



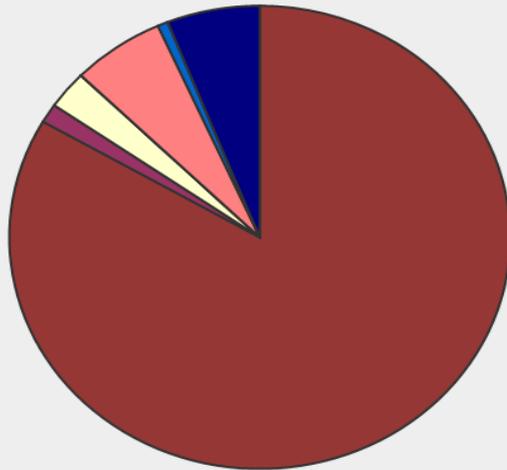
Key Findings: Pregnancy and Parenting with Arthritis Survey

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, CAPA has launched a project to identify patient information needs as it relates to pregnancy and parenting. 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. We received an excellent response (150 responses) to the survey due in large part to our efforts to promote the survey through the CAPA newsletter, Facebook and Twitter pages and through the assistance of our partners who promoted the survey on our behalf.

Who responded to the survey?

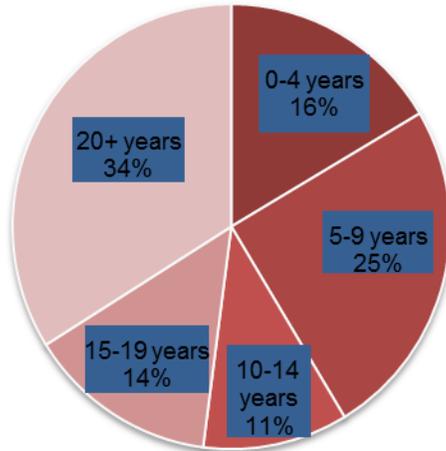
- Most people who responded to the survey are living with arthritis (83%). Approximately 50% live with Rheumatoid Arthritis following by 20% with Ankylosing Spondylitis, 9% with Psoriatic Arthritis and 8% living with Juvenile Idiopathic Arthritis. Other people completed the survey including rheumatologists (6% of total responses) and spouses/family/friends (refer to Chart 1 below).
- Most of the survey respondents were female (96%). There was a fairly equal distribution in the number of years people had lived with arthritis (refer to Chart 2 below).

Chart 1: Who are you?



- Person living with arthritis
- Spouse/partner of person living with arthritis
- Family member of person living with arthritis (e.g. mother or father)
- Friend of person living with arthritis
- Family physician
- Rheumatologist
- Member of extended health care team (e.g. Occupational Therapist, Physiotherapist)
- Obstetrician
- Other (please specify)

Chart 2: How many years have you lived with arthritis?



- 0-4 years
- 5-9 years
- 10-14 years
- 15 – 19 years
- 20 + years



What else can you tell me about who responded?

- Respondents of the survey were a representative sample of the Canadian population both geographically and in terms of rural (24%) and urban (72%) residents. (based on latest Statistics Canada figures)
- There were a significant number (81%) of survey respondents who had considered or planned a pregnancy while living with arthritis and 58% had actually experienced a pregnancy. There are 65% of respondents who are currently parenting while living with arthritis.

Overall findings

- The survey highlights many of the issues expected regarding the information needs for people living with arthritis when considering or planning pregnancy, or raising children. In reviewing the survey data, we reviewed what respondents rated as “Very Important” or “Important”.
- 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, as well as the fact that the needs of the children are inversely proportional to their age.
- The highest level of importance was noted for in the earlier stages (~80% or higher rated as important) of considering or planning pregnancy while the later stages were rated as less important (~50–60% rated as important). This indicates a stronger need for information in the earlier stages of parenting and while considering or planning pregnancy.

- The figure 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.
- The issues ranked as important for respondents varied slightly by stage. For example:
 - the physical care of children was rated to be of higher importance when parenting young children (age 0–5) likely because of the physical challenges of arthritis combined with the physical demands of parenting;
 - in contrast, the issues identified shifted when parenting school age children (age 5–12) when it became more important to have information on managing the demands of work, parenting and arthritis.

Chart 3: Importance of Topics: Parenting Stage

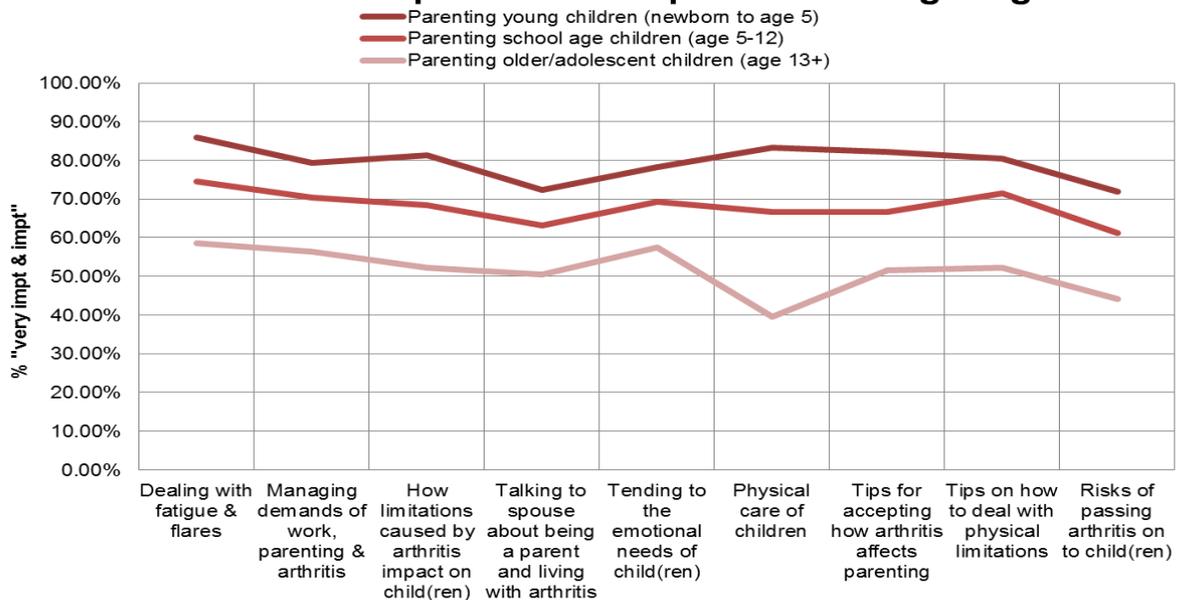
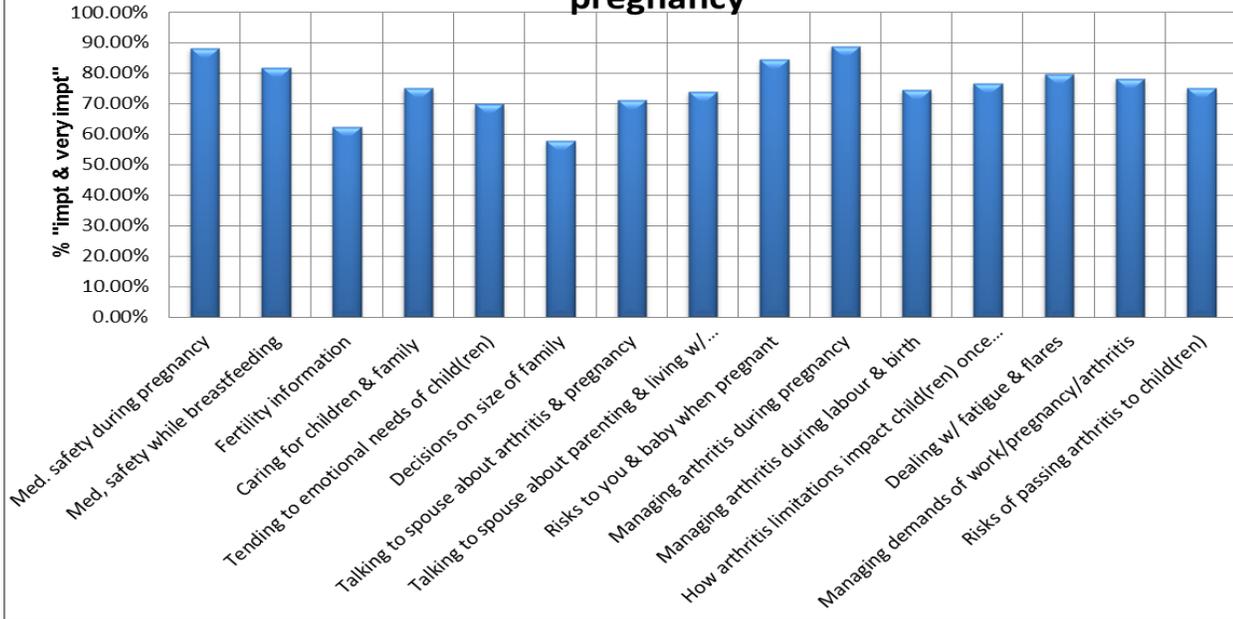


Chart 4: Importance of topics: considering or planning pregnancy



Awareness of Resources & Perceived Quality

- Differences were seen when comparing what source of information was accessed and how respondents perceived the quality of the information. A summary of the responses to these questions is included in the table below.



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%

- 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.
- In terms of the preferred method of accessing information, 90% prefer to access information on the Internet. When accessing the information on the Internet, 40% prefer to access the information on their phone followed by their desktop/laptop computer (31%).

Advice concerning pregnancy or parenting

- 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

"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."

Next steps

- 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.