

Background

Arthritis affects individuals in many aspects of their life, including decisions regarding pregnancy and 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 involved the development of a survey to identify 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

The objectives are to:

- Outline the survey development and launch; and,
- Discuss the survey results.

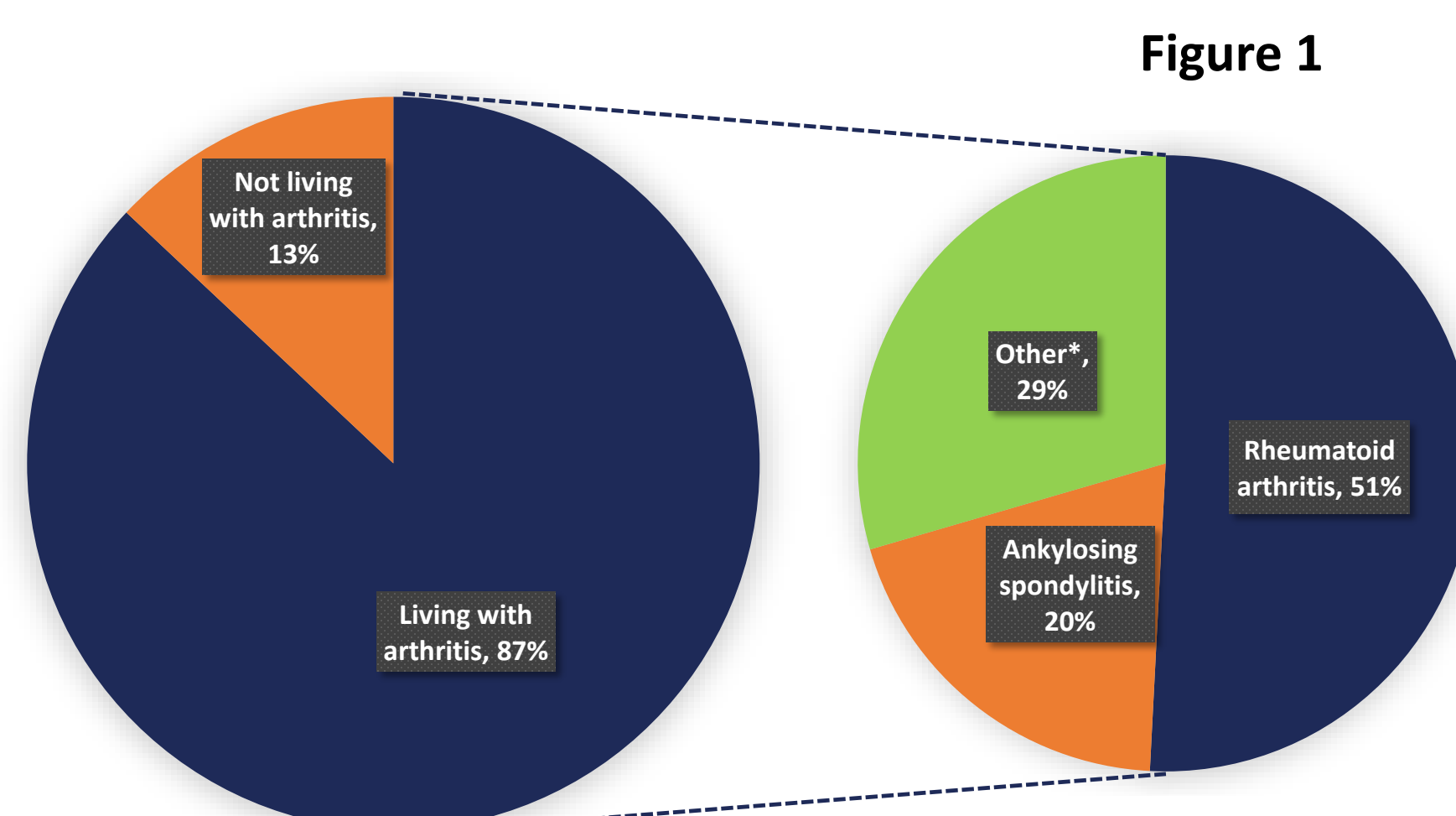
Methods

The survey was designed in Survey Monkey based on input from people living with arthritis who represented a range of perspectives (e.g. considering pregnancy, parenting school age children, etc.). Methods included phone calls, in person meetings and email. The survey was communicated by CAPA and other stakeholders using the quarterly CAPA newsletter and social media. The survey was launched in September 2015 during Arthritis Awareness month and remained open until January 2016. The survey targeted individuals living with arthritis and people in their social support network, such as spouses, rheumatologists and allied health care professionals.

Results

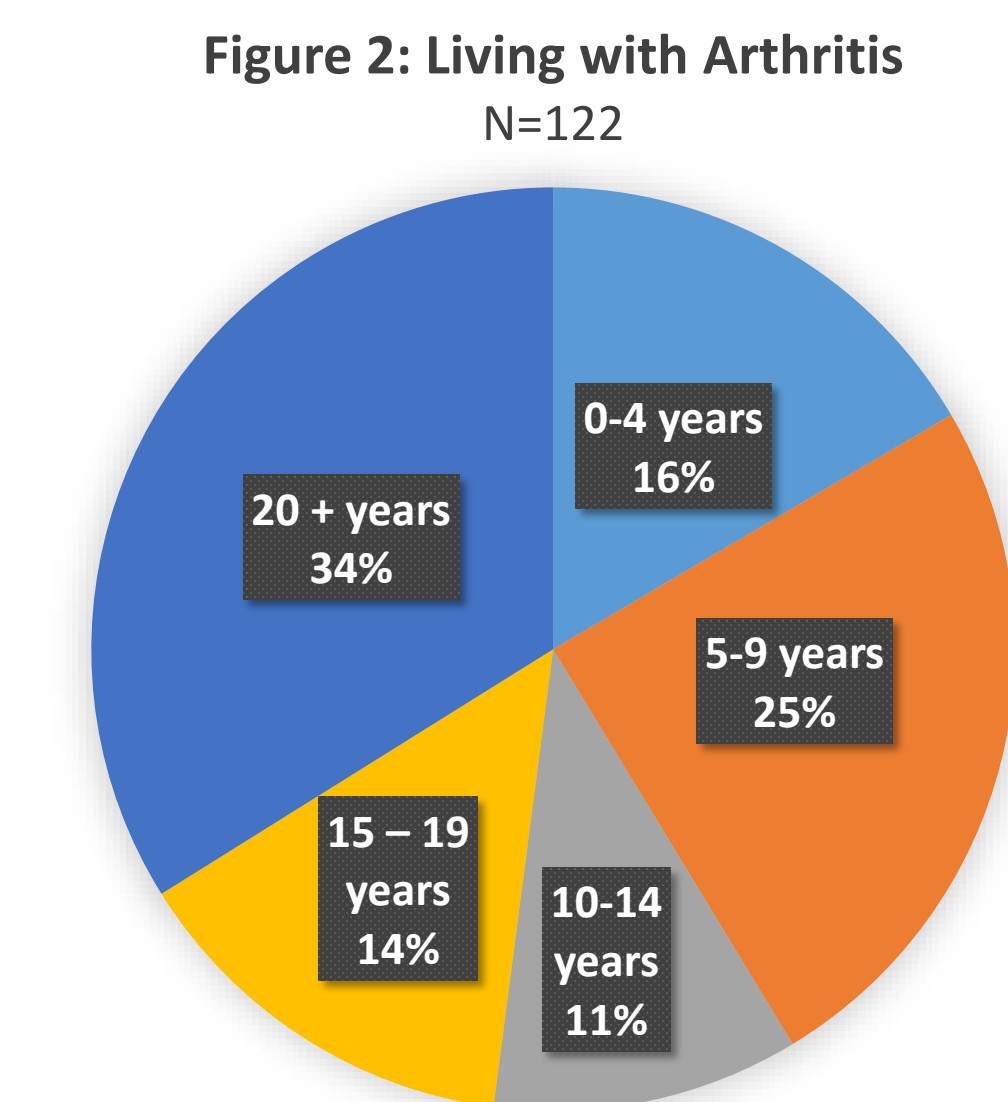
Variety of respondents

A total of 150 responses were received throughout the survey period. Respondents were mostly women (96%) with proportional geographic representation from across Canada. Figures 1 and 2 provide additional detail.



*Other forms of arthritis included: juvenile idiopathic arthritis, lupus, psoriatic arthritis, osteoarthritis

Results (cont'd)



Words of advice

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 Advice concerning pregnancy or parenting

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.

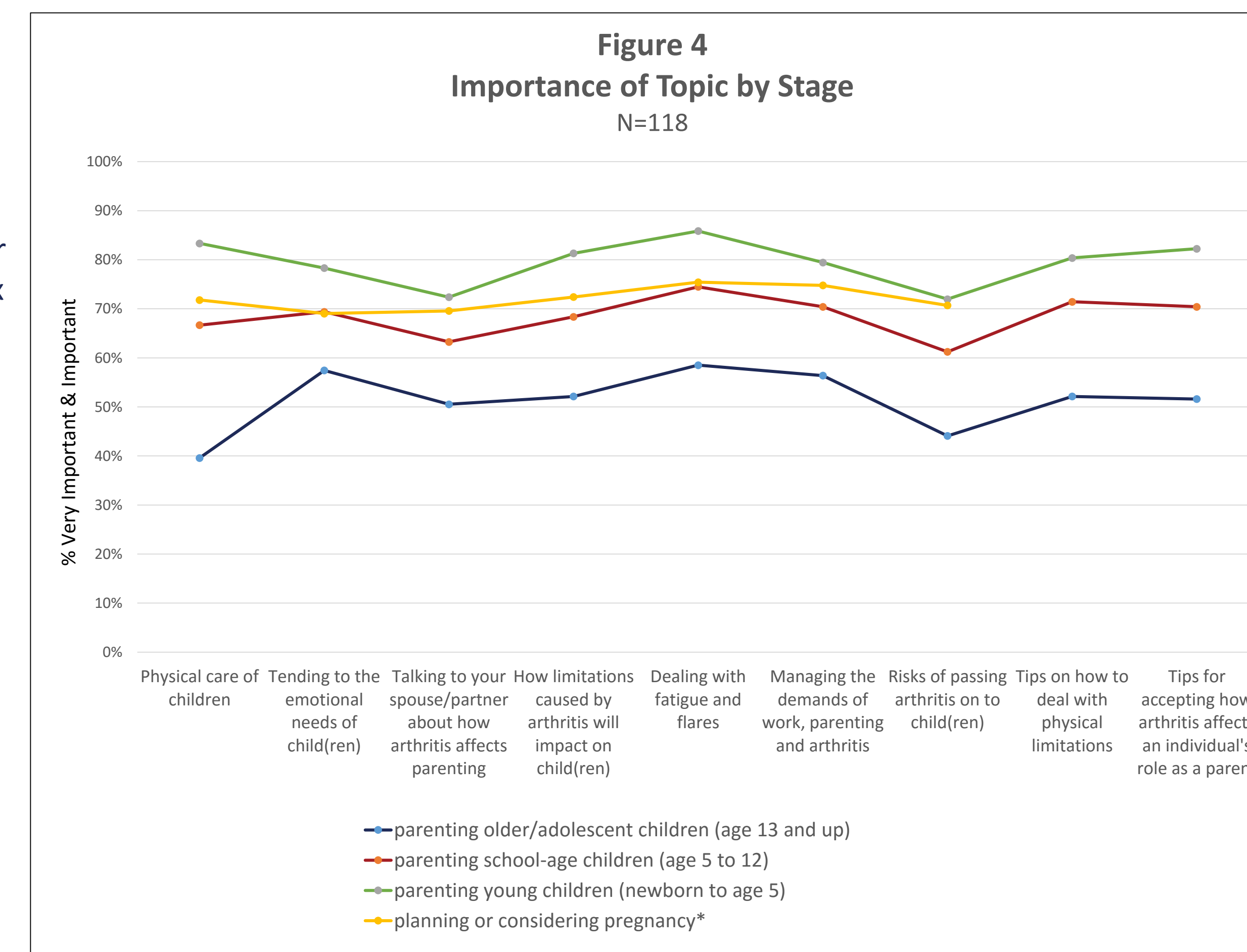
Pace yourself. Sleep/rest when the kids do. Kids come first, housework/work can wait.

Needs differ by stage

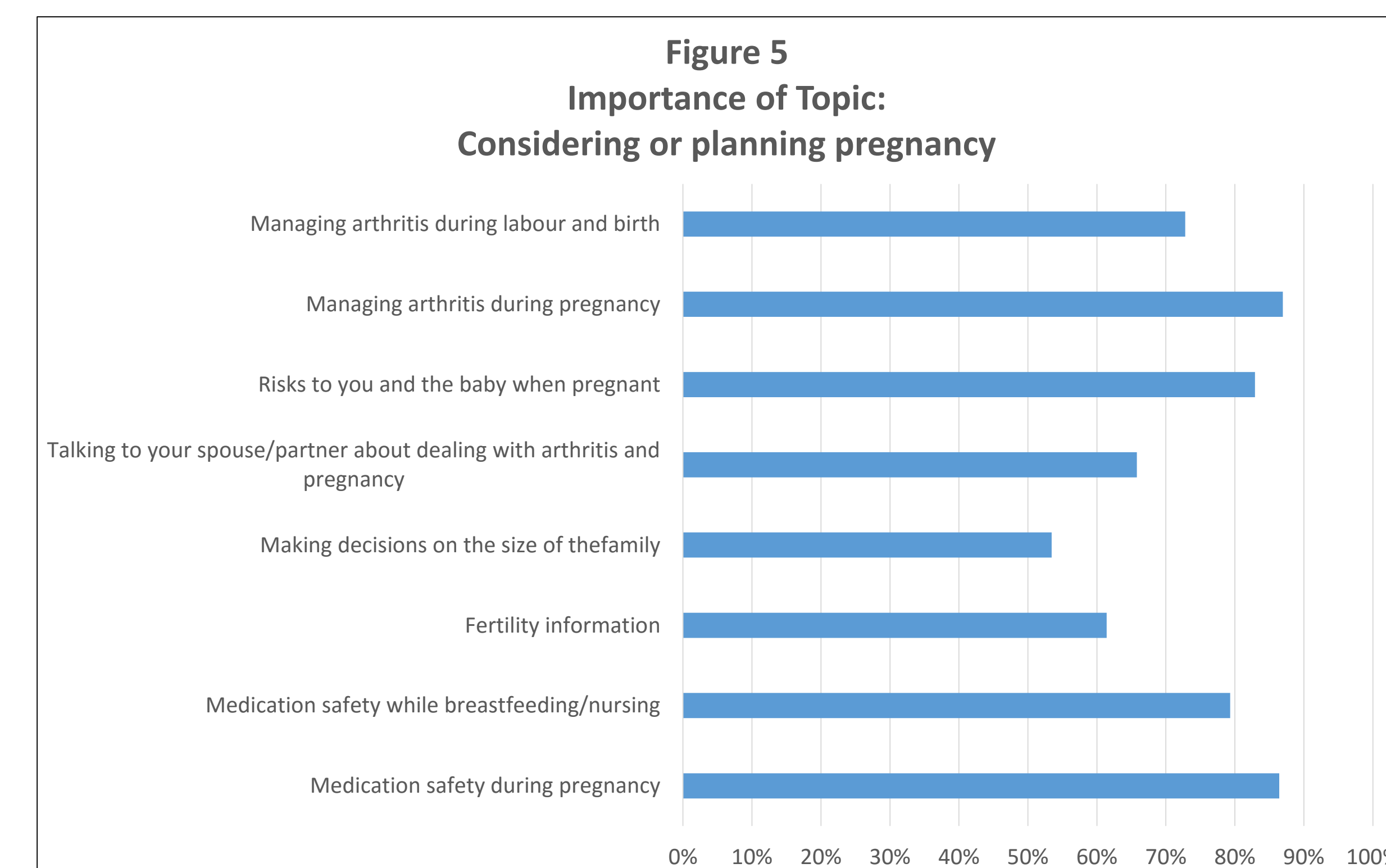
There was a general decrease in importance of the topics from planning or considering pregnancy to the latter stage of parenting older/adolescent children. This could represent greater confidence in undertaking the parenting role while living with the challenges of arthritis, as well as the fact that the needs of the children are inversely proportional to their age. Figure 4 shows the decreasing importance by pregnancy/parenting stage. The top issues, regardless of parenting stage include:

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

Figure 5 shows the importance of information specifically associated with considering or planning pregnancy, 4 areas of which were ranked over 75%.



*Questions were not the same for this stage of parenting; questions were mapped as appropriate.



Access and reliability challenging

Differences were seen when comparing what source of information was accessed, versus the perceived quality. A summary is included in Table 1.

Table 1

Source	Access/Awareness	Reliability/Quality
Motherisk	43%	77%
Family doctor	45%	73%
Patient group or organization	47%	49%
Someone you know who has arthritis	52%	46%
Obstetrician	63%	59%
Non-profit organization (e.g. The Arthritis Society)	68%	57%
Friends and family	70%	30%
Rheumatologist	89%	65%

Discussion

The survey highlights many of the issues expected regarding the information needs for individuals living with arthritis and considering or planning pregnancy, or raising children. Issues of particular concern include:

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

This information prompts the need for greater dialogue regarding the current gaps in the regulation of medications during pregnancy and breastfeeding, and that health regulators and pharmaceutical companies systematically capture post-market safety data and communicate this information to patients.

Conclusion

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; however, access to and reliability of this information is lacking.

The survey results will be communicated to the CAPA membership and our various stakeholders, including the arthritis community, researchers, regulators and obstetricians. This information will be used to develop an educational resource for patients living with arthritis. It is also hoped that these results will stimulate further research, healthcare delivery improvements and improve overall patient outcomes.

Who We Are

Canadian Arthritis Patient Alliance (CAPA) is a grass-root, patient-driven, independent, national organization with members across Canada and supporters both Canadian and International. CAPA believes the first expert on arthritis is the individual who has the disease, as theirs is a unique perspective. We assist members to become advocates not only for themselves but all people with arthritis.