THE GAP
BETWEEN ARTHRITIS HEALTH CARE PROVIDERS AND PATIENTS

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EXECUTIVE SUMMARY

OVERVIEW

A series of reviews conducted by The Arthritis Society from 2016 to 2017 explored the gap that is perceived to exist between people living with arthritis and their health care providers, notably family physicians and rheumatologists, with regard to developing a care plan that recognizes and addresses the full impact of living with arthritis, on all aspects of the patient's life.

The findings highlight common themes that represent obstacles to people with arthritis receiving the care they need to help manage the full impact of their disease on all aspects of their lives. The report offers recommendations for implementation or further study in order to address those obstacles and improve the way arthritis care in Canada is coordinated and delivered, in order to improve outcomes and quality of life for people with arthritis.

Background

There is a gap between how clinicians treating arthritis perceive the progress of treatment, and how patients experience their disease. Compared to health care providers, patients require greater improvement in their symptoms to experience satisfaction with how their disease is managed. Until they see a positive impact on their daily lives, many arthritis patients are not satisfied with, or may not see progress when it comes to their disease, even when their health care providers see progress and treatment success.

Goal

The goal of this project is both to raise awareness and understanding of this gap in the arthritis community, and to identify and propose strategies for how various players in the health care system, including The Arthritis Society, may contribute to closing the gap, and in so doing help to improve care and quality of life for Canadians living with arthritis.

Methodology

The Arthritis Society conducted a three-prong examination of the issue, including:

- a **literature review and environmental scan** of the key issues and strategies that have been documented to identify and respond to the gap;

- a series of **focus groups** (four face-to-face and one online) soliciting feedback from people living with arthritis, representing a variety of demographics including region, gender, age, diagnosis and stage of disease; and
- a series of **subject matter expert interviews** with health care providers in related disciplines.

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OVERALL FINDINGS

The gap is real. While arthritis patients report satisfaction with their health care providers in many respects, they also have important needs that are largely unmet in the current clinical setting with their rheumatologists or family physicians, and that can impact the progress of their disease, severity of symptoms and overall health.

The core issues identified were:

- a disconnect between clinical markers of disease progression and treatment effectiveness vs. the patient's lived experience of the disease;
- communication barriers in the clinical setting that leave patients feeling disempowered and unable or unwilling to engage their health care provider in a complete discussion of how their disease is impacting their life; and
- a system that leaves clinicians unable or unwilling to address the patient's overall condition and related symptoms, and their impact on the patient's quality of life.

The resultant gap has a number of impacts on the lives of arthritis patients, resulting in:

- potential reduced functionality and quality of life;
- increased pressure on patients to be the coordinator and facilitator of their own care, unilaterally communicating information to and between different health care providers; and
- potentially counter-productive influences on their decision making about treatment, such as when to stop a particular course of treatment, and whether to notify their health care provider.

Both patients and clinicians are aware of the gap, and have different perspectives on how to bridge it.

- Clinicians are looking for tools they can trust to accurately and reliably capture patient-reported outcomes (PROs), and that they can implement within the digital capacity, time, and human resourcing constraints of their everyday practice, to better reflect the whole picture of the patient's disease experience in their treatment plan.
- Patients need more time with, and more understanding from, their health care providers. They need their physicians to hear, understand and validate the many ways that arthritis impacts their daily life, to share that understanding with the rest of the health care team as appropriate, and to reflect those impacts in an

integrated treatment plan that addresses their overall quality of life. They also need assistance navigating the health care system to provide any support they may require outside of the clinic environment.

RECOMMENDATIONS

In the short to medium term:

- Identify and incorporate a standard resource or resources (Health-Related Quality of Life – HRQOL tools) into care guidelines, along with supporting education, to allow health care providers to consistently evaluate, communicate and better reflect PROs in treatment plans.
- Make patient education resources available to arthritis patients and their health care providers, focused on:
  - how to communicate effectively with and prepare for constructive appointments with the health care provider (including how to track and report on symptoms that may be related to their condition);
  - the role of mental health and well-being as an aspect of living with arthritis and other chronic diseases; and
  - how to navigate the health care system and advocate for the care they need.

In the longer term:

- Provide health care providers with further professional training in pain evaluation and management, and mental and psycho-social health, and their respective impacts on overall health.
- Evaluate and introduce systemic adjustments to permit longer, more effective interactions between arthritis patients and health care providers:
  - increase the number of rheumatologists in clinical practice in Canada;
  - explore the role that billing/compensation structures have in the way health care appointments are conducted, and suggest amendments to better reflect the needs of people living with chronic conditions (in particular, remove the incentive among primary care physicians to only address one reported issue or health concern per appointment);
  - develop mechanisms to encourage health care providers with an arthritis focus to establish integrated, multi-disciplinary practices; and
  - provide arthritis patients with a care coordinator whose primary role is to help patients understand and navigate needed services both within and external to the practice as required, ensuring that all parties are kept apprised of the overall care plan and any relevant developments in the patient's condition. (Start by studying models such as the Ontario Chronic Disease Prevention and Management Framework.)

While further study is warranted, implementing these measures will help increase patients' level of engagement in their own care and provide them with more comprehensive support appropriate to the complex and chronic nature of their condition. This will in turn result in more effective treatment plans, increased compliance with those treatment plans, more effective communication between and among patients and health care providers, and improved quality of life for people with arthritis.

LITERATURE REVIEW

ABOUT THE LITERATURE REVIEW

Goals

The goal of this literature review is to identify the key issues and strategies that have been documented to identify and respond to the gap between health care providers and patients in understanding the impact of arthritis symptoms and treatment.

Methodology

A review of existing work that has documented the arthritis information needs of patients was conducted through a combination literature review and environmental scan.

Literature review

Online research was conducted to identify, review and analyse existing research and reports that have documented how patients understand their experience of pain and fatigue, and the gap that exists between patients and health care providers about the impact of these symptoms on quality of life. The scope of the literature review included:

- Previously completed needs assessments, environmental scans, industry surveys and marketing surveys;
- Peer-reviewed journal articles and conference proceedings;
- Reports produced by patient organizations in the field of pain and fatigue management;
- Provincial, national and international best practices; and
- The Arthritis Society planning and other related documents.

Environmental scan

A scan was completed in areas where gaps in literature were identified. This step ensures that new or emerging programs that have not yet been evaluated or documented are identified and included in the analysis. Online searching identified and documented current Canadian, UK, US and Netherlands-based assets and resources that may not have been reflected in existing literature and documentation. Examples of assets and resources include online information and education, web applications, mobile applications, and alternative health care tools.

THE GAP BETWEEN PATIENTS AND CLINICIANS

There is a gap between how clinicians treating arthritis perceive the progress of treatment, and how patients experience their disease.[1,2,3] Compared to health care providers, patients require greater improvement to their symptoms to experience satisfaction with how their disease is managed.[4] Simply put, until they see a positive impact on their daily lives, many arthritis patients are not satisfied with, or may not see progress when it comes to their disease, even when their health care providers see progress and treatment success.

In a recent survey, patients were asked to rate their care.[5] While the results demonstrated that patients reported having moderate to high rates of satisfaction with their health care provider, they also reported a number of issues indicating that they were not satisfied with the results of their treatment, and were seeking strategies on their own to help reduce the impact of disease.

Clinical markers vs. patient experience

Clinical practice and decision making around arthritis management has traditionally focused on clinical measures of disease (e.g., physical, physiological, biochemical), and has only recently begun to include patient-based measures and outcomes.[6,7,8,9,10] Traditional clinical measures contrast with how patients view wellness and treatment outcomes, as many patients look at their disease through a lens of impact on their life. Evidence that patients use to assess their progress, and the areas of their life that are reflected in patient-defined treatment goals have included: the disease's impact on social roles, fatigue, daily activities, self-confidence, increased ability to do valued activities, improved mood, and a return to a "normal" work, family, and social life.[11,12]

The gap between the use of bioclinical markers of disease activity and how a patient experiences that same disease activity can be further complicated by the personal differences in how an event is experienced across patients (i.e. the experience of pain and the impact on daily living may not be experienced the same way by a 24 year old female and a 68 year old male), as well as differences in terminology used to describe and define an event. For example, one study outlined the variation in how patients experience and talk about symptoms associated with a "flare" in RA, and is used as an example of the challenge faced by health care providers when attempting to quantify a subjective experience.[13] In this study, what is considered a "flare" by some patients is experienced as pain, tenderness, and is seen through the impact it has on their daily living. However, the study outlined that not all patients experienced or identified a "flare" in the same way, and when they spoke to their health care providers about a "flare", it was often understood or assessed by their health care provider differently.

Communication barriers in the clinic

Many patients have come to understand and accept this gap, and have the perception that their health care provider does not value discussions about symptoms and management that are outside the scope of prescribed clinical treatment.[14] This study also identified a list of other communication challenges that made it difficult for patients to be fully engaged in treatment and management discussions. They included:

- Not feeling well informed about treatment options;
- Being given conflicting information;
- Having too much information to remember; and
- Lack of time at appointments to fully discuss concerns.

How the gap impacts patients

The gap between clinical practice and the patient experience of disease has been linked to reduced functionality and quality of life among patients, a more challenging and difficult process to navigate the health care system, and influences the decisions patients make about treatment and management of their disease.

Reduced functionality and quality of life

While it is the goal of the health care provider to offer a treatment strategy that reduces disease activity and symptoms, without understanding the day-to-day impact of arthritis on patients, health care providers are not working with information that reflects the complete picture of their patient's journey. For many patients, particularly those with inflammatory arthritis, daily living requires significant adjustments that impact their mood, social life, and their relationships with others. One study identified that patients were 'dosing their activities', 'using new strategies', and 'stretching their limits' as coping strategies, however, their disease continued to leave them with a sense of helplessness and uncertainty that led to anger and depression.[15]

Pressure on patients to communicate information

Without standardised tools that collect and share information between patients and their health care providers about how disease is experienced outside the clinic, patients become responsible for owning, managing and communicating key pieces of information that impact their treatment. This is especially challenging for patients who access multiple health care providers throughout their journey. Patients have reported frustration with having to repeat the same information for different professionals, and report difficulty with having health care providers understand their needs and the impact of symptoms on their lifestyle.[16]

Decision making about treatment

When there is a gap, patients are at risk of not being offered, or not being fully informed about treatment decisions. When there is a perception that health care providers do not take into consideration the patient experience, there is a risk that patients will make decisions about their care without engaging or notifying their health care team. In one study, patients were asked if they were taking their medication as prescribed. Among the patients that reported that they were not adhering to their prescribed treatment, younger patients were more likely to tell their doctor they had stopped their medication after their decision, or not tell their doctor at all.[17] Patients in this study also reported that while talking to their health care provider before prescribing clinical treatment was highly important, talking about other strategies to control and manage pain, such as over-the-counter medication, complementary treatments and lifestyle changes was less important.

When there is disagreement about the perceived severity of symptoms, physicians may be reluctant to explore all treatment options.[18] Similarly, when there is a lack of understanding of the true impact of symptoms on their life, patients may be reluctant to consider all treatment options, including those that would prevent the disease from progressing, or which would improve their symptoms. Among some patient cohorts, personal beliefs about arthritis and treatment outcomes, and how arthritis symptoms are prioritised alongside co-morbid conditions, can reduce the likelihood that patients will identify and report the complete impact arthritis has on their life, and can influence their willingness to undergo treatment such as surgery.[19] Examples of these beliefs include:

- Viewing arthritis and arthritis symptoms as an inevitable or normal part of aging;
- Having a negative experience, or hearing of a negative experience with treatment, such as surgery, for other conditions;
- Concerns about the impact of surgery on their ability to fulfill their caregiving role; and
- Cultural-based preferences for natural remedies.

TOOLS AND STRATEGIES TO CLOSE THE GAP BETWEEN PATIENTS AND CLINICIANS

From the perspective of clinicians

Clinicians require a set of tools and information that they perceive to be credible, and which they can implement with the digital capacity, time, and human resourcing available in their practice.

Inclusion of patient reported outcomes in clinical practice guidelines and tools

Increasingly, clinical research and clinical practice tools that are widely accepted by health care providers are including patient-valued aspects of disease, or patient reported outcomes as measures.[20,21,22] Clinicians value tools that they perceive to be as accurate and reliable as traditional measures, and which are sensitive enough to detect clinically meaningful changes.[23] Studies of measures that reflect patient reported outcomes have indicated that, while there is variance among tools, they have been effective at demonstrating changes in health status as effectively as physical or clinical measures, and have been found to be valid and reliable in group data.[24]

Health-related quality of life (HRQOL) tools, which include pain, functional status, psychological distress, fatigue, and other key patient symptoms, are also useful tools to assess the impact of conditions such as RA, and the effectiveness of arthritis treatment.[25]

Efforts to engage patients and to develop plain-language versions of the international treat-to-target (t2t) recommendations for RA were successful in identifying gaps in how the tools would be implemented in clinical practice (i.e. inconsistency in terms of how health care is delivered), while creating opportunities to increase shared decision making in the management of RA.[26]

While the number of clinical research and clinical practice tools designed to reflect patient reported outcomes and quality of life is growing, a 2015 review of RA studies indicated that the tools that are used in clinical practice rarely report other domains of health that are important to patients, such as fatigue, psychological status, productivity losses, sleep disturbance, and coping.[27]

Ease of use of HRQOL tools

Health assessment tools that do not require a large amount of time and which are easy to administer are more likely to be used by clinicians. Among the reasons that health care providers have given for not using HRQOL tools, include a perception that patient questionnaires are difficult to use, take up time from staff, and are not easy to follow.[28] Digital tools to facilitate in-office administration and scoring of questionnaires will improve patient care.

From the perspective of patients

Patients require the ability to name and document their experience, understand how their disease impacts their lives, share this information with their health care team, to be heard and understood, and to have their treatment and management strategies reflect their needs.

Understanding the connection between symptoms and daily living

When patients and physicians have an understanding of how symptoms are experienced and the impact it has on daily living, it provides a common framework to assist both patients and the health care provider to assess a greater spectrum of treatment options. When HQROL tools are in place, patients and health care providers have access to information that is relevant to both the patient and the health care provider, and offers significant predictors of functional status, work disability, and health care related costs.[29]

Just as they see health care providers as authorities on arthritis, patients want to be viewed as experts on their own bodies, and have their experience treated with the same value as clinical markers. When communication with their health care providers includes relying on patient information about their disease and how it is experienced, it enables them to 'take charge' of their life situation.[30]

Talking about difficult topics

Patients need to be able to have discussions about difficult topics, like depression and sexual health, and to have an understanding that these are valuable pieces of information that will impact how they make decisions about treatment, and what kind of additional supports they should be accessing. Depression is associated with worse functional status, however, for many patients, any discussion of depression is raised by patients, not their health care providers.[31] Pain, fatigue and decreased joint mobility frequently leads to decreased sexual health among patients with RA, however, communication about sexual health between patients and health care providers is rare, with few discussions about the physiotherapy and other supports that can make a difference.[32]

Effective communication

Patients want to be able to communicate effectively with their health care providers, both in terms of having discussions that are more relevant to their needs, as well as having communication tools and strategies that facilitate the translation of their experience into a clinical setting. For example, studies have demonstrated that patients who are more effective at communicating about the pain they experience to their health care provider are less likely to report higher levels of pain, physical and psychological disability, and pain catastrophizing.[33] HRQOL patient assessments can improve consistent documentation of patient care by facilitating the quantification of patient care, and by including complementary clinical information that can help inform health care providers about a patient's current status, inform predictions about future status, and influence decisions about management.[34]

Use of digital tools

Digital tools that assist with tracking symptoms and their impact, and that share this data quickly and easily with health care teams, are one strategy that is increasingly being used in various areas of chronic disease management, including arthritis and would be utilised by many patients. A recent survey of arthritis patients indicated that patients under 45 years old, and patients who experienced inflammatory arthritis, were interested in using digital tools to help record and track health symptoms, treatments, and professional advice.[35] Over half of all survey respondents indicated a willingness to share information from a digital tracking tool with their health care provider, and one-third of the sample responded "not sure". Most of the reasons given by those who said no reflected a perception that their health care provider would not have enough time to address their issues, only focused on prescribing medication and treating immediate concerns, and that their health care provider might view the internet as a poor source of credible medical information.

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FOCUS GROUP RESEARCH

PROJECT DESCRIPTION

Objectives

The purpose of the project was to obtain in-depth information to better understand the experience and perspectives of people living with arthritis and understand how:

1. People with arthritis understand and assess the impact of pain, fatigue and other symptoms of arthritis on their quality of life,
2. People with arthritis communicate this impact with their health care team, and
3. How to close the gap that exists between the patient experience and the clinical markers used by health care providers to assess the impact of pain, fatigue and other symptoms on the patient's quality of life.

Methodology

Recruitment

The Arthritis Society was the primary source of recruitment of study participants. In December 2016 the Arthritis Society sent out communications by social media (Facebook and Twitter) encouraging people living with arthritis to complete an online pre-selection survey. The survey was open for six weeks. In total 450 replies were received. Of these 109 consented to follow up by the market research company.

Focus Group Structure

A total of four face-to-face focus groups were conducted during January and February 2017, in Vancouver, Toronto, Montreal and Halifax and one online.

A market research firm was selected to support the project. The market research firm contacted the candidates on the list provided and extended invitations to people meeting the inclusion criteria.

Where there were insufficient qualified candidates available for a focus group, the market research firm applied the recruitment criteria to its internal database to identify the required number of participants. In total, 7 participants were chosen from the market research firm's database: one for Toronto; two for Montreal; two for Halifax and two for Vancouver.

The same moderator was used for the Toronto, Vancouver and online focus groups. The French language focus group in Montreal and the Halifax focus group used different moderators.

In total 36 people living with arthritis participated in the focus group with a mix of males, females, various ages and various arthritis diagnoses.

Toronto: 6 participants
Montreal: 8 participants
Halifax: 8 participants
Online Group: 6 participants
Vancouver: 8 participants

There were 30 female participants and 6 male participants. Of the 36 participants: 50% had rheumatoid arthritis; 33% had osteoarthritis; 28% had ankylosing spondylitis; 8% psoriatic arthritis; 6% juvenile idiopathic arthritis and 3% fibromyalgia. Note some participants reported multiple conditions.

Focus Group Discussion Guide

A discussion guide was developed for use at all the focus groups (Appendix B). The discussion guide final questions and prompts were developed with input from the market research firm. The discussion guide was intended to optimize the consistency and comparability of the focus groups discussions.

Reporting and Analyses

The market research firm provided verbatim transcripts and videos from each focus groups for analysis. The use of the transcripts, videos and audios provided the opportunity to examine themes that emerged and in some cases themes based on age, disease stage and different arthritis types.

The focus group sessions helped to illustrate the gap that exists between how clinicians treating arthritis perceive the progress of treatment, and how patients experience their disease.

Focus group participants spoke at length about the daily struggles and overall negative impact of arthritis on their quality of life.

KEY FINDINGS

Validation of the arthritis patient's condition and related symptoms by the health care provider

Focus group participants indicated that they want to be heard: they want their symptoms of pain, fatigue, depression and anxiety validated by a diagnosis by their health care provider.

They wanted to feel compassion, sympathy and/or empathy for their lived experience with arthritis from their health care provider, particularly their rheumatologist and family doctor.

Once validated by their health care provider by a diagnosis and further understanding, the participants expressed having more confidence in dealing with family, friends, co-workers, etc. who misunderstand their condition and its impacts.

Focus group participants also want to be heard and understood by their loved ones, friends, co-workers, and others in their extended circle; although arthritis symptoms aren't always visible they are real and are constantly changing. Participants want understanding that what they were able to do yesterday may not be possible tomorrow and that this is not a result of laziness or lack of interest; it's a result of changing symptoms of pain, fatigue and resulting depression and anxiety.

Tools to improve communication between the arthritis patient and health care provider

Focus group participants indicated they wanted to be able to explain ALL their arthritis symptoms to their health care provider, particularly their rheumatologist and family doctor, including the emotional as well as physical.

Participants indicated it is not always clear to arthritis patients what symptoms are associated with their arthritis; therefore a tool/questionnaire would be useful to effectively communicate their condition and related symptoms with their health care provider. "Sometimes you don't share information with your doctor because you are not asked, or you don't think it is related or helpful. A questionnaire would be useful. I have pain in my jaw, but I never linked it to my disease."

Focus group participants indicated they want their condition and the treatments to be explained in a way that is understandable. They want a prognosis "what to expect", and to be told what they can do, what can't they do. "Tell me what is the worst case or what to expect so if I experience symptoms, I know that they are related to my disease." They want clear expectations from their treatments, the side effects and efficacy and a backup plan if the suggested treatment does not work.

The majority of participants want more time with their health care provider, particularly with the rheumatologist and family doctor. They do not want to feel rushed in an appointment and experience anxiety when they can only raise one concern in each appointment. They want the opportunity to book extra time in their appointment with their doctor.

Shared-decision making

Focus group participants expressed that they want decisions about treatments to be made with their participation and an understanding of their treatment goals as well as their life goals. Decisions cannot just be based on test results and the physician's perception of how the patient is doing.

They want to know what the plan is, if or when a current treatment fails or stops working.

Coordination among members of the health care team

Participants expressed the need for communication and coordination among their health care providers. "I have to repeat the same information over and over again to different doctors and sometimes over again to the same doctor."

In some cases, participants indicated their rheumatologist does not share information with their family doctor about test results.

Focus group participants want to be able to change their doctor if they are not able to communicate with their current doctor or are not satisfied with the level of care.

Complementary treatment options

Many participants talked about complementary or "natural" treatments to help with pain and fatigue. They would like to be able to discuss these treatments with their health care provider, particularly their rheumatologist or family doctor, to get their opinion or suggestions.

Drug funding

Some focus group participants wanted more help from their doctor about where they can get funding for arthritis treatments.

Arthritis, what does it mean to those who live with the condition and what is its impact?

In each session, focus group participants were asked to name what comes to mind when they see the word arthritis. This led to a more in depth discussion about what it means to the participants to live with arthritis. The themes below are what emerged from this discussion.

Arthritis = Pain – in each focus group session the first word associated with arthritis was pain, because pain is invisible to the outside world, it is often misunderstood.

Arthritis is a lifelong disease that needs to be managed on a daily basis.

Arthritis affects each individual differently. It can add strain on spouses, family members, friends and extended circle such as co-workers, fellow students, managers, employees, clients, etc. "Before my diagnosis, I thought our marriage was going to end because my husband couldn't understand why I wasn't able to do more with the kids, around the house, or with our friends."

The biggest impact of arthritis is the "loss of life" the actual loss of what one was able to do before the disease struck. Participants provided many examples of the impact of the disease, including being no longer able to: finish university; do their job; participate in social activities; compete in sports; ride a horse; walk without a cane and do active things with children and grandchildren.

Additional, significant impacts participants indicated include: restricted mobility (getting around); stiffness (especially in the morning); brain fog; the fear of not being able to do one's job; the stigma, or perception of laziness, due to the impact of pain, fatigue and restricted mobility. "You could do it yesterday, why can't you do it today?"

It's a daily battle

- "Every few days, I hit a breaking point. You tell yourself that you're imaging it because of the way people react to it, [the symptoms are] not incredibly visible."
- "You're in pain and you're tired, but you can't give in to it, or you would have no life."

- The condition is constantly changing, pain moves around with no warning.
- Difficult to make plans, have to take each day as it comes.
- Medications:
  - that no longer work
  - side effects
  - costs
  - that work differently day to day and by individual, and
  - fear of medication addiction.
- Health care providers who don’t understand/empathize:
  - Challenging communication with health care providers, “if only my doctor would listen to me and not make me feel like he’s rushed and in a hurry to see the next patient”, “My doctor uses words I don’t understand, I have to go home and search the Internet.”
  - Health care providers who have different treatment goals than the patient “my doctor wants to achieve remission at any cost, I want quality of life to get back on a horse”,
  - Health care providers who treat the same patient but don’t communicate with one another, “my rheumatologist diagnosed me and didn’t send my test results to my family doctor”,
  - Health care providers who stereotype patients “she’s a constant complainer”,
  - The need to constantly coordinate among all the health care providers,
  - Health care providers who won’t prescribe strong pain medication or medical marijuana,
  - Long wait times to see a specialist and to have procedures done.

- Isolation due to lack of understanding or empathy by family, friends, co-workers, etc. "I lost my friends because they didn't understand that I wasn't able to do all the things I use to be able to do"
- Family, friends, co-workers, etc. who think they have the answers – exercise more, lose weight, eat healthier, stop eating gluten, try this treatment, etc.
- Dependence on caregivers, family members, even strangers, medications, devices such as braces, canes, splints and at times wheelchairs, "When you're a young person walking with a cane, people look at you funny."
- Exercise/physical activity challenges – weight gain, depression
- Anxiety, stress, depression associated with pain, fatigue, isolation.
- Witness the suffering of family members. "My mother lost both of her legs and then died at a very young age."

What can individuals do?

Focus group participants were asked to create their wish list of what they would want changed to better address their challenges regarding the impacts of arthritis on their lives. They were also asked to identify the things that they could address personally. This list is a summary of the discussions that ensued.

Individuals must be their own advocates. Some participants indicated the irony – advocacy is needed most when the individual is least able to self-advocate due to pain/fatigue and other symptoms.

Fight for a diagnosis – diagnosis helps to validate the individual's physical and emotional behaviour to loved ones, friends and extended circle, such as co-workers, etc.

Model behaviour – behave in a way that patients want their health care provider to behave – understanding of their time, limitations, etc.

Be prepared for the appointment and proper follow up – bring in a list of questions, ask for a longer appointment, talk to the nurse, make a follow up appointment to discuss more details.

Have reasonable expectations of the health care provider – understand the limits of the health care provider, ask "is this something within the scope of your practice", "is this something you have experience with", "do you think there would be someone more qualified who we can bring in".

Be prepared to change health care provider if the health care provider is not providing adequate care or if there is ongoing lack of communication.

Be forthright with information about how you're feeling and how that affects your arthritis symptoms.

Monitor lifestyle – diet, hobbies/activities to distract oneself from the pain, hot and cold packs for some immediate relief, meditation, exercise – stretching, walking, swimming, take time to rest, try to avoid crowded areas such as public transit during rush hour) where you can be moved or are risk of viruses, make changes in your home to protect joints, ergonomic work areas.

Follow the treatment plan and let the HCP know when something is not working.

Positive Health Care Provider Traits | Characteristics and Activities

Focus group participants were asked to describe their physician, the one they see most to treat their arthritis. They were asked to compare their physician to an animal. In each focus group session, this led to a discussion about the positive and negative characteristics of their health care provider. The points for each are listed below.

A health care provider who can be sympathetic, empathetic and compassionate.

- "My doctor holds my hand when I break down and cry."
- "Who makes eye contact, has positive body language, addresses me while sitting down."
- Respects the patient's lived experience and right to autonomy.
- Treats and relates to the patient as a human-being, not a problem or a diagnosis.
- A health care provider who is willing to be humble and willing to learn from a patient (particularly family physicians who may not be familiar with the condition or in some cases know less about the condition than the patient).
- A health care provider who recognizes that it is taxing on patients to make themselves continuously vulnerable to strangers who are in charge of their well-being.

A health care provider who makes decisions with the patient.

- Engages in shared decision-making.
- Makes a solid treatment plan with the patient, taking into account what the patient wants to achieve.
- If the patient wants to do something and the drug is going to limit the patient in some way, the health care provider takes that into consideration.

A health care provider who communicates clearly and realistically.

- Explains the diagnosis and treatments in language that the patient can understand or provides pamphlets that describe the condition.
- Who is realistic and clear about treatment outcomes.
- Builds confidence with the patient by explaining the treatment in practical terms and expected outcomes, and has a back up plan if treatment does not work.
- Does not make assumptions about what the patient may know about the condition, regardless of family history, etc. "He was my mother's doctor and she had it (arthritis) so he always assumed I knew what he was talking about, but I didn't."

Health care providers who coordinate care

- Patients appreciate all members of their health care team to be coordinated with their care and to all know what is going on with their condition and treatments.
- "My doctor called my other doctors and that made me feel really well cared for."
- Makes referrals to other, alternative or complementary resources such as naturopath, dietician, chiropractor, etc.

- Is open to alternative treatments.
- Makes suggestions about support for medication funding.

Negative Health Care Provider Traits | Characteristics and Activities

As described in the previous section, these themes based on negative traits and characteristics were derived from the focus group discussion in which participants were asked to describe the health care provider they see the most to treat their arthritis.

Lack of information provided to the patient.

- Some focus group participants indicated they experienced challenges associated with communication after diagnosis.
- Participants indicated not being able to focus on what the doctor is saying after diagnosis. "The tests show you have ankylosing spondilitis. You're going to need to take these 4 different medications, but first I'll have to send you for tests." The patient is not able to focus on anything the doctor is saying after the diagnosis is given. The patient wants to know more about the diagnosis. What is it? Where can I get more information? What do I need to know re: lifestyle dos and don'ts? "He knows he's going to give a diagnosis, why doesn't he have some sort of information pamphlet available?"
- Doctor prescribes medication but does not clearly explain the side-effects.

Health care providers who rush patients and are not understanding.

- Doctor who does not listen, doesn't understand or empathize and does not seem to care.
- Doctor seems rushed and is only going through the motions. Patient perception of what the doctor is thinking "patient is going to fight me on this treatment plan, and probably isn't going to adhere to these drugs anyway. I have to get on with the next patient."
- Doctors who only allow patients to deal with one issue in each appointment. "This is stressful, because I have a list of things I want to talk about, and now I have to think about which one is the most important and I have to make another appointment."

Health care providers who treat arthritis with a very narrow scope of practice

- Doctor who does not address prevention to the patient – "will the medication help to prevent further joint damage?"
- Doctor who does not take ownership when something goes wrong.
- Health care providers who are not comfortable, don't take the time or don't make the link between physical and mental health.
- Health care providers who only deal with depression caused by pain and other symptoms by prescribing anti-depressant. "When I discuss emotional issues, his solution is to prescribe an anti-depressant."

Additional comments:

- Young participants talked about being nervous or embarrassed about expressing themselves with their doctor, concerned that they will not be taken seriously or believed. They also feared asking for pain medication or medical marijuana.
- Participants indicated that people with arthritis develop a high pain tolerance and have to learn that not all pain is arthritis pain. One example was a participant walking on a broken leg for over a week and didn't realize the leg was broken.
- Several participants mentioned that the pharmacist is helpful. They are able to talk to the pharmacist about medications. "My pharmacist has a lot of time for me. We work together to find treatments that work."
- A lot of discussion from participants about trying to get off medication. They had concerns about the long-term effects.

SUBJECT MATTER EXPERT INTERVIEWS

Background

Research reported in the literature review indicates that there is a gap between how clinicians who treat arthritis perceive the progress of treatment and how patients experience their disease.

Clinical practice and decision making regarding arthritis management has traditionally focused on clinical measures of disease – physical, physiological, biochemical – and only recently has it begun to include patient-based measures and outcomes.

The bottom line – until individuals with arthritis see a positive impact on their daily lives, many are not satisfied with, or may not see progress when it comes to their disease, even when their health care providers see progress and treatment success.

While patients indicate a certain level of satisfaction with their health care provider, they also indicate that they are not satisfied with the results of their treatment and are seeking strategies on their own to help reduce the impact of the disease.

Rationale

The research reveals that the gap between clinical practice and the patient experience of disease has been linked to reduced functionality and quality of life among patients, a more challenging and difficult process to navigate the health care system, and influences the decisions patients make about treatment and management of their disease.

Objectives

Therefore, the overall objectives of this research project are to better understand:

1. How people with arthritis or persistent joint pain understand and assess the impact of pain, fatigue and other symptoms of arthritis on their quality of life,
2. How people with arthritis or persistent joint pain communicate this impact with their health care team, and
3. The GAP that exists between the patient experience and the clinical markers used by health care providers to assess the impact of pain and fatigue and other symptoms on quality of life.

The specific objectives for the subject matter expert interviews

To better understand how health care providers who treat arthritis or persistent joint pain:

1. Assess the impact of symptoms of arthritis/persistent joint pain on the quality of life of their patients,
2. Prefer that their patients share how the symptoms of arthritis/persistent joint pain impact their quality of life, and
3. Perceive the impact of the GAP that exists between the patient experience and clinical markers on patient disease management or patient outcomes.

Subject matter experts interviewed

Four subject matter experts were interviewed between January and March 2017. They included a family physician with a speciality in pain management, two rheumatologists who work in large hospitals and one oncologist who specializes in palliative care.

Summary comments and themes

Family physicians do not receive enough pain management education either while in medical school or afterwards.

Family physicians do not take the time, nor do they have a lot of time during appointments, to properly assess the pain of their patients.

Family physicians, as well as specialists, are reluctant to prescribe opioids to help their patients manage pain.

Rheumatologists do not have time to treat pain nor do they have time to assess the effects pain has on the patient's quality of life.

Due to lack of resources to treat mental health issues associated with the symptoms of arthritis, rheumatologists avoid discussing mental health with their patients, both as a result of their pain or as a possible contributor to their pain. "It's a huge burden, if we identify it (mental health issues) what do we do about it?" "Many physicians don't ask about it because they can't deal with it (mental health issues)."

Rheumatologists prefer that family physicians treat osteoarthritis patients, since the type of interventions required can be delivered by a family physician.

There is a definite need for more pain clinics where family physicians can refer chronic pain patients. An example of a good model exists in Nova Scotia, but it is under-funded and exists due to the willingness of the health care providers to make it work.

The health care gap for patients with chronic pain exists at the professional level as well. Even if the rheumatologist recognizes and acknowledges the patient experience and the impact on quality of life because of the symptoms of arthritis, there is little the rheumatologist can do for the patient. If the patient has emotional or mental health issues because of chronic pain, there is nowhere to refer the patient. Even if there were, it would take a lot of time and effort from the rheumatologist to navigate to the proper care for the patient. In most cases, it is time the rheumatologist does not have.

Family physician, pain specialist, Ontario

Pain is taught poorly to family physicians – the fact is they get almost zero education on pain management in medical school. Most family physicians are aware of pain scales but do not go beyond measuring the severity of pain to assess impact on quality of life.

Some family physicians care about pain and organize their time so that they can spend more time on pain.

The Brief Pain Inventory (BPI) [http://www.npcrc.org/files/news/briefpain_short.pdf] is a tool that pain specialists have been promoting for the last 20 years. It is a universal tool for measuring pain – pain scores, pain diagram, interference scores and how much pain impacts various aspects of life.

It is no longer ethical to simply lower pain scores without improving patient's function and quality of life – but how do you measure this? The BPI is a good tool, but family physicians are not educated on this tool and they do not have time to use it. Family physicians need to have more education; treating pain is not just about finding the right drug, pain affects mood and function.

In addition to the lack of education, our system is not set up to allow family physicians enough time to deal with pain. Pain is perceived as subjective and leads to depression and other emotional factors – family physicians get overwhelmed when a patient starts to describe their experience with pain.

Patients can be educated to present their symptoms in an organized way. Generally speaking patients are not good at describing their pain in a way that is helpful to the doctor.

A "bedside" app could be developed to help family physicians understand pain better and to be able quickly provide patients with self-management advice the patient can take before prescribing a pain medication. And, a companion "tableside" app can be developed for patients that present patients with tools that are evidence-based and informed. The app may include a decision tree. The patient app can also help patients to communicate their pain and its impact in an organized way. "What does the doctor want to know from you?"

There is a definite need for improved pain management delivered by the family physician. When patients are in pain, they suffer with depression and other emotional issues that in turn cause further physical ailments. It is hard to self-manage pain when you are feeling depressed and have no energy – daily activities are affected, quality of life is also affected.

Patients with rheumatoid arthritis are relatively well looked after by rheumatologists. There are treatments and decision tools for rheumatoid arthritis patients.

Rheumatologists are not generally interested in osteoarthritis, because there is not a lot they can do. With an osteoarthritis patient, they likely see their family physician who provides a prescription. If they are an informed consumer, they can ask, "Are there other options for me?" The patient can become a vehicle for educating the physician.

The best way for patients to navigate the system is if there were multi-tiered systems in place, for example, if there were somewhere for a family physician to refer a pain patient. One system example exists in Nova Scotia. In Nova Scotia there are three levels to the model:

The first level – improve education at the family physician level. The family physician initiates some basic treatments for patients. If the pain persists, the patient can be elevated to the secondary level.

The secondary level is a pain clinic where patients can be referred from the primary level. This level is a clinic for patients in pain staffed by family physicians, physiotherapists, psychologists or other health care providers dedicated to pain management. If the pain persists, a tertiary tier exists.

The tertiary level is a pain centre in a hospital staffed by rheumatologists and orthopaedic surgeons.

The model in Nova Scotia is poorly funded and largely survives because of the interest of the medical professionals in treating pain.

Rheumatologist, Quebec

This rheumatologist assesses quality of life from an informal point of view by asking questions about the things that the patient is having trouble with, hobbies that can no longer be done, other things that can no longer be done that brought happiness.

From a formal point of view, we have standardized function scales that we use with patients with rheumatoid arthritis, psoriatic arthritis and ankylosing spondylitis. This is the PROS – patient reported outcome survey. This physician uses the Health Assessment Questionaire (HAQ) – a two page questionnaire that includes questions regarding functions, various activities. It provides a standardized way to assess, measure and compare patient function over time.

There is a specific function test tailored for people with ankylosing spondylitis and it is the Bath Ankylosing Spondylitis Functional index BASFI – it is a standardized questionnaire used worldwide.

These are tools that are partly used in research but can be used in the clinic. This physician uses them, but is not sure how widely used they are.

There is no similar standardized scale or assessment for people with osteoarthritis, because it presents differently in each person. It can be localized to one finger, or other specific part of the body. Hard to ask standard questions. Instead, this physician asks questions about how symptoms affect function and activities.

Whatever method is used, it is important to have outcome measures to assess over time for improvement.

There are a number of things to consider when assessing people: how many and which joints affected, functional tests, blood tests, pain scales – visual analogue scale (VAS).

There is also the patient global assessment (PGA) – “considering all aspects of your arthritis, how are you doing on a scale of 0 – 10’? The PGA is very important and should be widely used at the bedside and clinic visits to monitor and keep track of the patient.

There is also a MD global assessment – here the physician assesses how the patient is doing on a scale of 0 – 10. The discrepancy between the patient and the physician is the gap.

When the patient provides a lower rating than the physician, this discrepancy is the gap. This physician uses the tools described above to help address the discrepancy. There are no great tools to address the discrepancy, it is up to the individual physician to figure it out.

This physician spends time talking to the patient to find out how they are doing, because there are so many factors that can influence how the patient is doing – emotional, psychological.

There are depression tools that can be used. This doctor does not because of the lack of time with the patient to complete and assess the tools and the lack of mental health resources for patient referral.

"It's a huge burden, if we identify it (mental health issues) what do we do about it? Many physicians don't ask because they can't deal with it (mental health issues)."

It is hard for the physician to navigate through a system that does not have resources on behalf of the patient.

The gap exits at the patient level, but also at the health care provider level. Even if the rheumatologists are able to recognize and acknowledge the patient experience and the impact on quality of life, there is little the rheumatologist can do for the patient. If the patient has emotional or mental health issues, there is nowhere to refer the patient. This doctor sees many patients who do not have a family doctor and are referred by a clinic.

One thing that would be helpful is a health care team, with a nurse who can see the patient separately from the doctor and help the patient navigate for mental health resources.

Rheumatologist, Quebec

This physician does not do anything formal in the clinical setting to assess quality of life, instead this physician assesses function by asking questions about daily activities, such as, do you leave the house, do their own groceries. This physician does not ask anything proactively about mood, unless the patient raises the subject. She does not ask because "there is only so much we can do, no time, limited resources". She only addresses things that she can help.

She does not use any formal assessment tools. Instead she asks her own questions catered to the patient to create a baseline. She will use the same questions for that patient each time to assess changes. She tests for function, independence, and mobility.

This physician is amazed at how much information a patient is willing to share, even intimate details. She says a lot has to do with whether or not the physician seems rushed and the general attitude of the physician. In this case, the physician schedules longer than normal appointments with her patients, 12 minutes instead of 5. She allows for a few longer appointments each day, one at the end of the morning and one at the end of the day.

There is a huge gap between the patient experience and the clinical markers used by health care providers to assess the impact of pain and fatigue on quality of life. This takes time, energy and resources and all of these are in short supply. It would be useful to have improved access to better pain clinics.

The gap that exists can exacerbate symptoms and have dramatic consequences.

All patients find it complicated to navigate our health care system. I advise them to get an advocate, someone who can help them book tests, find local resources such as physiotherapy, or local gyms for seniors.

"Pain is a big problem. I feel helpless. Medications are limited, not that effective and have many side effects." Osteoarthritis patients should be referred by their family physicians to pain clinics and back specialists.

Rheumatologists should be dealing with inflammatory illness and family physicians should be dealing with osteoarthritis or back pain. Currently, these patients are often poorly managed by family physicians.

Oncologist, palliative care specialist, Manitoba

There are many challenges in the health care system that have led to huge gaps in care for patients with chronic pain.

Health care providers do not have a good handle on pain, despite being taught and seeing many patients with pain – 20% of patients have some sort of chronic pain.

Therefore, patients with chronic pain are not being assessed properly and as a result are not referred to the proper physicians, although there is a general shortage of pain specialists and pain clinics across the country.

Furthermore, family physicians in particular are reluctant to prescribe treatments because of the concerns about opioid and other narcotic addictions being blown out of proportion by the media. Some patients take advantage, but they are the minority.

Physicians who come to Canada from other countries are even more reluctant to prescribe opioids because they do not want to appear to be doing anything wrong.

Family physicians do not take pain seriously because it will not kill the patient, but high blood pressure could. But chronic pain contributes to depression, self-medication, other drugs on the street.

Many osteoarthritis patients are older and have other co-morbidities that make treatment for pain expensive.

There is not enough of a push for pain management from the medical community. The concern is that doctors who treat pain want to keep their heads down, so they will not be noticed and taken to task by the public/media.

The Canadian Pain Society has developed guidelines on how to treat chronic pain. They are accessible but not well accessed.

Education for physicians is key, but it has to come from sources other than the pharmaceutical companies. One possible solution is to run webinars on an accredited site such as The Arthritis Society. Webinars could be developed to target physicians and others to target patients.

Appendix A

DIGITAL APPS FOR PATIENTS

Name	Description	Author/ Publisher	Link
Track + React	Tracks your daily activities and how your arthritis pain reacts to each item	Non Profit: Arthritis Foundation	https://itunes.apple.com/us/app/track-+-react/id543425812
The Arthritis Toolkit	Self-study package of print and electronic media	Non Profit: Arthritis Self Management Program	https://www.bullpub.com/catalog/the-arthritis-toolkit
Setting Goals	Goal Setting Tool Kit	Non Profit: The Arthritis Foundation	http://www.arthritis.org/toolkits/better-living/setting-goals/
Communicating with your Doctor	Communication Tool Kit	Non Profit: The Arthritis Foundation	http://www.arthritis.org/toolkits/better-living/communicate-with-doctor/
Walk with Ease	Walking Tool Kit	Non Profit: The Arthritis Foundation	http://www.arthritis.org/living-with-arthritis/tools-resources/walk-with-ease/
Predict your pain	Weather App	Non Profit: The Arthritis Foundation	http://www.arthritis.org/living-with-arthritis/tools-resources/weather/
Your Exercise Solution	App to generate exercises	Non Profit: The Arthritis Foundation	https://www.arthritis.org/living-with-arthritis/tools-resources/your-exercise-solution/
Rheumatrack	Track pain, stiffness, and medications easily on your mobile device. It will also track your activities, including days when you were unable to work, and fitness activity.	Private: axovis GmbH	https://itunes.apple.com/us/app/rheumatrack-ra/id419204884
My RA	Tracks your symptoms, medications, and your overall condition day to day	Private: Crescendo Bioscience	https://itunes.apple.com/us/app/myra/id563338979
My Pain Diary	Tracks chronic pain, symptoms, triggers, weather	Private: Damon Lynn	https://itunes.apple.com/us/app/my-pain-diary-chronic-pain/id338627856
Rave	Tracks your symptoms along with your dosage, so that you can learn how well your treatments are working	Private: DKBmed LLB	https://itunes.apple.com/us/app/rave-mobile/id505074662
@Hand: Rheumatology Checklist	Questions to ask and which treatments to talk about with your doctor	Private: Medical Wizards Corporation	https://itunes.apple.com/us/app/hand-rheumatology-checklist/id422933848
RA Helper	Track your disease score and lab results, as well as your goals	Private: Modra Jagoda d.o.o.	https://itunes.apple.com/us/app/ra-helper/id723402267

FOCUS GROUP RESEARCH

Appendix B

IN-FACILITY DISCUSSION GUIDE

A. INTRODUCTION & WARM-UP 10 MINUTES)

Objective: Participants will be familiarized with the objectives of the session and the agenda. The goal of this section is also to make them feel comfortable in expressing their opinions and warm-up the discussion.

Projective Exercise: Word Association

B. PERCEPTION OF ARTHRITIS (15 MINUTES)

Objective: To understand the patients' day-to-day experiences with the disease symptoms.

Projective Exercises: Brainstorm and Lobby Exercise Review

C. MANAGING ARTHRITIS (20 MINUTES)

Objective: To understand how patients currently manage their Arthritis symptoms as well as who is involved in the care of their Arthritis.

D. PATIENT SYMPTOM DEVELOPMENT GOALS (20 MINUTES)

Objective: To understand the patients' goals in terms of managing Arthritis.

E. COMMUNICATION WITH HEALTH CARE PROVIDERS (45 MINUTES)

Objective: To understand the communication between the patient and their HCPs who help them manage their condition at different points in the management of Arthritis so that we better understand the 'gap' between the patient's lived experience and the HCP assessment

Projective Exercises: Animal Quest and Roleplay/Thought Bubble

F. FINAL QUESTIONS & THANK YOU!

Appendix C

WISH LIST

Focus group participants were asked to write down their wishes for what would help improve their arthritis care.

Relationship with the physician:

- More recommendations for treatment, more information on side effects. Understandable information, accessible information (credible resources that the patient can check on his/her own). A physician fully informed and up to date with all the relevant information available in current research.
- Have a glossary of the technical words. It will help the communication with the physician.
- Provide a questionnaire. It will help patients to better communicate their symptoms and what they are feeling, in a way that physicians find useful.
- Have more education on the disease, what to expect in the future? Where are we with research for a cure? What are the alternatives for pain?
- Have more referral to other health care providers: nutritionist, naturopath, physiotherapist etc.
- Have the doctor refer the patient to useful resources in community (i.e. Arthritis Society, a community health team, other health care providers…)
- Have more time during the appointment (30 min instead of 10 min) to be able to ask questions / to discuss the pain and why it happens / to discuss about the "worst case scenario."
- Have a physician who takes in consideration the emotional part of the disease not only the physical part / overall care (physical + mental + emotional).
- A physician who cares and listens what the patient have to say (eye contact, compassion, empathy, one on one sit down discussion, transparency).
- "A physician who believes me when I say how I'm feeling with out questioning it."
- Better communication between all the health care providers (family physicians & specialists) / one doctor/individual who manages all the other doctors and health care providers.
- Shorter wait time to see a specialist (rheumatologist, physiotherapist, psychologist…)
- A physician open to discussions about alternatives treatments/medications.
- "I wish I could use the right words so the doctor understands the pain type."
- A physician who remembers the conversation from appointment to appointment.
- A single place (preferably online) to store all records, appointments and medications.
- A way to ask questions online and get response quickly from the physician and his/her team.
- Have access to support group with other patients and have the possibility to share experiences.

- To get into a pain clinic sooner to learn additional ways to deal with pain, without medications.
- To get the correct testing done / Have a correct diagnosis.
- Be entitled to a second opinion without feeling horrible for asking.
- Be treated as a human being, not a problem or diagnosis.

The treatment/drugs

- To not be drug dependent.
- Have more natural less invasive options.

The pain:

- Reduce the pain / cure the pain / pain relief
- Keep a pain diary, keep track of the symptoms.

Personal life:

- "Be able to do things when I want to do them not when my body tells me to do it or not too."
- To sleep through the night regularly.
- To feel good about yourself.
- "I don't want to say no to other parts of my life."

Society:

- No judgement from the society.
- Better understanding by the general public. This is not an old person's disease.

Cost/Insurance:

- More information about coverage.
- Medical funding / assistance / more funding from the government.
- "Rheumatoid Arthritis medication should be affordable or better yet free."
- "Cheaper drugs."

Appendix D

INTERVIEW QUESTIONS

1. When treating patients with arthritis or persistent joint pain, do you assess how their symptoms affect their quality of life? For example, their daily activities, things they enjoy doing, their mood, etc.
2. If so, please explain how you do that – what tools do you use?
3. Are you satisfied with the way in which your patients share this type of information with you?
4. Do you have a preference or any ideas on how to improve the way patients share information about how their symptoms impact their quality of life?
5. Do you acknowledge that there is a gap between the patient experience and the clinical markers used by health care providers to assess the impact of pain and fatigue and other symptoms on quality of life?
6. What is your perception of the impact of this gap?
7. Based on your experience in treating patients with pain/arthritis, what are the challenges that you perceive patients face when they are navigating the health care system to manage pain?
8. In your opinion, what would an effective/successful pain management system look like? For example, would it include, frontline health care providers trained in pain management? Would there be guidelines for training health care providers about pain? Is there a role that health care providers could play regarding self-management – for example, help the patient understand what she should or should not do when it comes to self-management?
9. Do you have any other comments about how best to bridge the gap between the patient experience and the clinical markers used by health care providers to assess the impact of pain and fatigue and other symptoms on quality of life?

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