

Background

The Canadian Arthritis Patient Alliance (CAPA) is a grass-roots, independent patient organization that seeks to provide a voice for Canadians living with all types of arthritis. CAPA's Steering Committee is comprised of people who live with different types of arthritis. CAPA works collaboratively with other organizations to achieve its goals, and has partners that are nationally- and internationally-based. Along with CAPA's advocacy efforts, we have recently started to build resources and tools for patients on topics for which they have told us they require more information.

As people who live with arthritis ourselves, we know that methotrexate is one of the first medications prescribed to help manage inflammatory and other types of arthritis^{1,2}. This key medication is used in combination with both non-biologic or biologic medications^{3,4}. Many people with arthritis have difficulties tolerating and taking methotrexate because of a variety of side effects they may experience. Because of this, many people with arthritis are not able to or choose not to use methotrexate as prescribed by their healthcare provider. This often means that patients may not get maximum benefit from methotrexate.

Objectives

We asked people about their attitudes and how they cope with taking their methotrexate so we could gain information and insights on their experiential tips and tricks. Here we present the findings of our survey. Our ultimate goal is to build and share resources based on this information, to best help people cope with taking methotrexate for their arthritis.

Methods

CAPA managed this project with financial and in-kind support from many arthritis stakeholders. One Board member acted as a project manager to construct an online survey. Methods to achieve input and feedback for the draft survey included phone calls and emails. Feedback was gathered from members of the CAPA Steering Committee (who are people who live with arthritis) and the survey was reviewed by a rheumatologist. Once finalized and agreed to, the survey was translated in to French. Distribution and promotion of the bilingual survey were achieved through CAPA's efforts (email blast to membership, social media promotion on Twitter and Facebook) and with stakeholders' help via online dissemination tools (and included efforts of other patient organizations, individual patients, and the Arthritis Society).

Results

Survey Demographics

363 respondents (88% female, 12% male) participated in the online survey, and most people were less than 60 years of age. Most respondents live with rheumatoid arthritis (77%), followed by psoriatic arthritis (22%) (and others types represented 1% of responses). The respondents to the survey represented a global population, with about 63% of responses from Canada, and also included responses from the US, Sweden, Turkey, Israel, Greece, the UK, and Australia (with others as well).

Methotrexate Use

59% of respondents went on methotrexate as one of their first medications. Of the people who stopped methotrexate, the number one reason was due to side effects.

In terms of method of methotrexate administration, this was evenly split between oral and subcutaneous methotrexate.

Respondents often took methotrexate in combination with other drugs, including:

- Plaquenil (20.0%)
- NSAID (30.7%)
- Biologic/biosimilar (34.3%).

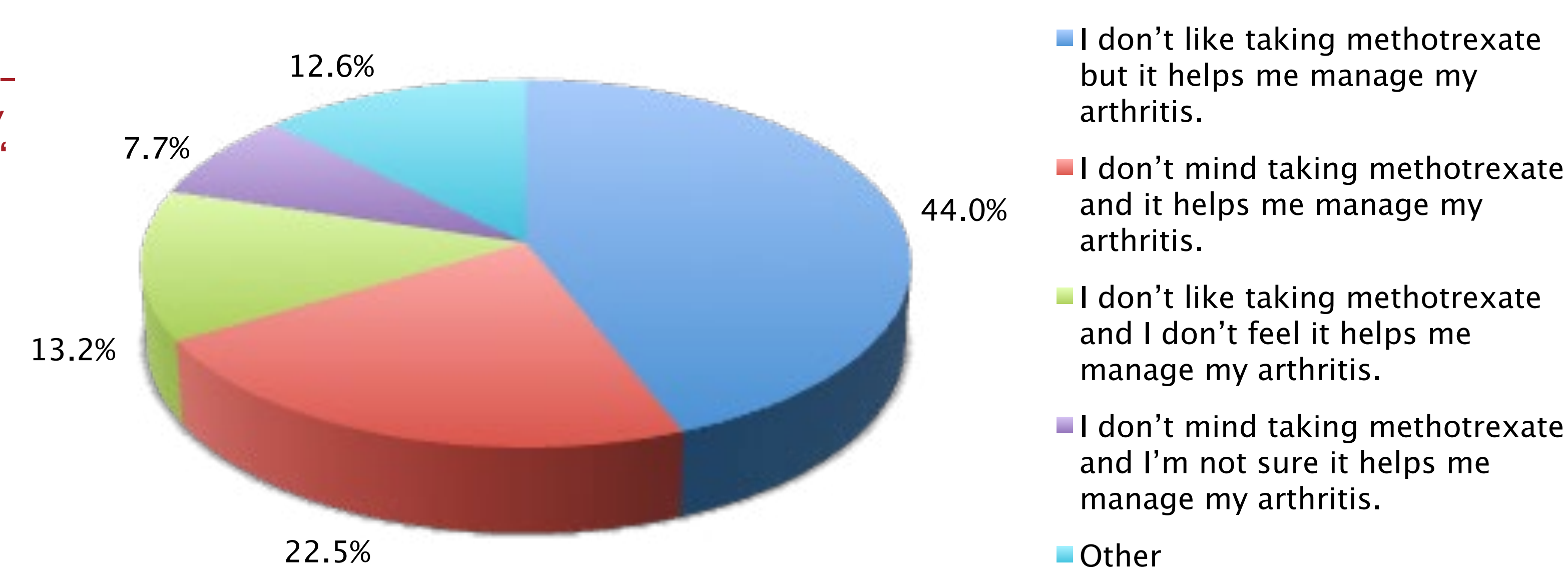
Attitude about Methotrexate

Figure 1. Respondents were asked which statement best described their feelings about methotrexate.

"I have been taking methotrexate for 7 months now along with other medication. It literally zaps all energy from me for five days, I then have average energy for two days before it is time to take the next dose."

"So far have had some minor relief. But the side effects have been rough. So just going to now try it by injection."

"I have been on injections for 6 months. The first 5 months the side effects were challenging for 4 or 5 days after injection. Just now tolerating so it doesn't ruin my days."



Adaptations

People indicated they made a number of adaptations to help them better tolerate their methotrexate, with most people doing the following:

- taking folic acid (75.7%)
- taking methotrexate right before bed (43.0%)
- taking methotrexate on the weekend (36.1%)
- taking methotrexate on a full stomach (30.5%), and
- switched from taking methotrexate as pills to injecting it (30.5%).

Many people had solutions that they shared including taking an anti-nausea medication, taking it with certain foods, etc.

Almost half of respondents reported skipping a dose to accommodate their lifestyle/personal events as well as adjusted their schedules the day after they take methotrexate. A large gap has been identified in that nearly 80% of respondents have not talked to their doctor or pharmacist to find another solution to dealing with their methotrexate. And while most respondents do not like taking methotrexate, 80% of respondents have remained on it to help manage their arthritis.

Discussion

Methotrexate is a well known drug that has been shown to be effective in treating arthritis. While newer and often more expensive drugs come to market, such as biologics and biosimilars, methotrexate is still an affordable and well known part of the treatment plan. Understanding methotrexate's benefits and risks are important given its prevalence. If most respondents taking methotrexate make adaptations to how it is taken without seeking medical advice, there is a question as to whether the maximum benefits of methotrexate are being realized. Without maximizing the full benefits of methotrexate, individuals with arthritis may seek other alternative drug treatments or solutions. Finding the right solution to help manage arthritis is difficult; the need to find additional alternate solutions is even more difficult, both physically, emotionally, and often complicated by formulary and insurance coverage.

Thus ensuring that people can maximize their use of methotrexate and make adaptations that suit their needs are important. Individuals living with arthritis have a wealth of experience. Documenting these experiences, having these reviewed by medical experts, and sharing other tips and tricks, will help open and stimulate dialogue around the use of methotrexate.

Conclusions

CAPA learned from people living with arthritis about their attitudes and how they cope with taking methotrexate. The biggest gap identified is that the majority of people living with arthritis have not talked to their health care providers about finding coping mechanisms for taking methotrexate. This and other findings will be used to inform medically-reviewed resources about managing to take methotrexate. Through sharing patient experiences, we hope to encourage people to try these tips or to have honest conversations with their doctor or pharmacist to find their own most appropriate solutions.

References

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