

# Utilization of an informational needs assessment to develop an education program for patients with Ankylosing Spondylitis

Rita Kang MEd, Rebecca Morton MSc, Christopher Hawke BSc PT, Laura Passalent MHSc PT ACPAC, Joan Blair RN, Marc Doucet MDiv, Alison Lake MHSc (OT), Debra MacGarvie RD, Dinny Wallis MD, and Dr Robert Inman MD

## What is Ankylosing Spondylitis?

Ankylosing Spondylitis (AS) is an inflammatory form of arthritis that predominantly affects the spine. (Ankylosing means fusing together. Spondylitis means inflammation of the vertebrae).

## Introduction:

The effectiveness of education programs for patients with arthritis has been well documented.<sup>1</sup> Despite this, there has been minimal investigation into patient education specifically for ankylosing spondylitis (AS) and axial spondyloarthritis (SpA). AS patient education programs have demonstrated positive effects with respect to mobility, function, self efficacy, and depression, however many of these effects are not sustained over the long term.<sup>2,3</sup>

## Purpose:

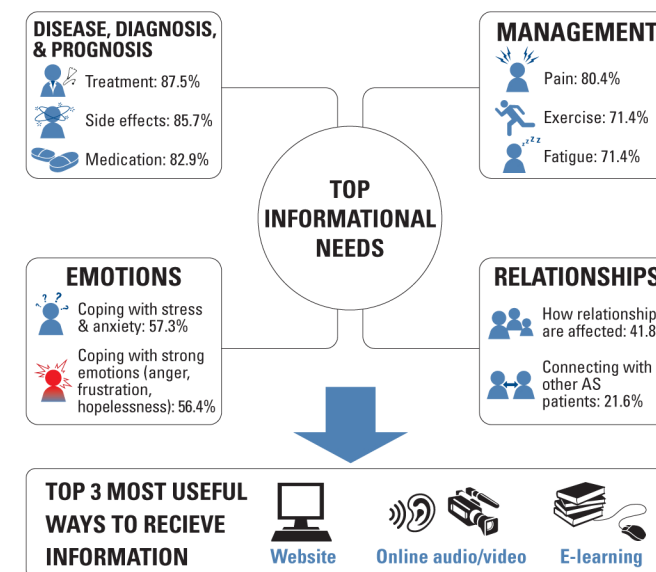
An interdisciplinary team formed to develop and evaluate the content and delivery for an evidence-based patient education program aimed at the AS patients attending the Toronto Western Hospital Spondylitis Clinic, Toronto, Canada. The team includes: a rheumatologist, nurse, dietitian, physiotherapist, occupational therapist, pharmacist, spiritual care provider and a patient education leader. It was established that an initial phase would be to identify the specific learning needs of the patients. The objective of the informational needs assessment was to identify what patients with AS felt their current informational needs were. In addition, the method of preferred information access was also assessed.

## Method:

Patients with AS and SpA were emailed a link with an Informational Needs Assessment Survey. This included five multiple choice sections: 1. Demographics, 2. Disease, Diagnosis and Prognosis, 3. Management, 4. Relationships, 5. Emotions. Descriptive statistics and bivariate analyses were used for data analysis. Qualitative statistical methods were utilized to address the open ended question section.

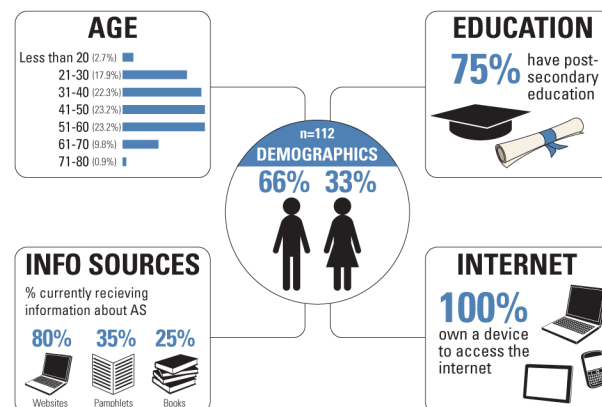
## Results:

The response rate was 32.1%. The average number of years since diagnosis was 11 years. Of those who completed the survey, 21 (19.4%) were newly diagnosed (diagnosed between 2010-2012) and 87 (80.6%) were diagnosed earlier than 2010. Overall, websites, pamphlets and books were cited as the most popular ways to receive information in all five sections. Qualitative analysis indicated three major themes concerning patients including medication/pain, fatigue/activity/work and long term prognosis.



## Conclusion:

Based on the needs assessment, it was determined to develop an e-learning module for this patient population followed by self-management focused face-to-face sessions. Although 'group class' did not have a high rating of usefulness, it was determined to offer a class to demonstrate and teach exercises, discuss effects of relationships and emotions, and offer an opportunity to ask healthcare professionals specific questions. It is anticipated this unique education program for patients with AS will be a successful model using best practice in patient education. The use of an online educational module is expected to ensure long-term benefits. The results of the formal evaluation will help to refine the content and delivery of the education program.



## References:

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Kristin Foster, Graphic Artist, UHN Patient & Family Education Program

## Contact:

Rita Kang, Manager, Patient & Family Education Program  
Toronto Western Hospital  
rita.kang@uhn.ca