and disease activity and quality of life in ankylosing spondylitis. *Rheumatol Int*. 2011;31(6):795-800.
2. Revicki DA, Rentz AM, Luo MP, et al. Psychometric characteristics of the short form 36 health survey and functional assessment of chronic illness Therapy-Fatigue subscale for patients with ankylosing spondylitis. *Health Qual Outcomes*. 2011;9:36.
3. Plasqui G, Boonen A, Geusens P, et al. Physical activity and body composition in patients with ankylosing spondylitis. *Arthritis Care Res*. 2012;64(1):101-7.
4. van den Berg R, Stanislawska-Biernat E, van der Heijde DM. Comparison of recommendations for the use of anti-tumour necrosis factor therapy in ankylosing spondylitis in 23 countries worldwide. *Rheumatology*. 2011;50(12):2270-7.
5. Hill J. A practical guide to patient education and information giving. *Baillieres Clin Rheumatol*. 1997;11(1):109-27.
6. Masiero S, Bonaldo L, Pigatto M, et al. Rehabilitation treatment in patients with ankylosing spondylitis stabilized with tumor necrosis factor inhibitor therapy: a randomized controlled trial. *J Rheumatol*. 2011;38(7):1335-42.
7. Zochling J, van der Heijde D, Burgos-Vargas R, et al. ASAS/EULAR recommendations for the management of ankylosing spondylitis. *Ann Rheum Dis*. 2006;65(4):442-52.
8. Sampaio-Barros P, Azevedo VF, Bonfiglioli R, et al. Consenso Brasileiro de Espondiloartropatias: Espondilite Anquilosante e Artrite Psoriásica Diagnóstico e Tratamento – Primeira Revisão. *Rev Bras Reumatol*. 2007;47(4):233-42.
9. Hennell SL, Brownsell C, Dawson JK. Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. *Rheumatology*. 2004;43(4):467-71.
10. Edworthy SM, Devins GM, Watson MM. The arthritis knowledge questionnaire. A test for measuring patient knowledge of arthritis and its self-management. *Arthritis Rheum*. 1995;38(5):590-600.
11. Jennings F, Toffolo S, de Assis MR, et al. Brazil Patient Knowledge Questionnaire (PKQ) and evaluation of disease-specific knowledge in patients with rheumatoid arthritis. *Clin Exp Rheumatol*. 2006;24(5):521-8.
12. Suda AL, Jennings F, Bueno VC, et al. Development

- and validation of Fibromyalgia Knowledge Questionnaire - FKQ. *Rheumatol Int.* 2012;32(3):655-62.
13. Maciel SC, Jennings F, Jones A, et al. The development and validation of Low Back Pain Knowledge Questionnaire - LKQ. *Clinics.* 2009;64(12):1167-75.
14. Schall VT, Struchiner, M. Educação em saúde: novas perspectivas. *Cad Saúde Pública.* 1999;15(Suppl 2):S4-6.
15. Kraag G, Stokes B, Groh J, et al. The effects of comprehensive home physiotherapy and supervision on patients with ankylosing spondylitis-- a randomized controlled trial. *The J Rheumatol.* 1990;17(2):228-33.
16. Sweeney S, Taylor G, Calin A. The effect of a home based exercise intervention package on outcome in ankylosing spondylitis: a randomized controlled trial. *J Rheumatol.* 2002;29(4):763-6.
17. Langer HE, Ehlebracht-König I, Mattussek S. Quality assurance of rheumatologic patient education. *Z Arztl Fortbild Qualitatssich.* 2003;97(6):357-63.
18. Krauth C, Rieger J, Bönisch A, et al. Costs and benefits of an education program for patients with ankylosing spondylitis as part of an inpatient rehabilitation programs-study design and first results. *Z Rheumatol.* 2003;62(Suppl 2):II14-6.
19. Analay Y, Ozcan E, Karan A, et al. The effectiveness of intensive group exercise on patients with ankylosing spondylitis. *Clin Rehabil.* 2003;17(6):631-6.
20. Claudepierre P, Flippe RM, Sibilia J, et al. Patient knowledge of their disease: a French multicenter study in ankylosing spondylitis. *Joint Bone Spine.* 2004;71(6):550-6.
21. Ehlebracht-König I, Bönisch A. Patient education in the early treatment of ankylosing spondylitis and related forms of spondyloarthritis. *Wien Med Wochenschr.* 2008;158(7-8):213-7.
22. Sudre A, Figueredo IT, Lukas C, et al. On the impact of a dedicated educational program for ankylosing spondylitis: effect on patient satisfaction, disease knowledge and spinal mobility, a pilot study. *Joint Bone Spine.* 2012;79(1):99-100.
23. Calin A. Can we define the outcome of ankylosing spondylitis and the effect of physiotherapy management? *J Rheumatol.* 1994;21(2):184-5.

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