

Background

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

Objectives

- Outline the process and timeline undertaken to develop and launch the pregnancy and parenting with arthritis survey
- Share the survey results and communicate next steps

Methods

The survey was launched in September 2015 during Arthritis Awareness month and remained open until January 2016. 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 tested the survey on various people living with inflammatory arthritis who represented a range of perspectives (e.g. considering pregnancy, parenting school age children, etc.). Testing methods included phone calls, in person meetings and email. The final survey was posted on Survey Monkey (in both English and French) and 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 January 2016.

Results

A total of 150 responses were received throughout the survey period. The following list describes the key characteristics of the survey population:

- the majority are individuals living with arthritis (87%)
- more than half (51%) live with Rheumatoid Arthritis and 20% live with Ankylosing Spondylitis
- represent an accurate geographic distribution of the Canadian population including both rural (24%) and urban (72%) residents
- the majority were female (96%)
- approximately half (52%) of respondents have lived with arthritis for 0-14 years.

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

Results (cont'd)

respondents when considering or planning pregnancy and Figure 2 depicts the results by parenting stage. There was a general decrease in importance of the topics from planning or 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: Pregnancy

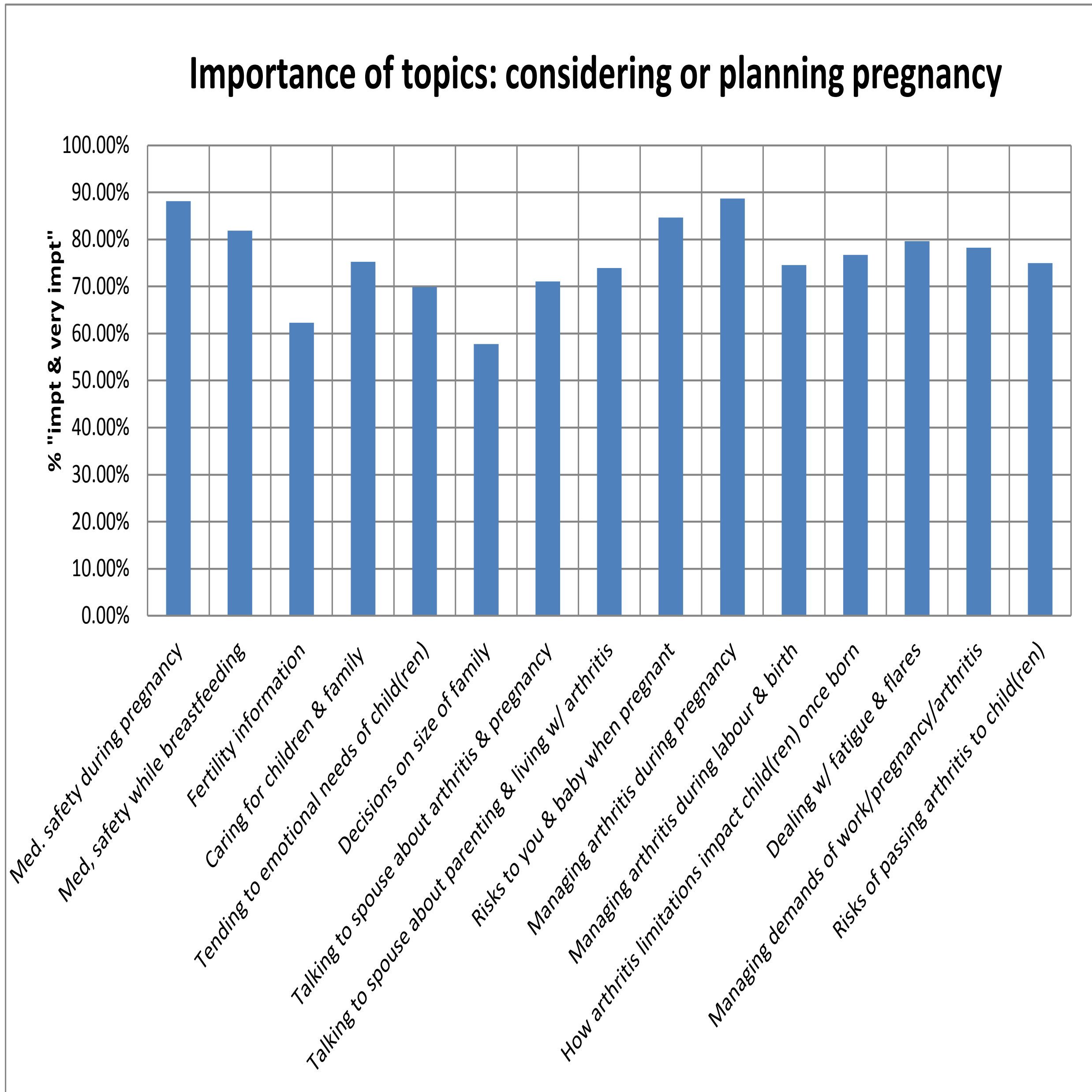
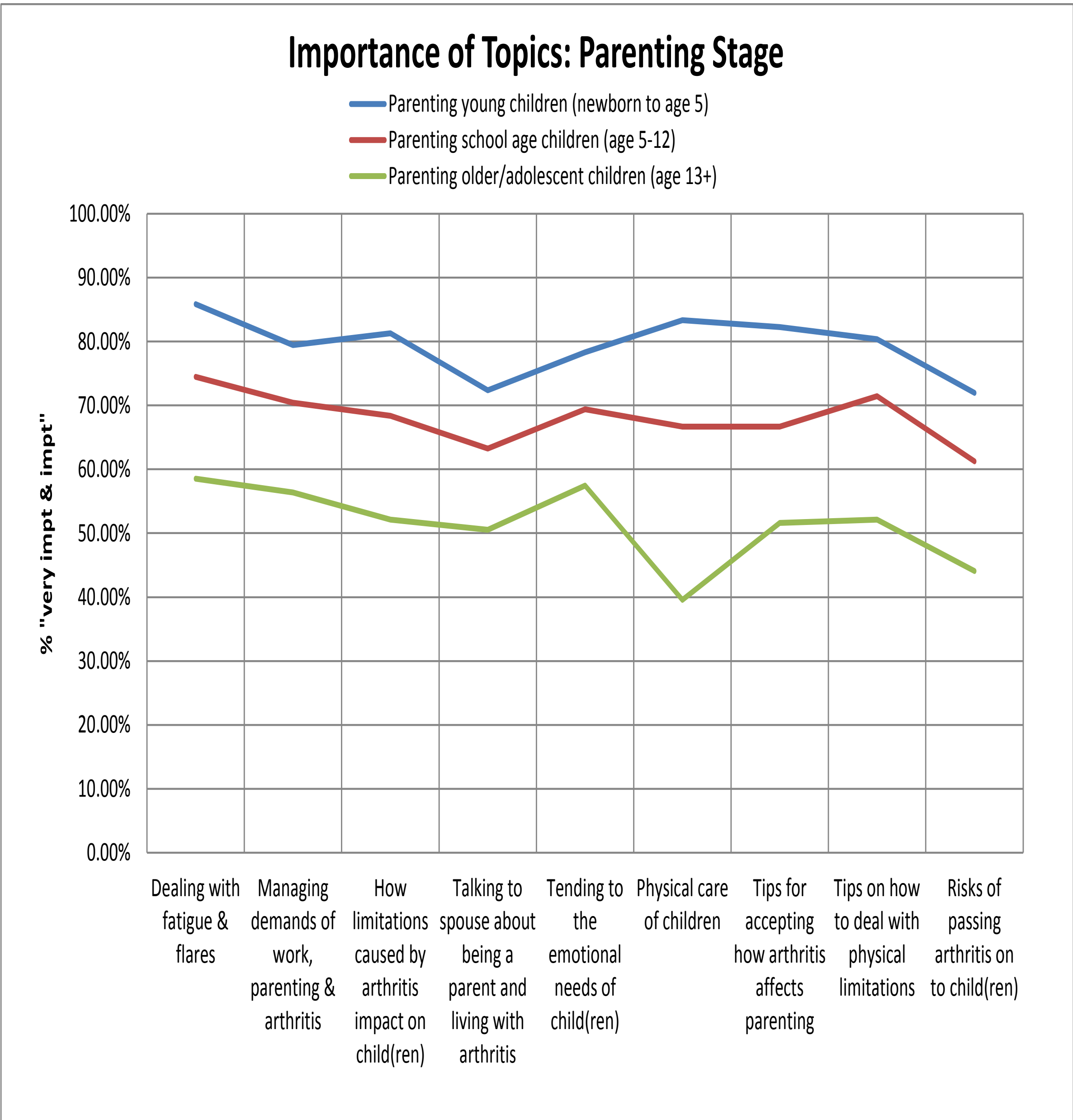


Figure 2 - Importance of Topics: Parenting Stage



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 “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. Box 1 provides key excerpts from these answers.

Box 1 - Excerpts of Advice

“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.”

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

Discussion

The survey highlights many of the issues we expected would be identified as patients living with arthritis. 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
- 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.

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. Issues identified by respondents include:

- medication safety during pregnancy and breastfeeding
- dealing with fatigue and flares
- physical care of children.

The survey results will be communicated to the CAPA membership and our various stakeholders, including the arthritis community, researchers, regulators and obstetricians. It is our hope that the survey results will stimulate further research, healthcare delivery improvements and improve overall patient outcomes.

References

- 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>
- Experiences of mothers living with inflammatory arthritis, Backman, C.L., Del Fabro Smith, L., Smith, S., Montie, P.L. & Suto, M. (2007).
- Project repository: <http://www.arthritispatient.ca/projects/pregnancy-parenting>
- TheSeatedView(guestpost)onthePregnancyandParentingSurvey(<http://theseatedview.blogspot.ca/2015/10/guest-post-pregnancy-and-parenting.html>)

Acknowledgements

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