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Sex and Gender Differences in Arthritis Health Information

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Abstract

Arthritis is a common disorder that may result in pain and inflammation, making it challenging to move or continue being active. Arthritis comes in a variety of forms. The two studies of this thesis aimed to identify the influence of intersectionality, especially sex and gender, in arthritis. The first study, a structured review, evaluated the inclusion of sex/gender and intersectional identities in patient resources of three arthritis societies: the Canadian Arthritis Society, the American Arthritis Foundation, and the National Rheumatoid Arthritis Society. The appraisal tool, the Sex/Gender and Intersectional Considerations in Patient/Consumer Health Information Appraisal Tool was used to evaluate patient resources. The second study, an interpretive description, found that there are challenges in accessing health information among arthritis patients. It was also found that patients are dissatisfied with the information or services provided by physicians.

Key words

Sex and gender, health information needs, structured review, interpretive description, arthritis, online resources.

Summary for Lay Audience

What is the problem?

Arthritis is joint inflammation (joints are regions where two bones meet like the elbow or knee). Patients' preferences and needs for health information are influenced by intersectionality: sex, gender, race, and other factors. Sex is a biological construct and gender is a social construct. Gender refers to gender-specific roles, behaviours, expressions, and identities of men, women, boys, and girls that are socially created. There are currently no standards or algorithms that provide precise recommendations on concerns of sex and gender differences.

How did we study the problem?

In the first study, we evaluated patient resources in arthritis societies using the Sex/Gender and Intersectional Considerations in Patient/Consumer Health Information Appraisal Tool. In the second study, we asked arthritis patients about their health information needs and their experiences with accessing and receiving health information.

What did we learn?

In the first study, we found that not more than half of the evaluated resources adequately considered sex/gender or intersectionality. The lack of gender-aware information was highlighted by the frequency with which sex and gender terms were inaccurately attributed, and the lack of description for how they are linked to differences in treatment responses, risks, or prognosis.

In the second study, the challenges patients have while accessing health information revealed the need to adopt a patient-centred strategy that focuses on their needs and allows them to express their opinions.

How can this research be used?

The first study highlighted the need to consider intersectionality, especially sex and gender. The second study highlights the need to identifying patients’ health information-seeking behaviours, sources of information, and barriers to accessing information. Patients need to be engaged in designing information systems and programs. Education alone is not sufficient; patients need to be active partners in their care and management of arthritis.

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Most importantly, I would like to express my sincere gratitude to my family, especially my mom, Hind Mohammed, for her unconditional love, support, and sacrifices. Your confidence in me has fueled my passion and motivation throughout this process. I hope I always make you proud. Thank you for showing me what resilience and determination mean. This thesis is dedicated for you.

Contributions

Tania Al-jilawi completed the evaluation of arthritis information resources using the appraisal tool. She also completed data extraction, data collection, data analysis, wrote manuscripts, and recruited participants, The research questions and study designs were reviewed and modified by Tania Al-jilawi and Dr. Joy MacDermid.

Dr. Joy MacDermid reviewed the two manuscripts. At every stage of the thesis, Dr. Joy MacDermid offered an enormous amount of valuable feedback via email, Zoom meetings, and student meetings. Dr. Joy Macdermid also designed the appraisal tool used in chapter 2.

Dr. Katherine Salter, supervisory committee member, reviewed both manuscripts and provided an immense amount of feedback and support through email, Zoom meetings, and committee meetings.

Dr. David Walton, supervisory committee member, reviewed the first manuscript (chapter 2) and provided important feedback through committee meetings and email.

Armaghan Dabbagh, an independent rater, who evaluated arthritis information resources using the appraisal tool (chapter 2), involved in data analysis and coding in chapter 3, and reviewed both manuscripts.

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Chapter 1: Introduction

What is Arthritis?

Arthritis is a group of conditions that affect the joints and other tissues. It impairs quality of life, causes pain, and limits mobility (National Institute of Arthritis and Musculoskeletal Diseases, 2022). Arthritis is a chronic condition; it affects 1 in 5 Canadians (Canadian Arthritis Society, n.d.). Arthritis conditions can be grouped into two categories: osteoarthritis and inflammatory arthritis. Osteoarthritis is the most common type of arthritis. Inflammatory arthritis includes rheumatoid arthritis, psoriatic arthritis, juvenile arthritis, and gout.

What is Health Information?

Information about a health condition or impairment. It involves information or opinions regarding injuries, disabilities, or illnesses (Australian government, n.d.). It should improve medical care's effectiveness and lead to more individualized and precise medical interventions (Battineni et al., 2020).

Importance of Understanding Patients' Health Information Needs

Improving people's access to health information and their ability to use it effectively is acknowledged as a public health objective and a factor in positive health results (Battineni et al., 2020). According to studies, a patient's level of health knowledge can be used to predict how they will behave in terms of their health and how often they will use healthcare services (Battineni et al., 2020). Health information seeking by patients is seen as a significant indicator of patient involvement in their healthcare and is considered a deliberate and goal-oriented action (Battineni et al., 2020). Patients who actively seek out health information frequently rely on media outlets such as the Internet (Dutta-Bergman, 2004). As the use of the Internet keeps growing, the focus of research has shifted to how individuals use the Internet as a source of health information (Yabarra & Suman, 2008). About 8.7 million Canadians access the internet for medical and health-related information, with women more likely than men to look for specific conditions in terms of health information (Daraz et al., 2011). Research indicates that consumers will continue to use it increasingly as a source of health information (Yabarra & Suman, 2008). However, findings constantly show a lack of quality for health websites (Yabarra & Suman, 2008). Therefore, it is important we examine online patient resources and understand patients' health information-seeking behaviours and needs, especially since patients are turning to alternative sources of health information. For instance, 50% of Americans say that physicians are their preferred first source for health information, but only 11% say they go to one as their initial point of contact, compared to 49% who say they turn to the Internet (Yabarra & Suman, 2008).

There are intersectional factors that influence patients' health information needs, such as sex, gender, age, literacy level, disability, class, ethnicity, and gender identity (Finnegan, 2022). Women are more likely than men to state that information they found online helped them cope with their condition, although men are more inclined to search for information regarding sensitive health topics (Rainie & Wellman, 2019). Research studies show that health information-seeking is influenced by age and sex, to what extent is yet to be understood (Yabarra & Suman, 2008). Thus, this thesis will focus on understanding the influence of intersectionality, especially sex and/or gender, on arthritis patients' health information needs.

Sex Versus Gender

Sex refers to "biological, genetic and physiological processes that generally distinguish males and females" (Tannenbaum et al., 2019, p. 138). Gender refers to "the roles, relationships, relative power and other traits that societies generally ascribe to women, men and people of diverse gender identities” (Tannenbaum et al., 2019, p. 138). The phrase “sex/gender” is used to emphasize the interconnected, multifaceted, and dynamic nature of the ideas of sex and gender.

Sex and Gender Differences in Arthritis

Sex differences are well-established in arthritis, knowing that females are two to three times more prone to developing arthritis than males (Favalli et al., 2018). The causes of these discrepancies are not yet fully understood (Tschon et al., 2021). Women are more likely than men to use health services, which may offer additional opportunities for receiving health information (Marrie et al., 2019).

Compared to men with arthritis or women with other chronic conditions, women with arthritis frequently report higher levels of anxiety, feelings of sadness, disability, and difficulty sleeping (Canadian Arthritis Society, n.d.). Dr. Angela How, a rheumatologist in Burnaby, BC, comments, "I think women may tend to have more disability because they do a lot at home and at work" (Canadian Arthritis Society, n.d.). "I think we sometimes forget about how different women's roles are. There is employment, but there is also home life, raising children, and recreational activities” (Canadian Arthritis Society, n.d.). In the last 30 years, women's rates of paid labour increased drastically; nevertheless, for those who have children, the gender gap in child care remains the same (Statistics Canada, 2017). Compared to men, women spend almost an hour longer a day on routine child care responsibilities (Statistics Canada, 2017). Caregiving for an adult family member or friend was three times as common among women than among men (Statistics Canada, 2017). Evidence suggests that there is a lack of understanding of the concepts of sex and gender, how they are interrelated, whether and how they affect health (Runnels et al., 2014). The challenge remains on how to adequately communicate information to arthritis patients considering sex/gender differences.

Current Gap in Literature

Although studies have shown that arthritis affects women more than men and symptoms differ between the sexes, literature still lacks how these differences affect patients' ability to cope with arthritis (Flurey et al., 2016). There are currently no standards or algorithms that provide precise recommendations on concerns of sex and gender differences (Maranini et al., 2022). Implementing sex and gender differences in research publications is not only a necessary step toward equality and inclusion but also a genuine effort to pursue personalized medicine (Maranini et al., 2022). Therefore, more research is needed in this area, where further evaluation is carried out in detail.

The objective of this thesis is to explore the health information needs of arthritis patients. In the first study, the goal is to determine if sex and gender are addressed in patient information resources while acknowledging how intersectional identities affect gender identities, roles, and information needs. In the second study, the main objective is to understand how a patient's sex and/or gender can influence their arthritis health information needs.

The two research questions guiding this dissertation were as follows:

1. Do current arthritis health information resources consider sex and gender differences?
2. what are the needs of patients with arthritis considering sex and gender differences when accessing resources?

Thesis Overview

This thesis consists of two papers presented in a manuscript style as Chapters two and three. Chapter two is a structured review. The paper evaluated the patient resources of three arthritis societies (Canadian, American, and British). A critical appraisal of sex and gender within an intersectional lens was performed using a structured item appraisal tool, the Sex/Gender and Intersectional Considerations in Patient/Consumer Health Information Appraisal Tool. Chapter three is a qualitative study, interpretive description, assessing the influence of patients’ sex/gender on their health information needs.

In summary, research in this thesis attempts to address the literature gap in understanding the influence of sex/gender on patients’ arthritis health information needs. Also, to evaluate the current arthritis patient resources and determine their inclusion for sex/gender factors.

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Chapter 2: Assessment of Arthritis Information Resources Reveals a Lack of Attention to Sex/Gender or consideration of intersectionality.

Assessment of Arthritis Information Resources Reveals a Lack of Attention to Sex/Gender or consideration of intersectionality.

Abstract

Background: Intersectionality is how social classifications or identities like race, class, gender, sexual orientation, and disability relate to one another when applied to a particular individual or set of people. Specifically, sex and gender are expected to affect the prevalence, etiology, presentation, concerns, treatment responses and life impacts of arthritis. Thus, including sex/gender considerations in health information designed for people with arthritis is essential.

Objective: The primary focus of this review is to determine if sex and gender are addressed in patient information resources while acknowledging that intersections between identities (including gender, class, ethnicity, etc.) affect gender information needs.

Methods: A subset of information resources was selected from arthritis societies (Canadian, British, and American). Information resources were included based on the following criteria: written in English, targeted to patients, and provided in various formats (text, video, etc.). A critical appraisal of sex and gender within an intersectional lens was performed using a structured item appraisal tool, the Sex/Gender and Intersectional Considerations in Patient/Consumer Health Information Appraisal Tool.

Results: Not more than half of the evaluated resources adequately considered sex/gender or intersectionality: 29% from the Canadian Arthritis Society, 22% from the American Arthritis Foundation, and 50% from the National Rheumatoid Arthritis Society discussed sex and/or gender factors and/or intersectional issues and how they can impact patients' experiences. Additionally, it was discovered that none of the patient resources discussed how arthritis patients might be affected by sex/gender and other intersectional identities including race, age, education, marginalization, and others. No website provided clear plans, goals, or strategies to track outcomes or reduce inequity by sex/gender, or intersectional issues at a personal or system level. The lack of gender-aware information was highlighted by the frequency with which sex and gender terms were inaccurately attributed, and the lack of description for how they are linked to differences in treatment responses, risks, or prognosis.

Conclusion: The information resources provided by the three major arthritis societies were mostly sex/gender blind and rarely addressed intersectionality. Although it may be challenging to address the range of these factors that affect individual patients, more effort to consider sex/gender and intersectional identities during resource development is needed.

Keywords

Health information needs, arthritis, structured review, sex, gender, knowledge translation.

Introduction

Arthritis is a group of conditions that affect the joints and other tissues. It impairs quality of life, causes pain, and limits mobility (National Institute of Arthritis and Musculoskeletal Diseases, 2022). Arthritis is a chronic condition affecting 1 in 5 Canadians (Canadian Arthritis Society, n.d.). In the US, 1 in 4 adults is diagnosed with arthritis, one in four females and one in five males (National Center for Chronic Disease Prevention and Health Promotion, 2021). Around 10 million people in the UK have arthritis (National Health Information Services, n.d.). The estimated annual cost of arthritis in terms of medical expenses and missed income is $303.5 billion in the US (Chronic Disease Prevention and Health Promotion, 2021). Arthritis conditions can be grouped into two categories: osteoarthritis and inflammatory arthritis. Osteoarthritis is the most common type of arthritis. Inflammatory arthritis includes rheumatoid arthritis, psoriatic arthritis, juvenile arthritis, and gout.

Intersectionality is how social classifications or identities like race, class, gender, sexual orientation, and disability relate to one another when they are applied to a particular individual or set of people (Corus & Saatcioglu, 2015). The primary focus of this review is to determine if sex and gender are addressed in patient information resources while acknowledging how intersectional identities affect gender identities, roles, and information needs. Sex differences are well-established in arthritis with women being more prone to developing arthritis than men (Favalli et al., 2018). While there is enough evidence to suggest sex differences in arthritis pathogenesis, research on how sex or gender differences affect health information needs and preferences is still limited. Collectively, the body of evidence appears to indicate that men and women with arthritis require different levels and types of support. According to research, men employ fewer and less varied coping mechanisms than women (Englbrecht et al., 2012;

Vervloesem et al., 2012). Currently, no standards or algorithms provide precise recommendations to address concerns about sex and gender differences in arthritis management (Maranini et al., 2022). Most of the current self-management strategies for arthritis have been created and evaluated focusing on women (Barlow et al., 2002). This is especially concerning if patients access online health information (information or opinion about a particular health condition, illness, injury or disability). This information can empower patients to make important health decisions. According to estimates, 8.7 million Canadians (35% of the population) used the Internet at home in 2005 to look up health-related information with women being more likely to seek health information (Statistics Canada, 2015).

Therefore, the objective of this paper is to better understand the online information resources that are available for consumers who have arthritis and to assess the degree to which they include considerations of differential needs based on sex, gender, and intersectional identities.

Methods

For this review, we accepted the definitions of Tannenbaum et al. for which sex refers to “biological, genetic and physiological processes that generally distinguish males and females” (Tannenbaum et al., 2019, p. 138) and gender refers to “the roles, relationships, relative power and other traits that societies generally ascribe to women, men and people of diverse gender identities” (Tannenbaum et al., 2019, p. 138). While sex-related processes may affect pharmacokinetics, immunological dysregulation, and pain processing with regards to arthritis (Tarannum et al., 2022), the effect of gender on arthritis can be explained in terms of how people perceive their health, how they seek medical attention, how they deal with or are managed by medical professionals, and how they cope (Vlassoff, 2007). Thus, in this paper, sex and gender will be distinguished.

Selection of resources

The following areas were evaluated from the arthritis society websites: pain, mental health/emotional well-being, daily living, relationships and families, and self-management. These areas were chosen to understand the differences in how arthritis is managed based on patients' sex or gender. The selection criteria were as follows: patient information, written in English, and is presented in text or video. Evaluating health information from Canada, the US, and the UK allows us to understand and compare the current state of health information globally.

The total number of patient modules we looked at was 29 across the three websites (14 on the Canadian website, nine on the American website, and six on the British website).

For the Canadian Arthritis Society, we looked at self-management, mental health, advocacy, arthritis and work, chronic pain and fatigue, symptoms and risks, and medical cannabis. Some topics had a composite set of modules and articles under their topics, so we looked at all components. These topics were self-management (the modules were daily living, staying active, eating well, arthritis advice, webinars and arthritis talks), mental health (the modules were well-being and self-assessment), chronic pain and fatigue (the modules were managing chronic pain, and overcoming fatigue), and symptoms and risks (the modules were online symptom checker and Arthritis risk factor assessment). To make this easier to read, each module has been colour-coded to match its results column (Table 2a to Table 2e). At the end of the table, the format of each topic and module we have looked at has been recorded.

For the American Arthritis Foundation, we looked at understanding pain, fatigue and sleep problems, emotional self-care, stress management, anxiety and depression, life hacks and tips, caregiving, dating & relationships, and family planning. For the National Rheumatoid Arthritis Society, we looked at RA symptoms, RA diagnosis and possible causes, living with RA, managing RA, self-management, and family planning.

Although information was available in other languages like Spanish and French, it is important to note that this evaluation combined the English and French resources. However, English patient resources were the main focus. French resources were partially evaluated as one of our team members could read some of the French resources in the Canadian Arthritis Society.

Critical Appraisal Tool

For the evaluation of the patient resources of the arthritis societies, the Appraisal of Inclusion of Intersectional Sex and Gender in Knowledge Translation (KT) Resources Checklist was used (figure 1). This tool allows us to evaluate the inclusion of intersectional identities in patients' health information resources. Additionally, the tool evaluates patients' health information by focusing on the state of literature/theoretical foundations and tailoring messages, resources, recommendations, or tools. This evaluation is based on 23 items ranging from questions about fundamental research to the content of health information resources used to assess whether patients' health information (whether text, video, articles, etc.) acknowledges intersectional sex and gender. It then assigns an overall rating of the adequacy of considering sex/gender KT tailoring and an overall rating of the adequacy of considering intersectional KT tailoring. Each item is evaluated using the y/p/n/na scale, where "Y" means yes, "P" means partially, "N" means no, and "n/a" means not applicable. To conduct this evaluation, two raters independently evaluated the information in each information resource. This was done by rating each module of the arthritis societies to determine to what extent sex and gender have been addressed using the 4-point scale (Y, P, N, n/a). If there is an explicit acknowledgment of sex/

gender (defining terms, sources of health inequity, plan for tracking outcomes by sex/gender and intersectional factors, differences in epidemiology and prognosis between intersectional factors and sex/gender subgroups, differences in treatment responses between sex/gender subgroups and intersectional factors) and intersectionality (age, race, education, poverty, disability, etc.), raters would choose “Y”. Whereas if there was a mention of only sex or not distinguishing between sex, gender, and non-binary terms, or not fully addressing how intersectional factors can be mediators/ covariates of the health issue, etc., then raters would mark this as “P”. Finally, if there was no acknowledgment of sex and/or gender, nor there are conclusions made about the key messages in terms of sex/gender, then raters would mark this as “N”. Raters then assign an overall rating of G (good), F (fair), P (poor), or X (No) for the adequacy of considering sex and gender KT tailoring and overall rating of the adequacy of considering intersectional KT tailoring based on the total number of “Ys”, “Ns”, and “Ps” given. If most of the items are “Ys”, then the overall adequacy of considering sex/gender and intersectional KT is “Good”. If some of the items (about half) are “Ys” or “Ps”, then the overall adequacy of considering sex/gender and intersectional KT is “Fair”. If less than half of the items are “Ys” or “Ps” with more “Ns”, then the overall adequacy of considering sex/gender and intersectional KT is “Poor”. Lastly, if there was no acknowledgment of sex/gender, then the overall adequacy of considering sex/gender and intersectional KT is “None/X”.

Arthritis Society	Topics and modules	URL
Canadian Arthritis Society	**Self-management** 1- daily living 2- staying active 3- eating well 4- arthritis advice 5- webinars and arthritis talks **Mental health** 6- well-being 7- self-assessment 8- advocacy 9- arthritis and work **Chronic pain and fatigue** 10- managing chronic pain 11- overcoming fatigue **Symptoms and risks** 12- online symptom checker 13- arthritis risk factor assessment 14- medical cannabis	https://arthritis.ca/support-education/online-learning/daily-living https://arthritis.ca/support-education/online-learning/staying-active https://arthritis.ca/support-education/online-learning/eating-well https://www.youtube.com/playlist?list=PLKAa4n_fskHKdzGdxdgqW0yQMPwGw-FFm https://arthritis.ca/support-education/arthritis-talks-webinars/past-webinars https://arthritis.ca/support-education/mental-health https://arthritis.ca/support-education/online-learning/mental-health-and-well-being https://arthritis.ca/support-education/support-resources/self-advocacy-guide https://arthritis.ca/support-education/arthritis-and-work/i-m-an-employee https://arthritis.ca/support-education/online-learning/managing-chronic-pain https://arthritis.ca/support-education/online-learning/overcoming-fatigue https://arthritis.ca/about-arthritis/signs-of-arthritis/symptom-checker/ https://arthritis.ca/about-arthritis/arthritis-risk-factors/arthritis-risk-factor-assessment https://arthritis.ca/treatment/medication/medical-cannabis
American Arthritis Foundation	15- Understanding pain	https://www.arthritis.org/health-wellness/detail?content=healthyliving

	16- Fatigue and sleep problems	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	17- Emotional self-care	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	18- Stress management	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	19- Anxiety and depression	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	20- Life hacks and tips	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	21- Caregiving	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	22- Dating & relationships	https://www.arthritis.org/health-wellness/detail?content=healthyliving
	23- Family planning	https://www.arthritis.org/health-wellness/detail?content=healthyliving
National Rheumatoid Arthritis Society	24- RA symptoms	https://nras.org.uk/information-support/information/ra-symptoms/
	25- RA diagnosis and possible causes	https://nras.org.uk/information-support/information/ra-diagnosis-and-possible-causes/
	26- Living with RA	https://nras.org.uk/information-support/information/living-with-ra/
	27- Managing RA	https://nras.org.uk/information-support/information/managing-your-ra/
	28- Self-management	https://nras.org.uk/resource-hub/?filter-search=&filter-persona%5B%5D=someone with-ra&filter-topic%5B%5D=self-management
	29- Family planning	https://nras.org.uk/resource-hub/?filter-search=&filter-persona%5B%5D=someone-with-ra&filter-topic%5B%5D=family-planning

Table 2. 29 selected arthritis patient resources and their URL links

Results

The results will be presented in three sections: Canadian Arthritis Society, National American Foundation, and National Rheumatoid Arthritis Society.

Intersectional Sex and Gender in Arthritis Societies

Generally, only eight patient modules (out of 29 patient resources) have checked “Did the developer acknowledge that there may be sources of health inequity due to sex/gender, or intersectional factors in?” but only 4 of those modules presented a plan that includes goals/strategies to reduce marginalization and measures the impact on inequity (figure 2). Additionally, about 66% of patient resources (19 out of the 29 patient modules) made evident efforts to engage intersectional viewpoints/ priorities in the development of the information resource/program or tool, about 21% (6 out of the 29 patient modules) made it clear that different sex/genders were included in knowledge users’ consultations or engagement, and 48% (14 out of the 29 patient modules) were patients/knowledge users included in the design process.

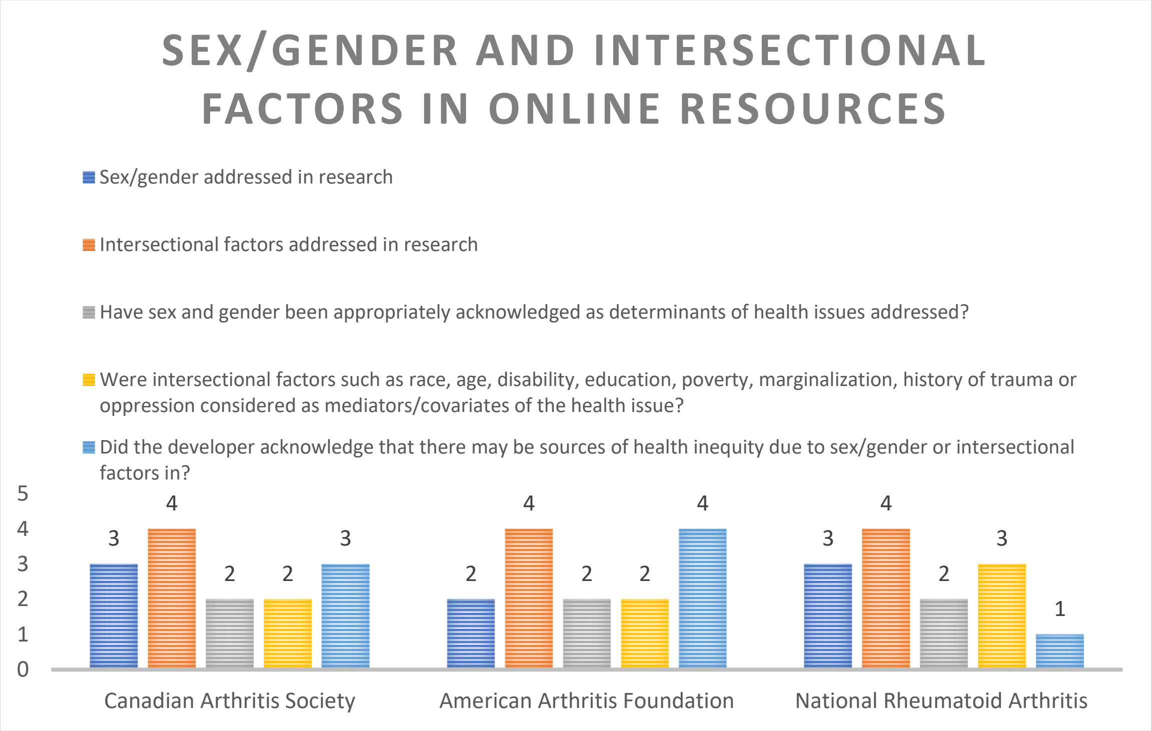

Figure 2. Sex/gender and intersectional factors in arthritis societies (number of options "yes" and "partially" to five questions).

Figure 2 shows the number of "Y- yes' and "P- partially' anytime sex and/or gender and intersectional factors were addressed in the patient resources (videos, articles, assessments) of the Canadian Arthritis Society, the American Arthritis Foundation, and the National Rheumatoid Arthritis Society. The figure also shows the number of times sex and gender have been appropriately acknowledged as determinants of the health issue.

The Canadian Arthritis Society

In the Canadian Arthritis Society, only 29% (2 out of 7 resources) of the patient resources acknowledged sex/gender. The overall ratings of the adequacy of considering sex/gender KT tailoring and the overall ratings of the adequacy of considering intersectional KT tailoring were both blind to sex and gender. Most modules/research articles did not sufficiently address how intersectional factors are integrated into the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, and language. Even when the information was related to managing pain, medication, or mental health, the mention of sex/gender and intersectional issues was either not stated clearly or partially mentioned (Table 2). Table 2 shows the various topics and modules we evaluated in the Canadian Arthritis Society. To to make this easier to read, each module has been colour-coded to match their results column. The format of each topic and module has been recorded at the end of the table. Only some of the modules discussed how sex and/or gender factors could impact patients' experiences, such as the arthritis risk assessment factor, the arthritis talks, and some research articles. In the webinars and arthritis talks module, there was a one-hour-long presentation that focused solely on arthritis and how it is experienced by women, the differences between sex and gender, and the high prevalence of osteoarthritis, rheumatoid arthritis, lupus, and juvenile arthritis in women compared to men. This presentation also included research articles that discussed issues concerning women with arthritis, such as family planning, pregnancy, childbirth, medications that they can take safely when pregnant, and supportive communities.

American Arthritis Foundation

The American Arthritis Foundation had a similar pattern of results, where only 22% of the patient resources (Two out of nine patient resource modules) addressed sex and/or gender, and 3 of the modules addressed intersectional issues as shown in (Table 3). The overall ratings of the adequacy of considering sex/gender KT tailoring and the overall ratings of the adequacy of considering intersectional KT tailoring Sex/gender and intersectional issues were addressed in family planning and emotional self-care modules only. For instance, “many people with RA experience swelling, changes in the shape of their hands and feet, weight gain or loss, and difficulty walking. These body changes can affect how a person views herself and her body" (American Arthritis Foundation, n.d.). Additionally, "Most women with lupus can get pregnant and have healthy children, but the disease may complicate the process. Pregnant women with the condition often need extra monitoring and care" (American Arthritis Foundation, n.d.), "a negative body image also increases vulnerability to emotional distress, anxiety, and depression. A 2019 study published in *Lupus* found that body image issues can worsen depressive symptoms in people with lupus" (American Arthritis Foundation, n.d.). However, non-binary sex and gender terms were not defined and used as factors for family planning for arthritis patients and caregivers. Additionally, intersectional factors such as race, age, disability, education, poverty, and marginalization were not clearly considered mediators for family planning (Table 3), despite these being important factors when it comes to family planning. Moreover, research has partially addressed how sex/gender affects patients' emotional self-care. The main focus was on women and body image, stating that "the Austrian study found that those with mild disease (mostly women) had more body worries than those whose spinal movement was severely limited" (American Arthritis Foundation, n.d.).

National Rheumatoid Arthritis Society

For the National Rheumatoid Arthritis Society, 50% of the patient resources (3 out of 6 patient resource modules) addressed sex/gender and 4 of the modules addressed intersectional issues partially as shown in Table 4. The overall ratings of the adequacy of considering sex/gender KT tailoring and the overall ratings of the adequacy of considering intersectional KT tailoring were none. The resource modules addressed intersectional issues: RA diagnosis, managing RA, living with RA, and family planning (table 4). The modules discussed mainly sex, referring to females and males; gender was not distinguished. However, sex/gender factors were partially mentioned in these modules, primarily stating that "age and gender can also make you more susceptible to getting RA. RA affects roughly 2-3 times more women than men and the average age of onset is around 40-50, though older in men. Still, it can develop at any age" (National Rheumatoid Arthritis Society, accessed on February 9, 2023). Intersectional issues were not clearly addressed, instead there was some focus on sources of disadvantages and risk factors for RA, "one of the biggest environmental factors in developing RA is smoking" (National Rheumatoid Arthritis Society, accessed on February 9, 2023).

Additionally, it was stated that "RA coming on after periods of stress or physical or mental trauma, or following an illness, and as previously mentioned, after giving birth" (National Rheumatoid Arthritis Society, accessed on February 9, 2023). Furthermore, in the module Living with RA, some topics clearly discussed the idea of sex/gender and its intersectionality with other factors such as emotions, pregnancy, relationships, and sexuality. Similarly, in the family planning module, there is information about RA and pregnancy, knowing that this information is likely more relevant to females: "RA is more common in females and often presents at an age when people are considering starting families. The management of RA before, during and after pregnancy, is an important topic" (National Rheumatoid Arthritis Society, accessed on February 9, 2023). There is also information available for parents on how to cope with children while having RA, including tips on how to hold the baby, personal stories shared by others, and baby clothes and accessories that do not add more pressure to the parent. Interestingly, this information did not specifically target one sex or gender; the website included pictures of females and males to avoid stereotypes regarding parenting. However, no clear use of sex or gender language was used in the module.

Discussion

This study demonstrated that patient resources distributed by arthritis societies lack sex/gender sensitivity and most of them are sex/gender blind. This pattern was similar to intersectional issues as we still lack clear language that links arthritis with intersectionality. Intersectional issues such as race, class, ethnicity, sexuality, and gender can shape patient's arthritis experiences (McIlvane et al., 2008). Men and women have different life experiences, needs, roles, and health issues that affect how they use information to manage arthritis. Information that is not gender aware cannot fully meet the needs of either men or women. Ideally, health information should be gender transformative, providing not only information tailored to men's and women's needs but also ameliorating the gender-specific barriers that people experience.

Some aspects of intersectionality were better addressed. There was more research/information on the connection between arthritis and age, risk factors, emotional issues, support, and body image. However, this information was partially addressed even then, meaning that only some modules have discussed these issues. While some intersectional issues were addressed, it was a concern that marginalization, sources of disadvantages, and the nature of intersectional disadvantage were not adequately addressed. None of the modules examined in this study addressed intersectional identities such as race, disability, education, poverty, culture, history of trauma, or oppression as mediators/covariates of the health issue. This can further contribute to the inequity issues that many patients from certain ethnic backgrounds, racial identities, economic statuses, education and health literacy levels face in accessing and utilizing health resources (Public Health Agency of Canada, 2018). In this way, health information can perpetuate, rather than alleviate health disparities. Since marginalization may be associated with lower health literacy, lack of access to care, and poorer health outcomes, health literacy and equity should be considered in the co-design of health information. Prior studies examining health information websites about fibromyalgia revealed that health literacy was poorly addressed (Daraz et al., 2011). This can further compound intersectional inequity since marginalized populations are more likely to have health literacy limitations. Studies on rheumatoid arthritis and systemic lupus erythematosus have shown that even within the same nation, different ethnic groups have varied views on the rheumatic disease and its treatment (Palominos et al., 2018).

These intersectional identities are crucial in shaping patients' unique experiences and barriers. It is evident that arthritis prevalence varies among ethnicities, for instance, RA primarily affects Caucasians (Yip & Navarro-Millan, 2021). In the bulk of epidemiologic research, trials, and evaluations of RA patients to date, only Caucasian patients or those without racial information were included (Yip & Navarro-Millan, 2021). Therefore, limitations in the primary research conducted are partially responsible for the lack of information that is presented to arthritis patients. So, how can information be representative of arthritis patients if there are almost no signs of inclusivity in research? What accommodations are available to ensure the inclusion of diverse populations?

There are some barriers to implementing sex/gender considerations effectively. First, evidence shows that the concepts of sex and gender, how they are related, and how they affect health treatments are generally poorly understood (Doull et al., 2014). The Key Health Inequalities in Canada report, 2018 states that "the disproportionate burden of arthritis of certain groups is driven by a complex system of social and structural drivers of health that remain to be fully explored and understood" (Public Health Agency of Canada, 2018, n.d.). Other barriers include insufficient access to data that is subdivided by gender, problems with data quality and reporting, difficulties measuring and analyzing gender, and a lack of methodological direction (Doull et al., 2014). A person may encounter difficulties within the healthcare system as a result of discrimination based on sexual orientation, gender identity, or gender expression in addition to a greater prevalence of arthritis for particular populations (Canadian Arthritis Society, n.d.).

Health information is supposed to represent different sexes, genders, ethnicities, cultures, ages, literacy levels, income statuses, and health conditions so that patients feel included, and their needs are addressed. These are seen as important factors in examining how different forms of prejudice interact and reinforce one another. Although the British Rheumatoid Arthritis Society had better patient/knowledge users' inclusion in their design process (about 4 out of 6 total patient resource topics considered patient stories), the overall numbers show that arthritis patient resources are not only lacking the inclusion of sex/gender and intersectional identities but also patient engagement during the development process of these resources. Higher patient engagement along with having the information, skills, and confidence to actively participate in their [patients] care are associated with improved health outcomes (Centers for Disease Control and Prevention, 2021). Patients who are actively involved in their care are better equipped to evaluate their options (WHO, 2016). Additionally, resources may be used more effectively if they align with patient priorities, which is necessary for the success of health systems worldwide (WHO, 2016). Patient engagement is part of the solution but should be supplemented by strategies to access hard-to-reach, marginalized people, and to sample larger populations to examine generalizability and subgroup differences.

Improvements in health resources could benefit from considering literacy and intersectional equity during the co-design process. Having a checklist appraisal tool, like the one used in this study, during the design process might help in future patient information designs. Health information resources should be pilot-tested and assessed by patients first to confirm their clarity, usefulness, and relevance. The bottom line is that knowledge users must be actively engaged throughout the designing and pilot testing of arthritis health information resources. This would not only ensure the effectiveness of information and empower patients to take active roles in their care, resulting in better health outcomes.

Summary and Limitations

Summary

While there is overwhelming evidence that sex and/or gender and intersectional factors are important determinants of health for arthritis patients, health resources still do not adequately fulfil gender needs. If this is not acknowledged in future research and development, it exacerbates health inequity, especially for those who are already facing marginalization and inequity.

Limitations

There are several limitations in this paper. Firstly, there is limited research on integrating sex and gender in health information so foundational knowledge and best practices are not well defined. Content can be more latent than obvious, affecting the interpretation of how well concepts were addressed. Secondly, we evaluated a subset of available resources which may not represent usual or best practice. Since we only assessed English resources, this may have limited our results. Thus, it does not represent all available information although the societies studied are well-supported compared to many other countries. Therefore, they should have had the resources to produce high-quality resources.

Figure 1. Appraisal of inclusion of intersectional sex and gender in KT resources checklist

Inclusion of Sex/ Gender and Intersectional Considerations in Patient/Consumer Health Information				
State of Literature/Theoretical Foundations	Y	P	N	n/a
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)				
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)				
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?				
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?				
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).				
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).				
Tailoring of messages, resources, recommendations or tools.				
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed				
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?				
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?				
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in the information provided, or evident in messages, resources, recommendations or tool adaptations?				
Are epidemiological differences (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in the information provided, or evident in messages, resources, recommendations or tool adaptations?				
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?				
Are differences in prognosis been between important intersectional factors /subgroups discussed in the information provided, or evident in tool adaptations?? Messages, resources, recommendations or tool adaptations?				

Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?				
Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?				
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?				
A plan for tracking outcomes by sex/gender is stated				
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.				
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?				
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity				
Were patients/knowledge users included in the design process?				
Was it clear that different sexes/genders were included in knowledge users' consultations or engagement?				
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?				
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	G	F	P	X
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language,				
Comments:				

Y= yes N=No, P= Partially; Make notes of errors, specific gaps and potential areas needing improvements as you evaluate nuanced evidenced-based tailoring based on sex/gender and other intersectional factors.

Adequacy of Tailoring:

G (GOOD to EXCELLENT) = excellent tailoring based on sex/gender and intersectional differences based on research findings with clear evidence for differential or transformative recommendations

F (FAIR)= Some acknowledgement of sex/gender or intersectional differences, with limited tailoring of evidence/health resources

P(POOR) = Minimal attention to sex/gender or other intersectional factors considered or superficially, and no tailoring evident.

X (NO)= Research is sex/gender blind or does not address intersectionality

Table 2a. Types of modules available under self-management topic on the Canadian Arthritis Society

Self-management					
Appraisal Checklist	**Daily living**	**Staying active**	**Eating well**	**Arthritis advice**	**Webinars and arthritis talks**
Is there a clear circulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device, etc.)	P	N	N	P	P
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N	N	Y	N
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	N	N	P	P
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N	N	Y	N
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N	N	P	P
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N	N	Y	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	N	N	N	P
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	N	N	Y	P

Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	N	N	N	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N	P	P
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N	P	N
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N	P	N
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N	N	Y	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N	N	P	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N	N	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N	N	Y	P
A plan for tracking outcomes by sex/gender is stated	N	N	N	P	N

A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	N	N	P	N
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N	N	P	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	N	N	N	Y	N
Were patients/knowledge users included in the design process?	N	P	N	Y	Y
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	P	N	Y	Y
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	N	P	N	Y	P
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**X**	**X**	**P**	**P**
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**	**X**	**P**	**X**
Format type	**T**	**T**	**T**	**V**	**V**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 2b. Continued types of topics available on the Canadian Arthritis Society.

Appraisal Checklist	**Advocacy**	**Arthritis and work**	**Medical cannabis**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the	N	N	N

health topic (health condition, treatment program, or device etc.)			
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N	N
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	N	N
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N	N
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N	N
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	N	N
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	N	N
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of	N	N	N

trauma or oppression considered as mediators/covariates of the health issue?			
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N	N

Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N	N
A plan for tracking outcomes by sex/gender is stated	N	N	N
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	N	N
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	N	N	N
Were patients/knowledge users included in the design process?	N	Y	N
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	P	N
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	N	P	N
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**X**	**X**

Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**	**X**
Format type	**T**	**T**	**T**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 2c. Types of modules available under the mental health topic on the Canadian Arthritis Society

Mental Health		
Appraisal Checklist	**well-being**	**self-assessment**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	P	P
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	N
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N

Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	N
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	N
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	P	N
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) between important	N	N

intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?		
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N
A plan for tracking outcomes by sex/gender is stated	N	N

A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	P
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	Y	N
Were patients/knowledge users included in the design process?	P	N
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	N
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	P	Y
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**X**
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with	**X**	**X**

appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language		
Format type	**T**	**T/A**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 2d. Continued types of topics available on the Canadian Arthritis Society

Appraisal Checklist	**Managing chronic pain**	**Overcoming fatigue**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	N
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N

Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	N
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	N
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources,	N	N

recommendations or tool adaptations?		
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N
A plan for tracking outcomes by sex/gender is stated	N	N
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	N

Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	N	N
Were patients/knowledge users included in the design process?	N	N
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	N
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	N	N
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**X**
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**

Format type	**T**	**T**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 2e. Types of modules available under the symptoms and risks topic on the Canadian Arthritis Society

Symptoms and risks		
Appraisal Checklist	**Online symptom checker**	**Arthritis risk factor assessment**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	Y
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	Y
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	N
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N

Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	P
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	Y
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	N	P
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	P
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	P
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or	N	N

evident in messages, resources, recommendations or tool adaptations?		
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	P
A plan for tracking outcomes by sex/gender is stated	N	P
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	Y
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	N	N

Were patients/knowledge users included in the design process?	N	P
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	N
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	N	Y
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**P**
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**
Format type	**T/A**	**T/A**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 3. Results of the sex/gender appraisal tool conducted on the American Arthritis Foundation.

	Resource modules								
Appraisal checklist	**Understanding pain**	**Fatigue**	**Emotional self-care**	Stress management	**Anxiety & depression**	**Life hacks**	**caregiving**	**Dating**	**Family planning**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	N	P	N	N	N	N	N	P
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	Y	Y	N	N	N	N	N	Y
Were the theories or issues that determine how sex/gender affect the	P	N	P	N	N	N	N	N	N

health issue stated clearly and accurately?									
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	Y	Y	P	Y	N	N	Y	Y
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender relations, socially constructed roles).	N	N	N	N	N	N	N	N	N
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N	N	N	N	N	N	N	P
Are non-binary sex	N	N	N	N	N	N	N	N	N

and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed									
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	P	N	N	N	N	N	N	N	Y
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	P	N	N	N	P	N	N	N	N
Are differences in epidemiology (prevalence, incidence, risk etc.) been	N	N	P	N	N	N	N	N	N

between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?									
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	N	N	N	N	N	N	Y
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages,	N	N	N	N	N	N	N	N	N

resources, recommendations or tool adaptations?									
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? Messages, resources, recommendations or tool adaptations?	N	N	P	P	P	P	N	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N	N	N	N	N	N	N	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented	N	N	N	N	P	N	N	N	

discussed for relevant intersectional factors?									
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N	N	N	N	N	N	N	Y
A plan for tracking outcomes by sex/gender is stated	N	N	N	N	N	N	N	N	N
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	P	N	N	N	N	N	N	N
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N	P	P	N	N	P	N	P
The tool or implementation plan includes goals/strategies to reduce marginalization and	N	N	P	N	P	N	N	N	

measures the impact on inequity									
Were patients/knowledge users included in the design process?	N	N	P	N	P	Y	Y	Y	N
Was it clear that different sex/genders were included in knowledge users' consultations or engagement?	N	N	N	N	N	N	N	N	N
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	Y	Y	Y	P	Y	P	Y	P	Y
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformati	**X**	**X**	**P**	**X**	**X**	**X**	**X**	**X**	**X**

ve are included in the KT plan									
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**
Resource format	**T & V**	**T & V**	**T & V**	**T**	**T**	**T & V**	**T**	**T**	**T**

T= Text, **V**=Video, **T/A**= Text/assessment

Table 4. Results of the sex/gender appraisal conducted on the National Rheumatoid Arthritis Society.

	Resource Topic					
	RA symptoms	**RA diagnosis**	**Living with RA**	**Managing RA**	**Self-management**	**Family planning**
Is there a clear articulation of the extent to which sex/gender have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	Y	Y	N	N	Y
Is there a clear articulation of the extent to which intersectional issues have been addressed in research on the health topic (health condition, treatment program, or device etc.)	N	P	P	Y	N	P
Were the theories or issues that determine how sex/gender affect the health issue stated clearly and accurately?	N	P	Y	N	N	Y
Were the theories or issues that determine how key intersectional factors affect the health issue stated clearly and accurately?	N	N	Y	Y	N	N
Was sex/ gender considered at an individual and organizational/system and/or societal level (e.g., gender	N	N	Y	N	N	Y

relations, socially constructed roles).						
Were individual and organizational/system and/or societal level intersectional factors considered (e.g., gender relations, socially constructed roles).	N	N	N	N	N	N
Are non-binary sex and gender terms defined and used clearly/appropriately acknowledged as determinants of health issues addressed	N	Y	Y	N	N	N
Have sex and gender been appropriately acknowledged as determinants of health issues addressed?	N	P	N	N	N	P
Were intersectional factors such as race, age, disability, education, poverty, marginalization, history of trauma or oppression considered as mediators/covariates of the health issue?	N	Y	P	N	N	P
Are differences in epidemiology (prevalence, incidence, risk etc.) been between sex/gender subgroups discussed in information provided, or evident in messages, resources,	N	P	Y	N	N	N

recommendations or tool adaptations?						
Are differences in epidemiology (prevalence, incidence, risk etc.) between important intersectional factors /subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	P	N	N	N
Are differences in prognosis been between sex/gender subgroups discussed in information provided, or evident in messages, resources, recommendations or tool adaptations?	N	N	Y	N	N	P
Are differences in prognosis been between important intersectional factors /subgroups discussed in information provided, or evident in tool adaptations?? messages, resources, recommendations or tool adaptations?	N	N	N	N	P	N
Were disaggregated treatment effect sizes presented or differences in treatment responses presented/discussed for relevant sex/gender subgroups?	N	N	N	N	N	N

Were disaggregated treatment effect sizes presented or differences in treatment responses presented discussed for relevant intersectional factors?	N	N	N	N	N	N
Were conclusions stated for the key messages/facts in terms of relevant sex/genders?	N	N	P	N	N	N
A plan for tracking outcomes by sex/gender is stated	N	N	P	P	N	N
A plan for tracking outcomes considering intersectional issues at a personal or system level is stated.	N	N	N	N	N	N
Did the developer acknowledge that there may be sources of health inequity due to sex/gender or intersectional factors in?	N	N	N	N	N	N
The tool or implementation plan includes goals/strategies to reduce marginalization and measures the impact on inequity	N	N	N	N	N	N
Were patients/knowledge users included in the design process?	N	N	Y	N	Y	Y
Was it clear that different sex/genders were included in	N	N	Y	N	Y	N

knowledge users' consultations or engagement?						
Was it clear what efforts were made to engage intersectional viewpoints/ priorities in development of the information resource/program or tool?	N	N	Y		N	P
Overall rating of the adequacy of considering sex/gender KT tailoring? Tailoring of KT strategies should be gender sensitive or gender transformative are included in the KT plan	**X**	**X**	**P**	**X**	**X**	**P**
Overall rating of the adequacy of considering intersectional KT tailoring? Intersectional issues are integrated in the KT plan with appropriate tailoring e.g., culture, literacy, preferences, trust, accessibility, language	**X**	**X**	**P**	**X**	**X**	**X**
Resource format	**T**	**T**	**T**	**T**	**T & V**	**T**

T= Text, **V**=Video, **T/A**= Text/assessment

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Chapter 3: Sex and Gender Differences in Health information Needs for Arthritis Patients

Sex and Gender Differences in Health information Needs for Arthritis Patients.

Abstract

Background: The onset and progression of both degenerative and inflammatory arthritis can be affected by sex and gender. Both age and gender can affect people's decisions about their health. Men, for instance, may employ fewer, and less varied coping mechanisms than women.

Objectives: To focus on the health information needs of arthritis patients and investigate the experiences of arthritis patients from various sexes and genders, as well as how they think their sex and/or gender might influence their health information needs. It also sought to determine whether they would benefit from a health information intervention, and if so, what kind of intervention they would like and how it should be delivered.

Methods: This study followed a qualitative approach, interpretive description, where 13 participants were recruited from Roth McFarlane Hand & Upper Limb Centre at St. Joseph's Health Centre. The inclusion criteria were patients with confirmed arthritis aged 18-75, who could speak and understand English, and could consent to participate. Thematic analysis was conducted.

Results: Ten overarching themes were identified with various subthemes across 13 transcripts. These themes were: positive therapeutical alliance with physicians, need for online resources, men are more reluctant to seek help, systemic challenges to accessing healthcare, patients' health information needs, perceived facilitators, level of satisfaction with the information or services provided by physicians, gender affects information needs but not the ability to establish a therapeutic alliance, dire need for more access to arthritis information programs, and mixed understanding about the meaning of sex/gender.

Conclusion: The demands of patients for health information are influenced by their gender and/or sexual orientation. Given patients’ challenges while accessing health information, it is critical to adopt a patient-centred strategy that focuses on their needs and allows them to express their opinions.

Key words

Sex and gender, health information needs, thematic analysis, interpretive description, arthritis, online resources.

Introduction

Arthritis is joint inflammation (National Institute of Arthritis and Musculoskeletal and Skin condition, 2022). Arthritis comes in various forms; each with a unique etiology and course of treatment. Joint discomfort, redness, heat, and swelling are all typical signs of arthritis. Although arthritis is more prevalent in older adults, it can affect anyone at any age, including men, women, and children. Studies in the literature reveal that females were more likely than males to develop osteoarthritis, particularly after age 50 (rising sharply around menopause), and to feel restraining pain (Tschon et al., 2021). Therefore, there is a need for better knowledge of patients' needs because the burden of arthritis continues to rise with the aging of the population.

Both sex and gender can affect the onset and development of rheumatic and autoimmune diseases. In fact, males and females react differently to both internal and exterior antigens from a hormonal and genetic standpoint (Voskuhl, 2011). Compared to men with arthritis or women with other chronic conditions, women with arthritis frequently report higher levels of anxiety, feelings of sadness, disability, and difficulty sleeping (Canadian Arthritis Society, n.d.). Dr. Angela How, a rheumatologist in Burnaby, BC, comments, "I think women may tend to have more disability because they do a lot at home and at work" (Canadian Arthritis Society, n.d.). "I think we sometimes forget about how different women's roles are. There is employment, but there is also home life, raising children, and recreational activities” (Canadian Arthritis Society, n.d.). Compared to men, women spend almost an hour longer a day on routine child care responsibilities (Statistics Canada, 2017). Caregiving for an adult family member or friend was three times as common among women than among men (Statistics Canada, 2017).

In addition, sex, gender, and culture play a significant role in how patients experience arthritis (Tschon et al., 2021). In some cultures, males are expected to be strong to be “masculine”, and females are expected to be sensitive and more expressive of their pain to be “feminine” (Flurey et al., 2018). Thus, these stereotypes can affect one’s willingness to seek help (Flurey et al., 2018). As a result, males may choose not to talk to healthcare professionals about their pain (Flurey et al., 2018). “Men with rheumatoid arthritis (RA) report a challenge to their masculine identity due to the impact of RA. They therefore employ strategies to hide their RA in public to maintain their masculine image” (Flurey et al., 2017, p. 331). For women, role expectations can work differently in that some women have reported being dismissed because their concerns are not considered valid by professionals (Samulowitz et al., 2018).

The onset and progression of both degenerative and inflammatory arthritis can be affected by sex and gender (Maranini et al., 2022) and both age and gender can affect people’s decisions about their health (Xie et al. 2014). Men, for instance, may employ fewer, and less varied coping mechanisms than women (Englbrecht et al., 2012). While the causes of these variations are not yet fully understood, it is essential to comprehend how health information needs differ in arthritis patients depending on their sex and/or gender, to provide improved more personalized health Information in the future. The current study explored the experiences of arthritis patients and their health information needs. The goal is to understand how a patient’s sex and/or gender can influence their arthritis health information needs.

Methods

Sex vs. Gender

Sex is a biological construct and gender is a social construct. Gender refers to “socially constructed roles, behaviours, expressions and identities of girls, women, boys, men, and gender diverse people” (Canadian Institutes of Health Research, 2023, para. 2).

Health Information Needs

Information about a health condition or impairment. It involves information or opinions regarding injuries, disabilities, or illnesses (Australian Government, n.d.).

Interpretive Description

This study followed a qualitative approach, interpretive description. Interpretive description provides a practical and theoretically flexible method for analyzing qualitative data in the context of research on medical education (Burdine et al., 2020). Since interpretive description can address challenging experiential concerns and produce valuable results, it is a suitable methodological alternative for research on medical education (Burdine et al. 2020). It permits the expanding our understanding of the educational experience without compromising the methodological integrity of long-standing qualitative methods (Burdine et al., 2020).

Data collection methods and instruments

Patients with confirmed arthritis (any type), aged 18 to 75, at the Roth McFarlane Hand & Upper Limb Centre (HULC) of St. Joseph’s Hospital in London, Ontario, Canada, were invited to participate in individual interviews. Patients with arthritis were recruited using purposeful sampling. This technique ensures the recruitment of participants who can provide in-depth and detailed information about the topic. Participants in the study were selected based on the information available in the medical charts provided by the research team at the clinic. The recruitment process was stopped once data saturation (where new information or insights stop emerging from additional interviews) was achieved.

The interviews followed a semi-structured guide, meaning that there is a guide the first author will follow, but specific questions and prompts may come up. This study followed a qualitative approach to interpretive description. A topic guide was created based on literature review and consultations with the research team (see Appendix). We assessed the information that patients are looking for, how it is delivered, their interactions with healthcare professionals, their satisfaction with the information received, perceived benefits and difficulties, and the available resources. To develop interview questions that appropriately address our objective, we reviewed questions from previous research studies that addressed the information needs of arthritis patients. We then modified and added questions to assess the information needs of patients and determine whether sex/gender affected the information needs/experiences.

The first author conducted these interviews. The interviews were audio recorded, transcribed verbatim and lasted between 10 and 30 minutes. Ethics approval was granted by the Health Sciences Research Ethics Board (reference 2022-121896-74465). Written informed consent was obtained in person from each participant at HULC. No participation incentives were provided.

Demographic information was drawn from a demographics form collected during the interview (Sex, gender, age, marital status, highest level of education, employment status, and citizenship).

Inclusion and Exclusion Criteria

The inclusion criteria were patients with confirmed arthritis aged 18-75, who can speak and understand English and can consent to participate. Exclusion criteria were patients under the age of 18, who cannot speak or understand English, and have no confirmed arthritis.

Demographic information

Table 1 shows the demographic information of the study participants. The average age for participants was 61 years. In total, 13 participants completed interviews, 46% were males (n=6) and 53% were females (n=7).

Data Analysis

Two researchers analyzed thirteen anonymized transcripts. First, each anonymized transcript was read, re-read, and coded. Coding was done manually to enable us to examine data at the micro-level. Then, overarching themes were identified using thematic analysis. Thematic analysis is “a method for identifying, analyzing and reporting patterns (themes) within data” (Braun & Clarke, 2006, p. 79). Quotes that best exemplified themes were colour-coded based on interview questions. This allows us to focus on and extract the needs of patients and determine their health information preferences.

As part of the rigor of coding, a calibration was performed after coding two interviews. The researchers met to discuss the themes after coding two transcripts to ensure that the results were consistent. Meetings were consistent after coding 3 or 4 transcripts to address any concerns and ensure coherence in results.

Table 1. Participant demographics (n=13)

pseudonym	**Age, years**	**Sex**	**gender**	**Marital status**	**Employment status**	**Highest level of education**	**Citizenship/ ethnicity**
Laura	61	F	Woman	Married	Teacher	University (Masters)	Canadian
Sally	48	F	Woman	Common law	Team lead (warehouse)	High school	Canadian
John	62	M	Man	Divorced	Sales manager	University	Canadian
Nora	58	F	woman	Married	No employment	Community college	Canadian
Sarah	64	F	woman	Married	Retired	University	Canadian
Sid	55	M	Man	Married	Self-employed	2 years of college	Canadian
Amir	71	M	Man	Common law	Retired	High school	Canadian
Liam	70	M	Man	Married	Retired	University	Canadian
Susan	68	F	Woman	Divorced	Retired	University	Canadian
Ryder	50	M	Man	Married	Custodian	College	Canadian
Gina	70	F	Woman	Divorced	Retired	High school	Canadian
Layla	59	F	Woman	Common law	Personal manager	Some college	Canadian
Tom	58	M	Man	Single	Janitor	High school	Canadian

F=Female, M=Male

Results

Important themes have been derived from patients' interviews. These themes ranged from challenges to accessing health information to preferences and sources of health information.

1. Positive therapeutical alliance with physicians

The majority of participants, 61% (8 out of 13) of respondents, mentioned that they feel comfortable around healthcare providers.

"I: Tell me about your experience with your family doctor and your specialist, how has it been?

> *M: It's been great since I've moved here [London]. The family doctor has been good. He's been very willing to send you out to specialists, see a surgeon. The doctors at the hospital there at (St. Joseph's Hospital) have been fantastic. They've been very informative, very helpful. The one that I had when I was living back in (city), they were a little more reluctant to want to do anything as far as work on my shoulder. So that's why I'm saying that they've been exceptional"* (Man, 50).

However, participants' individual positive experiences differed. For instance, some participants have stated that their family doctors were helpful and approachable, while others have found that specialists were not.

> *"Specialist not really, no. The family doctor just does preliminary and then refers you to a specialist. So, I'm going to say, yeah, I'm pretty comfortable with what I've been receiving to this point"* (Woman, 70).

One participant felt that they were rushed because physicians have limited time to spend with patients. As a result, this participant felt uncomfortable to seek professional assistance when they needed help.

> *"Sometimes I find the doctors have a limited time with patients. That it's either a nurse practitioner or another medical person that makes a recommendation, and I'm presuming because he's your doctor, he has to give the recommendation, so sometimes I do feel uncomfortable talking about things or asking them questions. I just sometimes feel rushed"* (Woman, 64).

2. Need for online resources

Most of the participants, 69% (9 out of 13) of respondents, have indicated that they used online resources, such as Google and YouTube, to learn more about arthritis and the kinds of support available to them. Participants have sought online resources because they are more convenient and more accessible since healthcare providers are not always available or do not have time to answer patients' questions.

> *"F: Usually fairly quick. The Internet has been a massive help in terms of understanding what a shoulder replacement surgery actually is, and understanding what the implications of that are, and helping me to ask the right questions when I do get into a doctor's office"* (Woman, 68).

However, despite online resources being easy to access for most participants, 31% of respondents (4 out of 13 participants) did not find them to be helpful for a variety of reasons. These reasons include technological challenges, literacy challenges, inaccessible online information, and reliance on healthcare providers' input for accurate health information.

> *".... but* it can be sort of scattered information that is just confusing" (woman, 64)
>
> *"Sometimes when you go on the website you don't always know if the information is accurate"* (Woman, 59).

> *“The internet is a valuable tool. If it's not coordinated properly* or they're organized, *I don't know that every individual could have some sort of access because not all people have computers either*” (Woman, 70).

3. Men are more reluctant to seek help

Some participants (both men and women), 31% (4 out of 13) of respondents, have explained that men are less comfortable with demanding their medical needs or opening up. Some women have found that men are direct and know what they want, whereas women are more nervous and non-assertive.

> “*I think men deal with healthcare differently. Just personality differences. Men and most men I know are generally more together level-headed, direct, know exactly what they want and go for it, whereas my female friends are more nervous about things. They're not as serious, I would say, not as assertive. More passive females generally, now that there's always the exception”* (Woman, 59).
>
> *“I think women seek out a little bit more emotional support, men, I don’t think, we usually don't get into any emotional issues too much and keep that inside from what I've known. They're not openly, they don't get super excited and all happy and lovely, no, they're pretty considerate”* (Man, 55).
>
> *“Maybe I don't know. Maybe it's just me. It just seems like males tend to hide it more, suck it up and whereas it seems like women they'll open up more to females, right?”* (Man, 71).

women have reported that their partners are less likely to seek help from healthcare providers even if they need it. This is because men are more stubborn and prefer not to be seen as weak.

> *"I think when it comes to males and them having anything wrong with them, that they're pretty stubborn about reaching out and getting help or even trying to find out what is wrong with them. Personally, I think my husband has osteoarthritis, but he's not doing anything about it, he's just 'Ohh, it's because we're old and it's because we work hard'. But I still think that's where his pain is coming from because he describes a lot of it, the same as and feelings that I've had with my shoulder and my osteoarthritis"* (Woman, 48).

As a result, 23% of participants (3 out of 13) have felt that women and men are treated differently in healthcare. Men have noticed that their spouses were not receiving the same information as them.

> *"Yeah, my partner, she's got a couple of issues herself, she doesn't seem to be getting a lot of information or any help in dealing with it or managing it. So I think I'm actually a little luckier that way"* (Man, 55).
>
> *"I would say treated differently, I wouldn't say negatively but or positively. But yeah, I would say there's a difference in the way females and males are treated, yes"* (Man, 62).

4. Systemic challenges to accessing healthcare

In this theme, several challenges have emerged based on participants' responses. These challenges were: impacted by COVID-19 (coronavirus disease), lack of community resources in smaller communities and dependence on online resources, long wait times and slow processes, the importance of distance, age discrimination and societal stigmatization, lack of resources/funding, and other issues such as the age of physician, rushed by physician's time, and problems with accessing technology.

a. Impacted by COVID-19

About 23% of respondents (3 out of 13) reported that COVID-19 affected their healthcare services. Participants described how the limited access to services they experienced during COVID-19 impacted their ability to access health information.

"Now the pandemic slowing down a bit, getting a little more access than that and it kind of put me off when I had a doctor before one that's operated on my shoulder who I never ever met and it was all phone, phone interviews and stuff and "well, go do this, go do that, that," and to me that was pretty hard sight unseen, no examinations, no nothing, right. As it stands now like I said, we're slowing down, I seem to have better access and information from the doctors" (Man, 62).

"The beginning of the pandemic, I was a little shy about going to or got shy, but I felt that I could try and work through it myself, cause I'd worked through a lot of things myself prior" (Woman, 70).

b. Lack of community resources in smaller communities and dependence on online resources

Thirty-one percent of participants (4 out of 13) had limited access to resources due to their location, especially those in smaller and remote communities. As a result of this, these participants depended on online resources for health information.

> *"Well, I think we'd all prefer it in our town. I know that's not always possible a lot of things happen in the bigger cities, London, Toronto, Ottawa, like the bigger places rather than a small community like*

> *(community). I just can't imagine they'd bring anything like that to a small community. And that's where actually the Webex or the Zoom is good in that case."* (Woman, 59).

Those participants mentioned that their healthcare providers might have not directed them to support groups or other resources because of their location. Location was a big hurdle in accessing services or receiving support.

> *"And I've never had any of my (doctor's name) or (doctor's name) even say 'Are you interested in talking to someone in a support group or something like that'. So I'm going to presume because I'm in a rural community"* (Man, 71).

c. Long wait times and slow process

About half of participants, 46% (6 out of 13) of respondents, discussed that long wait times to receive services and/or referrals or undergo surgical procedures have negatively affected their health.

> *"Even in the afternoons, that's busier. The last time I was in there, it was three hours and a half I waited for my appointment, but I do find that the better doctors they're more busy. Because they don't give them enough time to have the conversation, they're booking two patients at a time. They're trying to jam as many patients in as they can, and I get that. I mean, I waited a long time for my appointment. I got a piece of paper mailed to me 'Here's when your appointment is'. That's how long these things take, right? So I get it you know the whole system, but it puts the doctor, any good doctor behind"* (Woman, 70).

In addition, participant’s mental health was also affected, resulting in confusion, frustration, and uncertainty.

> *“So, I really don't know what to expect. I guess I've had this shoulder problem for probably 25 years already and just been taking Tylenol for arthritis and pain meds. And it just keeps gradually getting worse and worse and worse”* (Woman, 68).

d. Distance

Forty-six percent of participants (6 out of 13 participants) emphasized the value of having healthcare programmes and services in their local communities. When asked, "If there is a new arthritis health information programme, do you prefer it to be at the hospital or your hometown?" Forty-six percent of participants said that having such a program close to their hometown is significant. Participants indicated that commuting to bigger cities can be challenging due to parking, weather, time, and other factors.

> *“If it was anywhere closer it would be beneficial just because it is a bit of you know, one-hour drive to London and an hour drive back. So if it was any closer it would certainly help”* (woman, 70).
>
> *“I: If there is a new arthritis information program, where do you think this should be delivered at the hospital or elsewhere in your hometown?*
> *M: It is helpful elsewhere. Just gonna find a hospital is hard to get into, and hospital parking”* (Man, 50).

e. Age discrimination and societal stigmatization

Some participants, 31% (4 out of 13), felt discriminated against because of their young age, especially women in their early 50s. Participants said that specialists did not take their concerns seriously, almost not believing them.

> *".... a lot of stigma over my age. Stigma because I was diagnosed with arthritis at 50 and I felt that I was discriminated, you know, she's only 50 instead of 60 or 70."* (Woman, 59).
>
> *"Just with the surgeons, you know, because of my age and while you're only 50, blah blah, that sort of thing. But once they realized how extensive it was, then the tone kind of changed*" (Woman, 61).

Participants also felt that there was a societal stigmatization because they were diagnosed with arthritis at a young age. Society believes that arthritis is exclusively an older adult's problem.

> *"I said I was having hip surgery and she said 'you know you're one of the fittest people I know for you to be having hip surgery.' I'm not sure if I said arthritis at the time"* (Woman, 58).

f. Lack of resources and funding

The majority of participants, 61% (8 out of 13 participants) of respondents, pointed out the lack of arthritis resources available to them. Resources were lacking for gender-diverse people (LGBTQ+ community), young people with arthritis, and arthritis patients in general. Participants said they did not find enough resources to support them or answer their arthritis-related concerns.

> *"…that you know have sort of landed on my own. I've done my own investigation and like I said, you put language to something that I*

> *recognized a year ago. And so when I recognized that, I went looking for what are the things that I can do to help alleviate some of the pain that I'm experiencing"* (Woman, 61)
>
> *"I guess the support is a little bit lacking in some ways because it seems like my surgery is happening very quickly"* (Woman, 68).
>
> *"Are we gonna be in pain for a very long time before anybody would do anything? I waited a long time. That's a really hard thing"* (Woman, 70).

5. Patients' health information needs

We found that participants were mostly looking for the following arthritis information: pain management (4 out of 13 participants), conservative management from online resources (4 out of 13 participants), treatment options (3 out of 13 participants), advancement of disease (1 out of 13 participants), lifestyle choices (1 out of 13 participants), and additional support programs (2 out of 13 participants).

> *"Well, I'm trying to find things to ease the pain. Everybody wants to push drugs and I'm having hard time with that. So that's my main goal is to keep doing research on a natural basis of how to cope with the pain and how to deal with the arthritis if I actually really do have"* (Woman, 68).
>
> *"Mostly discussions on you know treatment, any ways to lessen this to make it easier to live with, options like surgeries or call it pain management"* (Man, 62).

On the other hand, 46% of participants (6 out 13 participants) indicated that their primary source of information is their physician.

> *"Well, I just don't know, they went to school for it, they're the professionals. They know what they're doing. So if I'm going to talk, if there's some situation that I have to deal with, I'm going to talk to professionals about it and not make any assumptions on my own"* (Woman, 70).

In comparison, 54% of participants (7 out of 13 participants) reported that they rely on online sources for information and that they trust them.

> *"First time it would be Internet; second step would be my general physician. She is good, have to give her a chance to do her work. Sometimes if you just go to diagnose, your doctor is not very helpful. It's easy to do so when you're not wanting to go out in the winter"* (Woman, 58).

6. Perceived facilitators

Participants have suggested a few things that might help or have helped in improving health information access. These recommendations included: the availability of doctors in big cities, multiple ways of information delivery, particularly for those living in rural communities, and allowing patients to provide feedback on programs.

> *"I don't know for sure if rural, we don't get as much information as the urban areas. Like I mentioned, send it to the hospitals, send it to all the doctors first, if they got together and say, 'Well, how many patients do you have with arthritis and so on'. And so do you think it would be beneficial if there's a number of us that could get together and have a*

> *meeting with the Arthritis Society? And help these people learn more about their disease"* (woman, 70).
>
> *"So perhaps multiple ways of delivery is the most helpful to retain it. Certainly, to highlight the most important things"* (Female participant)
>
> *Sometimes I think if there was a way people could input what they're feeling about the healthcare system. Feedback, yes"* (Man, 62).

7. **Level of satisfaction with the information or services provided by physicians**

Almost all participants, 76% (10 out of 13) of respondents, said they were dissatisfied with the information or health services they received from their physicians. Participants felt that their needs were not addressed because physicians sometimes provide too much information without further explanation or do not give their patients sufficient time to ask questions.

> *"…he didn't like answering questions. He was the best word I can use is aloof. Couldn't feel like you talked to him, he just sat at the computer all the time and just looked it up there and then, send you off to some other doctor or specialist or whatever. I didn't have him very long, I wasn't the only one that talked that way, I know somebody else with him, he was just the way he was"* (Man, 50).
>
> *"I would think just simply because when you go to see the surgeon, it's, you know, a lot of information too. So I don't know, I guess I try to get the information I need and not really be kind of overwhelmed, I guess overwhelmed would be the best way to describe it. With all of this lingo*

> *and jargon that the doctors use. I prefer to be, I guess kind of streets spoken as possible."* (Man, 58).
>
> *"I tend to go out and find it myself and put it all, try and put it together. Do they provide me with enough information? No, not none of them do"* (Man, 55).

In Contrast, 30% of participants (3 out of 10 participants) said that they were satisfied with the information they were receiving.

> *"Yeah, they'll discuss it with you. They also give you a pamphlet of pre-op and post-op information, so you know how to prepare yourself and what to expect after"* (Man, 71).

8. Gender is not a priority in establishing therapeutic experience

Only 38% of women (5 out of 13 participants) said they prefer women physicians because they are more empathetic, understanding, and sincere. On the other side, men physicians were seen as rigid and quick in their answers. Additionally, they added that they feel more comfortable around women physicians in general.

> *"No not at all. Sometimes I find that females are a little bit more empathetic, they spend more time. Males I find a little more rigid, but I don't mind that approach at all++ I like both"* (woman, 68).
>
> *"I think a male doctor will just say quick answers compared to a female doctor because female doctors* will get arthritis more than a male doctor would. Females get arthritis more than males*"* (Women, 59).

In comparison, 61% of participants (8 out of 13 participants) had no preference for the gender of their physicians. This is due to a lack of physicians; as a result, patients have learned to be adaptive.

> *"I do feel more comfortable with a female doctor, but you know doctors are in shortage. So a doctor is a doctor"* (Woman, 61).
>
> *"I: Do you have a preference for a male doctor over a female doctor, or vice versa?*
>
> *M: No, no, it's just kind of like what was available sort of thing"* (Man, 70).

9. Dire need for arthritis information programs

All of the participants agreed that delivering an arthritis information program would be highly beneficial. Respondents believed that having an information program tailored for arthritis is important despite the accessibility of online resources. Forty-six percent of participants (6 out of 13 participants) said they would rather access this information program online (on the hospital's website). The remaining 53% of participants (7 out of 13 participants) chose an in-person, nearby program that they could easily access.

> *"Well in in the city of (city's name). You mean somewhere like the (Centre's name) or the (Centre's name) or whatever? Oh, yeah that would be helpful. I wouldn't have to drive so far"* (Woman, 61).
>
> *"It might take away from the time it takes to see the doctor, that if it was clinic or support group or something maybe that you could go"* (Woman, 70).

10. Mixed understanding about the meaning of sex/gender

In response to the question, "In the context of health care, when you hear the word sex or gender, what does it mean for you?" seven participants said that sex and gender are the same thing and they mean female or male, two participants preferred not to answer, three participants found the concept of sex and/or gender confusing, and only one participant had a clear understanding of the concept.

> *"For society has me confused with all the different variables they have now: male, female, transgender, whatever else lesbian. I don't think it's really necessary to get into all that detail, but that's just my opinion"* (Woman, 61).
>
> *"I don't have an issue with gay, they're entitled to live their lives. I don't have an issue with it. I don't like it necessarily being forced on my throat. I do have an issue somewhat not an extreme issue, but an issue with this transgender, maybe because I don't understand it or whatever, but I think maybe it just slowed down a little bit to let people absorb all the information and stuff that's out there."* (Man, 71).
>
> *"Interesting question, I'm sure for others that are born one way, but feel another would answer that differently, but since I am female and my partner is male, then it's pretty black and white"* (Woman, 48).
>
> *"Male and female. Yeah, I mean, I know there's other stuff out there, but you know, in my faith, I just believe male and female."* (woman, 70).

Discussion

This study highlighted that men and women struggle to get timely information and that inadequate time or mechanisms for clarification or personalization limit their ability to benefit from the information provided. Sex/gender was one of many factors that influenced information needs, and a therapeutic alliance was achieved through information exchange with their physicians. While there is a growing awareness about sex/gender and information preferences, respondents were often unclear about what was meant by these two terms and prioritized access concerns above gender concerns. At present, we still lack clear guidelines about how to make health information more inclusive and tailored to people of different sexes and genders. To create more tailored gender-transformative health information interventions, it is crucial to understand how sex and gender differ and how they may affect patients' health information-seeking behaviours. Although arthritis is a health condition that can affect females/women and males/men equally, health information needs can vary greatly (Gignac et al., 2018). According to study participants, numerous factors can explain these discrepancies, including lengthy wait times, age- and societal-related stigma, a lack of resources, the use of complex technical terms, a drawn-out process, and the effects of COVID-19. The general population is typically aware that many groups face discrimination due to a variety of reasons, such as age, gender, ethnicity, sexual orientation, religion, or disability (Joint Health, 2007). However, less widely acknowledged is the fact that persons with certain conditions frequently experience unfair, inequitable treatment based on the health issue they have (Joint Health, 2007). One of those ailments is arthritis (Joint Health, 2007). Some of the women in this study highlighted age discrimination and societal stigmatization, describing how they were overlooked, disregarded, and made to struggle to meet their health needs due to their young age. Participants reported that family physicians and specialists were overlooking arthritis, which had an adverse effect on their health. There is a societal stigma, believing that arthritis is an “old person’s disease”. Participants felt this way not only because of their physicians but also because it is widely accepted among the general public that arthritis is associated with old age. Some participants even held this belief and tried to hide their arthritis from others.

Our research identified various areas of the healthcare system that require improvement, particularly in terms of patient access to services and information. Participants discussed the barriers that prevent patients from receiving adequate health information from physicians. One of the primary factors was the limited amount of time allocated for each medical appointment, which led patients to turn to alternative sources of health information, such as online resources. This is due to their ease of use, variety of information, and convenience of access. Some participants noted that, in addition to physicians not providing sufficient time for patients, there are limited opportunities to ask questions and that the language used in healthcare is difficult to understand. Receiving adequate health information was further restricted by lengthy wait times and processes, particularly during COVID-19. Participants also found that the lack of in-person resources in smaller and rural communities led them to rely on online resources. As a result, patients were dissatisfied with the health information provided by physicians.

Data showed that sex and/or gender can play a role in shaping patients’ experiences. Men reported more reluctance to seek help from healthcare professionals, even when symptoms were worsened. This reluctance was reported by both men themselves and by women about their partners. As shown in a previous study, “many men reported not talking to their friends about their RA due to a perceived lack of understanding and support” (Flurey et al., 2016, p.331). “Men with RA report being reluctant to discuss emotional issues with their rheumatology team unless explicitly asked with a direct question" (Flurey et al., 2016, p.331). Our knowledge of how men perceive the psychosocial aspects of arthritis, especially rheumatoid arthritis, is currently based on research that either makes no assumptions about gender differences or only concentrates on women (Lack et al., 2011). Some women participants believed it was important to have a woman physician because they tend to be compassionate and understanding.

Even participants who claimed that gender was not their top concern when selecting a physician, still preferred a woman physician, but the lack of physicians made them more flexible and accommodating. While older women tended to have a gender preference, younger women had no preference. Although most participants valued their interactions with healthcare providers, there was still considerable dissatisfaction with how those providers delivered and communicated health information. This needs to be addressed because many participants preferred online resources to physicians because they found them more helpful. Patients' health information-seeking behaviours- involve accidentally encountering information, experiencing the need for information, discovering, choosing, and using it, and even rejecting it (Lalazaryan & Zare-Farashbandi, 2014)- have changed over the years due to advancements in convenience information sources (Lalazaryan & Zare-Farashbandi, 2014). Now, patients can access information from sources other than their direct interactions with healthcare providers (Lalazaryan & Zare-Farashbandi, 2014).

Moving forward, it is important to understand patient needs and address them based on sex and/or gender. This study highlighted the need to identifying patients' health information-seeking behaviours, sources of information, and barriers to accessing information. Patients are turning to alternative sources of health information, such as the Internet, due to the rising levels of dissatisfaction with the healthcare system. Although the Internet is easier and faster to access, it still contains false and inaccurate information (Fiksdal et al., 2014). To create more effective methods for accessing health information, we need to understand patients’ needs, not only in terms of sex and/or gender, but race, socioeconomic status, education, age, ethnicity, and literacy level. First, we need to establish clear communication between patients and healthcare providers by understanding patients’ information-seeking behaviours.

Most importantly, we need to acknowledge that patient information needs vary according to sex and gender. Multiple studies have found that women with OA and RA experience more frequent and severe pain than men do (Affleck et al., 1999). When coping with pain or discomfort on a given day, women more commonly sought emotional support (Affleck et al., 1999). Due to the intersection of their sex, age, race, and high rates of chronic illnesses such as osteoarthritis (OA), older and middle-aged African American women are at an especially high risk of having pain and consequent pain-related disability (Walker et al., 2018). Second, various methods of information delivery are required to accommodate patients’ needs, especially those living in rural communities, who lack access to computers, experience technical challenges, prefer print information, etc. Finally, patients must be engaged in designing information systems and programs. Education alone is insufficient; patients need to be active partners in their care and management of arthritis. Collecting feedback from patients can be useful in ensuring the effectiveness and inclusivity of health information. Many participants mentioned that having an information program and a support group available to them, whether virtual or in-person, will be useful. Not all health information found online is believed to be trustworthy (Imes et al., 2008). Therefore, to overcome barriers, we must disseminate health information through channels that enable both men and women to voice their concerns safely and comfortably.

Summary and limitations

Summary

Patients' preferences and needs for health information are influenced by their sex, gender, and other factors. This study revealed some gaps and barriers in accessing and delivering health information. Therefore, not allowing to create more personalized gender-transformative health information. This suggests that patient engagement and co-design with diverse users might be needed to achieve inclusivity, equity, and effectiveness of information.

Limitations

There are several limitations in this study. Despite attempts for inclusive recruitment and a non-white interviewer, only white participants were included. However, two non-white participants were approached but were unwilling to participate in the study. This supports the claim that minorities are less willing to participate in health research (Wendler et al., 2005). This was also seen in previous research studies. The majority of studies on pain disparities have focused on the following ethnicities: non-Hispanic white, Hispanic/Latino, and black/African American (Anderson et al., 2009). Asian Americans, Arab Americans, and Native Hawaiians have rarely been included in research studies (Anderson et al., 2009).

Future research should focus on investigating patients' health information needs in relation to sex/gender and ethnicity, with a focus on minority groups like Arabs and Asians. Finally, patients recruited in this study have access to physicians, specialists, surgeons, and other resources, thus, their health information needs might differ from those that do not have much support.

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Chapter 4: General Discussion

Conclusion

Overall, this study provides evidence that more attention is required to understand patients' health information-seeking behaviours and needs. Our evaluation revealed some gaps and barriers in accessing and delivering health information. While previous research studies showed that arthritis experiences can differ due to sex, age, and other factors, we still found that arthritis information resources were sex/gender blind. Most importantly, patients were not satisfied with the health information they were receiving from physicians. As a result, the Internet was the source of information for the majority of patients.

Strengths and Limitations

This thesis focuses on the influence of sex/gender on patients' arthritis health information needs. Although previous studies suggested sex differences in arthritis, research on how these differences affect patients' health information needs. This study allowed patients to share their experiences and understand their needs. This helps identify the challenges that patients encounter while trying to access and receive information. This study found that not only sex/gender are important factors in health information needs, but intersectionality (such as age, literacy, gender identities, and race) are also important to consider during the co-design process. It highlighted the importance of patient engagement and co-design with diverse users to achieve inclusivity, equity, and effectiveness of information. Having a checklist appraisal tool, like the one used in this study, during the design process might help in future patient information designs.

To overcome barriers, we must disseminate health information through channels that enable all users to voice their concerns safely and comfortably.

However, this thesis has some limitations. Firstly, there is limited research on the integration of sex and/or gender in health information so foundational knowledge and best practices are not well defined. Content can be more latent than obvious, which can affect the interpretation of how well concepts were addressed. Secondly, we evaluated a subset of available resources which may not represent usual or best practice. Since we evaluated only English resources, this may have limited our results, and thus, it is not representative of all available information although the societies studied are well-supported compared to many other countries. Thirdly, patients recruited in the second study have access to physicians, specialists, surgeons, and other resources, thus, their health information needs might differ from those that do not have much support. Finally, only white Caucasian participants were included, which can be different from other patients' health information needs.

Implications

This thesis has direct implications for research and policymaking. It explains why healthcare professionals and policymakers should be concerned about this topic. Our work will serve as a helpful resource for guideline developers, researchers, and healthcare professionals to understand patients' health information needs, preferences, and information-seeking behaviours. They can assess potential advantages, highlight quality concerns, and establish guidelines for evaluating online health information. Healthcare professionals should be aware that not all patients use the Internet equally, despite it being a significant source of health information for individuals.

Future Directions

This thesis identified substantial gaps in arthritis health information resources ranging from lack of intersectional awareness (especially for sex/gender), challenges in accessing and receiving information, to dissatisfaction with health information. Based on our results, we recommend that patients engage in designing information systems and programs. Patients need to be active partners in their care and management of arthritis. Collecting feedback from patients can be useful in ensuring the effectiveness and inclusivity of health information. knowledge users will have to be actively engaged throughout the designing and pilot testing of arthritis health information resources. Additionally, future studies can further explore this area to develop effective patient-centred arthritis information resources.

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Appendix 1. Demographics Form

Sex/Gender differences in Health Information Needs in Arthritis Patients

Demographics Form

Age: _____ years
Sex: _________
Gender: _________

Education and Employment

1) Highest Level of Education:

- Elementary School
- High School
- High School Diploma
- CEGEP
- Community College/University
- Other ______________________

2) Are you currently employed?

- Yes
- No

Migration

3) Are you a Canadian citizen?

- **Yes**
- **No**

4) Have you ever been one of the following?

- **Refugee**
- **Permanent Resident**
- **Other ______________**

If so, when did you come to Canada ________

Appendix 2. Ethics Approval

Date: 6 January 2023

To: Dr. Joy MacDermid

Project ID: 121896

Review Reference: 2022-121896-74465

Study Title: Sex/Gender Differences in Health Information Needs in Arthritis Patients

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 24/Jan/2023

Date Approval Issued: 06/Jan/2023 13:22

REB Approval Expiry Date: 06/Jan/2024

Dear Dr. Joy MacDermid

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study**.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Semi-structured interview qs	Interview Guide	11/Dec/2022	2
Study Protocol	Protocol	11/Dec/2022	2
LETTER OF INFORMATION AND CONSENT FORM	Written Consent/Assent	11/Dec/2022	2
Demographics Form. Dec 19, 2022	Paper Survey	19/Dec/2022	2

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Electronically signed by:

Karen Gopaul , Ethics Officer on behalf of Dr. Emma Duerden, HSREB Vice-Chair, 06/Jan/2023 13:22

Reason: I am approving this document

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations, See Electronic System Compliance Review)

Appendix 3. Letter of Information and Consent

Project Title: Sex/Gender Differences in Health Information Needs in Arthritis Patients.

Investigators

Dr. Joy MacDermid, PT Ph.D. (Principal Investigator)
Department of Physical Therapy, Western University

Tania Al-jilawi, MSc. Student (Student investigator)
Health Information Science, Western University

Ms. Katrina Munro, MPT Ph.D. (Research Co-ordinator)
HULC, St. Joseph's Hospital

What is the purpose of this study?

The following study is a graduate student project studying at Western University. The purpose of this study is to focus on the health information needs (information or opinion about a certain health condition, illness, injury or disability. This information can be extremely useful, empowering patients to make important health decisions about their care) of patients with arthritis. This study can provide insights for healthcare professionals and policymakers on the importance of considering sex and gender differences. The goal is to understand how a patient's sex and/or gender can influence their arthritis health information needs. Patients diagnosed with arthritis will be asked to participate in a one-on-one interview asking about how their health information needs are influenced by their sex and gender. The interview will help gain a deeper understanding of how gender and sex differences play a role in health information needs and decisions. You are being invited to participate in this study because you are a patient at the Hand and Upper Limb Centre of St. Joseph's Hospital and this interview may help us gain insights about health information needs. The interview will be semi-structured, meaning we have a guide we will follow but certain questions and prompts may come up that are not anticipated.

Recruitment

Approximately 20 participants with confirmed arthritis at St. Joseph's Hospital, 18 years of age and older, who can speak, read/write in English, and have given informed consent will be recruited from the Hand and Upper Limb Centre (HULC).

Study Procedures

This study is an interview. You have been approached by research support staff, Katrina Munro, after your circle of care (treating clinician) has approached you, asking whether you are interested in participating in this interview, or you have heard about this study through social media (Facebook, Twitter, Instagram). Please read through this letter of information and if you have any questions, you may ask the research support staff or email the student investigator, Tania Al-Jilawi. If you are willing to participate you will be asked to sign a consent form in-person and provide your contact information (phone number) if you feel comfortable. You will then be contacted by phone or in person to set up a date and time for the interview, and at this point, you can ask any additional questions you might have about participation. The interview will take place at St. Joseph's Hospital in the Hand and Upper Limb Clinical Research Lab (D0 139). However, there is also an availability of a virtual interview through WebEx or a telephone interview. Your e-mail addresses and telephone numbers would be collected if you opt for the virtual interview session. When you arrive, we will ask if you are still willing to participate in this study. We will then get you to conduct your interview. You will be asked to respond to the interview questions honestly. The interview should take approximately 30 to 40 minutes. Furthermore, if you opt for a virtual interview session on WebEx, you will have the flexibility of keeping the camera on/off as per your wish and choice. You will be informed about this at the beginning of the virtual interview session as well as at the start of the recording. Any information regarding your name or demographics will be kept separate from the interview and accessed only by members of the research team. As part of the procedure, audio-recording is mandatory during interviews for analysis of study results. The interview will be recorded using an encrypted recording device and stored on a password-protected computer in an encrypted file. The in-person, virtual (WebEx), and telephone interviews will be audio-recorded using Olympus DS-3500 Encrypted voice recorder. Furthermore, the interviews will be transcribed by the student investigator, Tania Al-Jilawi.

Participation in the Study:

Participating in this study is voluntary. You will receive a copy of the letter of information and consent form for your records. You do not waive any of your legal rights by signing the consent form. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future care. If you decide to stop your participation in our study, we will ask you how you would like us to handle the data collected up to that point. You have the right to withdraw all data collected for the study. It is important to note that your data can be removed, but a record of your participation must remain with the study as such, the researchers will not be able to destroy your name on the master list, and/or the signed letter of information and consent. If you have concerns or would like to withdraw you can contact the principal investigator, Dr. Joy MacDermid, or research assistant, Katrina Munro.

What are the benefits of this study?

There are no direct benefits to you associated with your participation in this study. However, your study participation will have health research benefits. The study can benefit healthcare professionals and policymakers by highlighting the importance of considering sex and gender differences. As the literature (body of written works, including books and writings) lacks a qualitative aspect (meaning data that is interpretation-based and descriptive. It helps us understand why, how, or what happened relating to a specific topic/subject) on the topic of sex and gender factors in health information needs, the study will contribute to the literature and accelerate the process of more studies being conducted on this topic. Thus, the study will surely benefit arthritis patients in having resources safely created for their needs along with the already mentioned advantages to clinicians, policymakers, and researchers.

Are there any risks or discomfort associated with this study?
There is a potential for a privacy breach, as identifying information is being collected. However, identifying information will be kept separate from the data. Instead, the data will be de-identified.

How many people are in this study?
There will be approximately 20 people in this study, however, for qualitative research (meaning data that is interpretation-based and descriptive. It helps us understand why, how, or what happened relating to a specific topic/subject), data collection will stop when we reach theoretical saturation, meaning we are not learning any new information from the participants.

Is there any compensation if I participate?
You will be compensated for your participation in this study. Upon completion of the interview, you will receive $5.

Will my results be kept confidential?
Your results will be held in strict confidence. No person, other than the study team will have access to the study data.

Upon study recruitment, participants will be given a unique numerical identifier (Participant ID) that will be entered on all data collection forms containing personal information in lieu of their name. This identifier will be randomly generated and will not include any personally identifying information (such as name or hospital ID). The study investigators will keep a master copy of the unique identifier assigned to each participant. This list will be stored on the SJHC secure G drive. Participants' contact information and consent forms will also be collected and stored separately from the master list of unique identifiers. All paper files will be stored in a locked file cabinet in the HULC clinical research lab, and all electronic files will be stored on a password-protected computer on the secure hospital network. A summary of this study might be put on our lab website for public viewing; however, this would not identify you in any way. Direct quotes will be used in publications, presentations, and media, but again no identifiers will be linked to the quotes. Representatives of the University of Western Ontario Health Sciences Research Ethics Board and Lawson Quality Assurance and Education Program may contact you or require access to your study-related records to monitor the conduct of research and to ensure that proper policies and guidelines are being followed. Under the Lawson Ethics Board policy, the study investigators will retain your information and study data for 15 years.

Publication
If the results of the study are published, your name will not be used. There may be direct quotes, but they will not be associated with your name. If you would like to receive a copy of any potential study results, please provide your name and contact number on a piece of paper separate from the Consent Form.

Whom you may contact to find out more about this study?
You will be given a copy of this letter. If you have questions about taking part in this study, you can directly contact:

Dr. Joy MacDermid, Principal Investigator
Katrina Munro, Study Research Assistant
Tania Al-Jilawi, Student Investigator

If you have any other questions about your rights as a research participant or about the conduct of the study, you may contact: St Joseph's Health Care London Patient Relations Consultant.

Consent to Participate: Sex/Gender Differences in Health Information Needs in Arthritis Patients

Investigators:

Dr. Joy MacDermid, PT Ph.D. (Principal Investigator)
Department of Physical Therapy, Western University

Ms. Tania Al-Jilawi, MSc. student (Student investigator)
Health Information Science, Western University

Ms. Katrina Munro, MPT Ph.D. (Research Co-ordinator)
HULC, St. Joseph's Hospital

- I have read the letter of the information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

________________________	____________________________	_________
Signature of Participant	Print Name of Participant	Date

- My signature means that I have explained the study to the participant named above and answered all the questions.

________________________	____________________________	_________
Signature of the person obtaining consent	Print name of person obtaining consent	Date

Appendix 4. Topic guide used in individual interviews

1. Tell me about your experience with doctors and specialist, how has it been?

2. What do you need to know when it comes to arthritis? What do you most need to know (exp. progression, impact of daily life, exercises, supports available to you)?

3. When you look for information, who do you trust the most? (People who have experienced this before, library, doctors, internet) who do you trust to give you accurate information?

4. What kinds of information do you get from your doctor (links, brochure, conversations, questions and answers etc.)?
   - Do you value this?
   - Does it represent your needs?

5. Having a conversation with your doctor is great, but would you also like to have it in print, on YouTube, links to videos, link to community support groups or people who are experiencing these things (community group)?

6. Do you think your physio/doc treats you differently because you are women/man?

7. Is your doctor male or female? Did you specifically get the female doc and why? if male, why specifically male doc? talk more about it.
   - Do you feel comfortable asking them about different things without concerns of being judged or feeling needy, do they allow you to do that?
   - Do you get the same info as your husband/wife? do you feel comfortable talking to your doctor about arthritis, do you think it needs to be different?

8. With your interaction with you h-care providers, do you think you need more info? do you have enough information to support you and you're getting enough info?

9. Are you satisfied with the information you get? Do you wish there has been more? Are your needs as female/male met? Do your needs get dismissed sometimes or not taken seriously because of your sex/gender?

10. What do you think is important to include in an arthritis information program?
- Who do you think should deliver this type of group (e.g., male/female)?
- Where do you think the group should be delivered (at the hospital/elsewhere)?

11. Would you like to change anything about the care or support you receive?

12. Do you think women receive different information than men?

13. Do you think women/men deal with arthritis differently than men/women? (If so how?)

14. Is there anything positive about being a man/woman with arthritis? (What?)

15. In the context of healthcare in arthritis, when you hear the word gender/sex, what does it mean for you?

Curriculum Vitae

Name: Tania Al-Jilawi

Post-secondary Education and Degrees:

The University of Western Ontario
London, Ontario, Canada
BSc Honors Specialization in Health Sciences
2016-2020

The University of Western Ontario
London, Ontario, Canada
MSc Health Information Science
2021-2023

Honours and Awards:

Western Graduate Research Scholarship
The University of Western Ontario

Related Work Experience:

Graduate Teaching Assistant
The University of Western Ontario
London, Ontario, Canada
2021-2023

Research Assistant
Lawson Health Research Institute
St. Joseph’s Hospital
London, Ontario, Canada