

## Background

Arthritis affects individuals in many aspects of their life including decisions regarding pregnancy and in carrying out their role as a parent. As a result, the Canadian Arthritis Patient Alliance (CAPA) launched a project on pregnancy and parenting in 2015. The first phase of the project involved the development of a survey to identify patient information needs as it relates to pregnancy and parenting. This was identified as a CAPA priority as there is a lack of complete and readily available information to assist people living with arthritis during this critical point in their lives. The priorities identified through the survey will guide the development of an educational resource for patients living with arthritis regarding pregnancy and parenting.

CAPA wishes to provide greater dialogue regarding the issues facing patients and their families, when faced with the additional complexities of pregnancy and parenting while living with a serious, debilitating chronic disease. We hope that awareness of the issues facing patients with arthritis and their families when facing these new challenges will stimulate further research, healthcare delivery improvements and improve overall outcomes for patients.

## Objectives

The objectives of this poster are to:

1. Inform of the process and timeline undertaken to develop and launch the Pregnancy and Parenting with Arthritis survey;
2. Share the survey results;
3. Communicate next steps including how the survey results will be used to increase awareness of issues facing patients during these critical life events and inform health care policy discussions.

## Methods

The survey was launched in September 2015 during Arthritis Awareness month. The survey was intended to be completed by individuals living with arthritis and people in their social support network, such as spouses, rheumatologists and allied health care professionals.

One Board member acted as project manager and obtained feedback on the survey from various people living with inflammatory arthritis who represented a range of perspectives (e.g. considering pregnancy, parenting school age children, etc.). Methods to achieve this feedback included phone calls, in person meetings and email. A survey that included all feedback was created on Survey Monkey (in both English and French) published on the CAPA website, newsletter and Facebook page. Subsequent distribution and promotion of the survey were achieved through CAPA's efforts and partnership with various stakeholders from September to November 2015.

## Results

A total of 150 responses were received and the majority were completed by individuals living with arthritis (87%). More than half (51%) live with Rheumatoid Arthritis followed by 20% with Ankylosing Spondylitis.

## Results (cont'd)

Respondents represented the geographic distribution of the Canadian population and represented both rural (24%) and urban (72%) residents. Most of the survey respondents were females (96%) and approximately half (52%) of respondents have lived with arthritis from 0-14 years. There were a significant number (81%) of survey respondents who had considered or planned a pregnancy while living with arthritis and 65% of respondents are currently a parent.

The survey was analyzed from a number of perspectives, such as the mostly highly ranked topics and trends by stage (pregnancy to parenting adolescent children). Figure 1 highlights the importance of the topics identified by respondents per parenting stage. There was a general decrease in importance of the topics from planning/considering pregnancy to the latter stage of parenting older/adolescent children. This could represent greater confidence in undertaking the parenting role while living with the challenges of arthritis.

Figure 1 - Importance of Topics by Stage

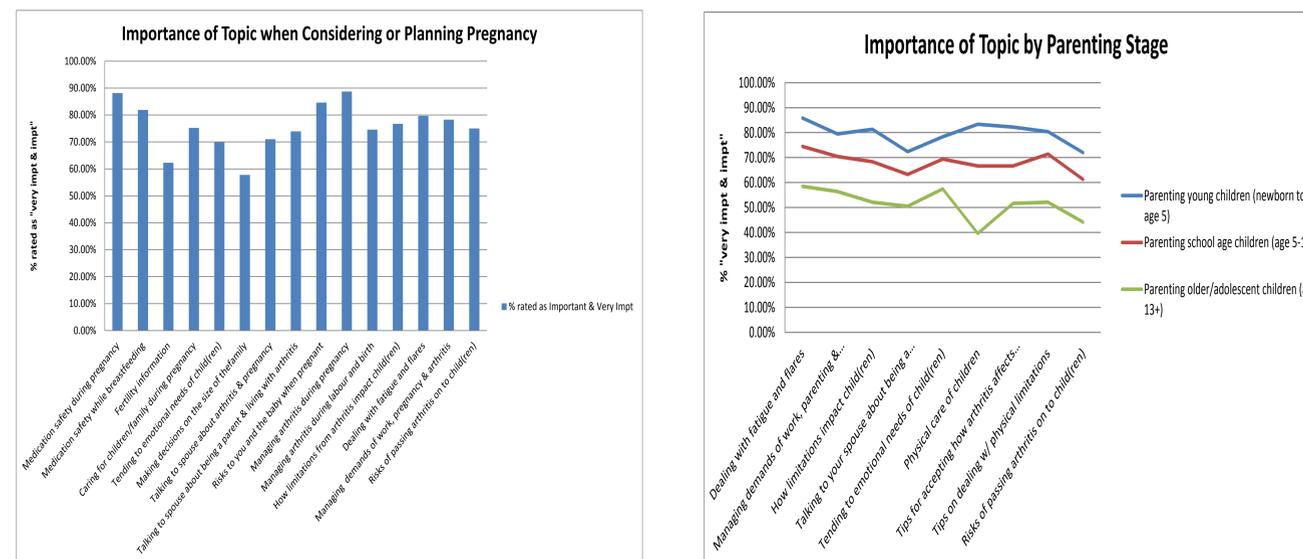


Figure 2: Excerpts of Advice (Q17)

*"I would say take the facts from the experts but do what you need to do."*

*"You may have to work a little harder, but you can be an excellent parent to your children....you just have to go about it a little differently!"*

*"You have to take care of yourself too. If you can't take care of your baby because you can't walk or pick him/her up it's ok to stop breastfeeding and go on medication. It doesn't make you a bad mom."*

*"Vivre au jour le jour. Respecter ses limites. Ne pas se sentir coupable de notre état."*

*"Do not allow this disease to prevent you from experiencing the joy and love that comes from being a parent. Just be smart and ask for help, whether it from family or professionals."*

*"Pace yourself. Sleep/rest when the kids do. Kids come first, housework/work can wait."*

## Results (cont'd)

Respondents were also asked to rate the resources available to them and how useful they were. Respondents indicated that:

- they consulted their rheumatologist (57%) followed by the family doctor (44%) and non-profit organization (43%) for information;
- the quality of the information received (those who responded as "Good" or "Very Good") ranged from 58% to 21%.

At the end of the survey, respondents were given the option to provide advice concerning pregnancy or parenting while living with arthritis and Figure 2 provides a key excerpts from this question.

## Discussion

The survey highlights many of the issues we expected would be identified as patients living with arthritis who have dealt with these situations first hand. Issues of particular concern include:

- current challenges in accessing reliable, high-quality information regarding the safety of medications before and during pregnancy and while breastfeeding, and
- gaps in the regulation of medications during pregnancy and breastfeeding.

More needs to be done by the health regulators and pharmaceutical companies to ensure post-market safety data is captured systematically and communicated to patients.

The survey results will be communicated to the CAPA membership and our various stakeholders, including those in the arthritis community, researchers, regulators and obstetricians. It is our hope that the survey results will stimulate thoughtful discussions in a variety of forums to improve health care delivery and patient outcomes.

## Conclusions

The results of the survey indicate that patients have a high need for information when considering pregnancy and in carrying out their role as parents. As a result, the survey results will be used to create an educational resource to assist people living with arthritis when considering pregnancy and in carrying out their role as a parent. CAPA aims to raise the profile of this issue and help people living with arthritis engage in more dialogue with their health-care providers during these critical life events.

## References

1. A systematic review of interventions to improve knowledge and self-management skills concerning contraception, pregnancy and breastfeeding in people with rheumatoid arthritis - <http://www.ncbi.nlm.nih.gov/pubmed/26638162>
2. Experiences of mothers living with inflammatory arthritis, Backman, C.L., Del Fabro Smith, L., Smith, S., Montie, P.L. & Suto, M. (2007).
3. Project repository: <http://www.arthritispatient.ca/projects/pregnancy-parenting>
4. The Seated View (guest post) on the Pregnancy and Parenting Survey (<http://theseatedview.blogspot.ca/2015/10/guest-post-pregnancy-and-parenting.html>)

## Acknowledgements

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