




Networks of Care: A Social Network Perspective of Distributed Multidisciplinary Care for People With Inflammatory Arthritis

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Objective. To explore how multidisciplinary inflammatory arthritis (IA) care is accessed from the perspectives of people with IA and their health care network members.

Methods. In this phenomenological study, we used purposive sampling to recruit patients with IA for less than 5 years and age of more than 18 years who spoke English and reported two or more health care network members. We conducted one-to-one interviews with patients and their health care network members. Data were analysed using a social network perspective.

Results. We interviewed 14 patient participants and 19 health care network members comprising health care providers and informal caregivers. An overarching theme of whole person (holistic) IA care was identified, with the following two broad multifaceted subthemes: 1) connected networks and whole person care and 2) network disconnect and disrupted access to care. The first subtheme notes how access to health care providers and social support was fundamental to holistic care and how care was facilitated by communication pathways that promoted care. The second subtheme illustrates impediments to access, including appointment time pressures, inadequacies in communication delivery modes, and family physicians' unfamiliarity with rheumatology care. Inequities in care were also reported.

Conclusion. Participants shared a goal of whole person care. Although health care networks included multiple disciplines, they did not always provide coordinated multidisciplinary care. Communication modes, linkages between network actors, and organizational structures governed the flow of information and resources through networks and influenced access to equitable whole person care. The development of health care system structures to support the flow of information and resource transfer is needed to promote network collaboration and equitable access to resources.

INTRODUCTION

Multidisciplinary patient-centred care is considered a standard care pathway for inflammatory arthritis (IA) to reduce symptoms, limit joint damage and disability, and improve patient outcomes (1–3). Multidisciplinary care (Table 1) is typically provided by family physicians, rheumatologists, nurses, physiotherapists, occupational therapists, patients, and others (1,4–6). However, many patients with IA are not receiving timely and appropriate multidisciplinary care (4,7–11). Delayed access to primary and secondary care can negatively affect patients' health outcomes (12,13), prolong physiological and psychological distress (14,15), and negatively impact social relationships (13,15,16). Moreover, inequitable access to IA care,

particularly pharmacological therapies, can exacerbate disease progression and lead to poorer overall health outcomes (17,18).

To our knowledge, there is a dearth of studies exploring how people with IA access multidisciplinary care from both patient and health care provider perspectives. Studies typically report on experiences of patients recruited from multidisciplinary outpatient and arthritis treatment centres, where team members are co-located and which provide holistic face-to-face care (19) (Table 1). Experiences of nurses (14), rheumatologists (4,14), and physiotherapists (20) have been explored through surveys. Pollard et al (21) interviewed patients and health care providers (one-on-one and in focus groups) at an outpatient clinic. Their findings emphasised family physicians' concerns regarding their

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SIGNIFICANCE & INNOVATIONS

- A social network lens provided nuanced insights to distributed team-based practice. Team members were distributed across different locations, yet they shared a goal of timely access to multidisciplinary holistic care.
- The flow of information (communication) and resource transfer through patients’ health care networks and ease of contact (reachability) can foster seamless (vs fractured) practice within a patient’s health care network.
- Health care structures that foster relational network ties and flow of information and resources have potential to contribute to equitable access to multidisciplinary inflammatory arthritis care.

gatekeeper role to secondary care, their reluctance to refer patients, and the need for further qualitative research in other care settings to enrich insights. Presently, there is little understanding of how patients and their health care network members perceive access to distributed multidisciplinary community care (Table 1).

The purpose of this study was to explore how multidisciplinary IA care is accessed from the perspectives of people with IA and their self-defined health care networks. Employing a social network lens (Table 2), which does not assume any particular view of team care, we explored factors such as network structures and processes that govern patient access to timely and appropriate multidisciplinary health care.

PATIENTS AND METHODS

Study design. We used a social network ego-centered perspective for this phenomenological qualitative study to answer the

following two research questions: How do people with IA and their health care network members perceive access to multidisciplinary IA care? What health care network structures and processes influence timely and appropriate access to IA care?

Social network paradigm. A social network paradigm (Table 2) is orientated toward relations and the patterns they form to construct social life (22). Sets of ties link network actors and enable or block communication and resource transfer between actors, which facilitate ‘action’ (23). In relation to IA care, ‘action’ refers to delivery of health care services for treatment and long-term management. Particular attention is given to characteristics and relationships that enable or constrain choice and agency (23–25). We focus on the ways relational ties form between network actors and how these ties influence network coordination mobilizing communication and resources. Relational ties can be described as interactions between people (24). The concept of reachability characterises the flow of communication and resources between actors (24): specifically, the ease or difficulty with which communication and resource transfer occur (24). This ego-centred approach focuses on participants’ perceptions and mappings of their social world (24). We assumed that the ego networks of patients and health care providers are interwoven with organizational and institutional networks (23,26).

Recruitment. Participants were recruited from metropolitan Vancouver, British Columbia, Canada. A two-phased purposive sampling process was used to recruit patients with IA and members of their health care networks. First, patient participants were recruited through local arthritis clinics and social media platforms. Inclusion criteria for patients included diagnosis of IA (eg, rheumatoid arthritis, ankylosing spondylitis, and psoriatic arthritis) within the previous 5 years; age of more than 18 years; understanding and speaking English; and the ability to identify two or

Table 1. Health care terminology

Term	Definition
Multidisciplinary team	In their integrative review of health care team terms, Chamberlain et al (5) note that the term ‘multidisciplinary team’ is used mostly to identify teams that consist of members from different disciplines who work independently of each other. Although members may share information, they may not necessarily share goals of care. Chamberlain et al (5) also note that ‘multidisciplinary team’ is often used interchangeably with ‘interprofessional team,’ in which members of different disciplines work interdependently in a structured way, particularly around shared decision-making and patient goals.
Whole person/holistic care	An approach that considers the whole person and life context and attends to all health care needs in terms of normality, capacity, independence, and well-being (6).
Distributed teams/care	Care that people with arthritis receive from health professionals and informal caregivers located at different sites throughout the community.
Community care	Care that people with arthritis receive in various locations in their community versus at an outpatient clinic or arthritis treatment center or clinic.
Co-located	Having several health care providers located at the same site or clinic
Arthritis clinic program	Publicly funded, specialized medical, rehabilitation, and education service provided by different disciplines (rheumatologist, physiotherapist, occupational therapist, psychologist, social workers, and others) to people with IA in a single location.

Abbreviation: IA, inflammatory arthritis.

Table 2. Social network paradigm terminology

Term	Definition
Ego-centred network	The network is centred on the perceived network of a specified individual (eg, the patient defines their network by identifying their formal and informal healthcare providers).
Network actors (or members)	People identified as being part of a network.
Network structures and processes	Structures: relational ties and resource availability. Processes: for example, referral processes.
Relations	Face-to-face relationships, political/professional associations, economic transactions, and geographical connections
Ties	Links individuals have with people and between people in their network.
Relational ties	Links between individuals formed by relations.
Communication	Flow of information between network actors that enables exchange of ideas and views about a specific issue to promote understanding.
Resource Transfer	Transfer of resources such as material goods and services (eg, physiological, psychological, and pharmacological therapy, and social support services) between network actors that facilitate action (treatment and management of IA).
Reachability	The ease or difficulty with which communication and resources flow between network actors and the number of steps required to obtain the required contact.
Communication pathways	Communication modes (eg, in-person communication and electronic documents or systems).
Network cooperation	Network actors collaborating to deliver a goal (26); in this instance, delivery of coordinated care for people with IA.
Network disconnect	Absence of or disruption of communication and/or relations.

Abbreviation: IA, inflammatory arthritis.

more health care network members. Study information was sent to interested participants. We sought a purposive sample based on gender, age, diagnosis, and socioeconomic status. Second, during their interviews, patients were asked to identify health care network members who they perceived as important in their care (27). These individuals could be health care providers and informal caregivers (family and friends) (27). With patient permission, network members were invited to participate. Responding network members were provided with study packages. Written informed consent was obtained from all participants. The University of British Columbia Behavioural Research Ethics Board approved the study (H15-01751) in compliance with the ethical guidelines of the 1975 Declaration of Helsinki.

Data collection. Semistructured, in-depth interviews lasted 20 to 60 minutes. Participant interviews were conducted in person (13 patients and three care providers), by phone (one patient and 15 care providers), or by email (one care provider). Interview questions, codeveloped by researchers and patient partners with varied experiences, focused on participant perceptions of patient experiences with diagnosis, interactions with their health care team, and support managing IA (Appendices 1 and 2). Interviewers compiled field notes and all interviews were audio recorded and transcribed verbatim. Personal identifiers were removed to preserve confidentiality. Patients were represented by pseudonyms.

Data analysis. Data were coded to describe phenomena around how participants perceived access to multidisciplinary IA care. NVivo 11 was used to help organize data. The analysis followed a systematic three-stage iterative process (28) as follows:

item analysis, pattern analysis, and structural analysis. Item analysis involved compiling groups of similar items of interest (eg, waiting for diagnosis and pharmacological support), which led to the identification of primary codes for organising the data. Pattern analysis involved a process of comparison, contrast, integration, and organizing items together in higher order patterns (eg, the family physician does not know about IA and arthritis programs). Structural analysis involved bringing together pieces of an analytic puzzle to create an overall picture of the phenomena under exploration (28). During structural analysis, we incorporated initial codes and developed theoretically informed themes that drew on social network concepts. This latter analytic stage elucidated structures and processes involved in access to care.

RESULTS

We recruited 14 patient participants and 19 of their network members (Table 3). Patient participants were a diverse group differing by age, socioeconomic status, and IA diagnosis yet included only two male participants despite repeated recruitment attempts. Four patients did not provide permission to interview their network members, thus the 19 care providers are associated with 10 patients. Although the majority of patients had access to more than one health care professional, they accessed most professionals individually and not as a unified multidisciplinary team. The majority of professionals were not co-located but were geographically distributed in the community. Cam and Geoff's physiotherapists and occupational therapists were co-located. Network composition varied (Table 4), but participants generally had similar goals for care. Participants described how relational ties between network actors and the broader health care

Table 3. Participant characteristics (N = 33)

Patients (n = 14)	Healthcare Providers (n = 16)	Informal Care Providers (n = 3)	Interview Methods
Age: 20-70 yr 12 female patients and two male patients Disease duration = 5-48 months RA = 7 AS = 3 PSa = 2 Undefined = 2 Income range = PWD ¹ -\$200,000 EHC ² : n = 10	Rheumatologists (n = 4) Family physicians (n = 5) Physiotherapists (n = 3) Occupational therapists (n = 1) Counsellors (n = 2) Nurses (n = 1)	Spouse (n = 2) Parent (n = 1)	In-person = 13 patients and three care providers By phone = one patient and 15 care providers By email = one care provider

Abbreviations: AS, ankylosing spondylitis; EHC, Extended Health Care Insurance; PSa, psoriatic arthritis; PWD, People with Disabilities assistance; RA, rheumatoid arthritis.

environment shaped patient care. We identified an overarching theme of whole person (holistic) care, which involved treating the person in their social context, and the following two main sub-themes: 1) connected networks and whole person care, and 2) network disconnect and disrupted access to care. Tables 5 and 6 highlight exemplar quotations, with additional quotations in Appendix 3.

Whole person care: treating the whole person in their social context. Notions of whole person care permeated all participants’ descriptions of care. For example, Cam’s family physician felt it was important to provide “holistic” care as arthritis was only a small piece of the “jigsaw” puzzle of Cam’s health and wellbeing. Whole person care was also described in terms of getting back to normal. For instance, resuming previous household, sport, and social activities, caring for children, returning to work, or finding a new career to accommodate health. Treatment needed to be dynamic, encompass the whole body, consider

patients’ life stage, foster independence, and provide a sense of being a person (with IA) not just a patient. Nadine’s family physician recounted: “And that was really quite a long and difficult road to finally get [Nadine] to a place where she was feeling normal again. Feeling like she could engage in activities that were important to her.”

Access to health care professionals from different disciplines (Table 4) was an important part of participants’ care expectations. Differences in patients’ care were in part due to unique needs and life circumstances. However, in some instances, descriptions of care hinted at potentially unfair and inequitable disparities in care. Network structures and processes appeared to influence network connectivity and whole person care.

Subtheme 1: connected networks and whole person care. The way that network members connected with each other was important. Several patients cited the importance of being closely located geographically to their health care providers. For

Table 4. Patients and their health care networks

Patient Pseudonyms	Healthcare Networks	
	Interviewed	Not Interviewed
Amber	PT	R, FP, MT, CH, and M
Brenda	Permission not obtained	R, FP, PH, and M
Cam	R, FP, OT, PT, and RON	FF
Danielle	CL (psychologist)	R, FP, and FF (intermittent)
Erica	Permission not obtained	R and FF
Francois	R and FP	CH, MT, SP, and RF
Geoff	R, FP, PT, and SP	-
Helen	FP	R, N, and PH.
Ingrid	Permission not obtained	R, FP, OT, FF, NR, DM, IM, and AU
Jamie	R and M	FP
Kathy	CL (psychologist)	R, FP, PT, and MT
Lucy	Permission not obtained	R, FP, and OP
Marie	SP	R and FP
Nadine	FP	R, PY, SM, and PS

Abbreviations: AU, audiologist; CH, chiropractor; CL, counsellor; DM, dermatologist; FF, family and friends; FP, family physician; IM, immunologist; M, mother; MT, massage therapist; NR, neurologist; OP, ophthalmologist; OT, occupational therapist; PH, pharmacist; PS, pain specialist; PT, physiotherapist; PY, psychologist; R, rheumatologist; RF, reflexologist; RON, rheumatologist office nurse; SM, sports medicine physician; SP, spouse.

Table 5. Example quotes about holistic care networks: treating the whole person in their social context

	Quotes
Whole person care	<p>Francois' family physician: "[I]n this particular case the treatment needs are primarily having a physician who believes her descriptions of her discomfort. Because when it's less evident and more difficult to measure with objective tests, it's more frustrating for someone who has pain and symptoms. So she needs trust and the support and the belief of her physicians particularly and then she needs practical prescribing for medication for pain, for activities and rehab that will enhance function. Because that's been really greatly affected by her pain. She needs lots of support through that, so it's going to extend beyond just the physician's relationship."</p> <p>Lucy: "Yeah, like, alternative care I think would be good. Because what I find is that it's just, here's your drugs, there you go. That's it. That's all that the treatment plan provides. So everything else I have to do to treat myself, quote unquote, is done personally. And I think that's wrong because it should be all encompassing with your body."</p> <p>Cam's nurse: "...helping him out ... with things about diet, exercise. Just the roles they play in his disease and just how to optimize his, you know, diet and his exercise and his, you know, getting off his smoking and getting off his valium and stuff like that. Also ... he didn't have any pharmacare coverage for quite some time, because he hadn't done his income tax...I liaised on with the drug company to try to get him free, like, try to have them help him out with the drugs...So I was finally able to help him with a plan to get it done... So we made a step-by-step plan."</p>
Life stage and life context	<p>Jamie's mother: "And they [patient and rheumatologist] worked very closely together around the timing of when she [Patient] could start that drug and then bring her off again to plan for the next baby. So she feels she's got a real partner there in crime, if you like, who is really listening to her needs as a young woman with one baby who wants to have another baby, you know. Who's trying to deal with this diagnosis as well."</p> <p>Brenda: "As a young mom I had lots of concerns. I had to go back to school, actually, after being diagnosed and start a whole new career...they were really good at supporting me and kind of giving me insight and helping me make little goals to help me to get to my big goal...my main goal was to find a career that would be good for me in the long run, wasn't so hard on my joints, and I saw a counselor as well through the arthritis clinic program. And she was really good at just helping me write down like mini-goals to help me get to my big goal."</p>
Getting back to normal	<p>Geoff's spouse: "Like, he did the dishes today and a lot of things he still can't do, but what he can, he does, like the dishes and things like that, so that helps...Little bit of cooking now. He used to do most of the cooking, so that helps a lot too."</p> <p>Amber: "Well, my rheumatologist works with me in terms of finding medications that will work and help me get back to a normal-ish life. Because all I want is- I want to be pain free. I want to keep going in life and I'm starting to understand that that may not be something that will be achievable any time soon. So kind of just working with him with that. My physiotherapist and my massage therapist and my chiropractor, they're all working towards getting it so that I can go back to my sports which is very helpful. I'm just working with all them in terms of that."</p>

others, consistency of care and comfortable relationships with health care providers overrode location: "I think my biggest hope and so far blessing has just been consistency of care...the nurse and the receptionist and the doctor, like, every time I go it's the same three women" [Jamie]. Patients and health care providers indicated that minimizing disease progression, treating symptoms, and resuming social activities was important for patients to "get back to normal." Physiotherapy, for example, was organized both to improve mobility, and revive social connections: "So progressing those exercises, getting him back- specifically for him getting him back on the bicycle so he could go to the gym and socialize which was a big part of his life" [Geoff's physiotherapist].

In terms of whole person care, some patients also benefited from having access to publicly funded arthritis clinics that provided rehabilitation services, counselling, and disease management education. Specifically, patients felt that clinic programs addressed the negative impact IA had on physiological, psychological, and social well-being. Relational qualities, such as physician empathy, trust, support, and belief were important considerations for whole person care. Willingness to listen to patients created opportunities for care providers to better understand patients' concerns, goals, and day-to-day experiences of living with IA. This enabled collaborative discussion of treatments, timing of medication to facilitate

work schedules, and managing pregnancy and breast feeding. These relational connections appeared to foster information and resource flow through the networks.

Face-to-face communication appeared to enhance network connectivity and information and resource flow. For instance, co-location of health care providers provided opportunities for regular meetings and facilitated effective patient treatment discussions. Network members in distributed sites relied on electronic communication systems for information sharing. However, depending on system access policies, some network members were excluded from communications. In these instances, patients would share information among their health care providers, although sometimes the information might be incomplete: "... when I'm transferring information from one of them to the other, I'm either over-simplifying it...Or my memory's really not that great...it's not super accurate" [Kathy]. Moreover, patients were not always convinced that electronically transferred information reached its intended recipient. Disrupted communication experiences were just one aspect of network disconnect that impeded access to care.

Subtheme 2: network disconnect and disrupted access to IA care. All patients experienced disrupted access to whole person care. Patients reported difficulties finding new

Table 6. Example quotes about subthemes: connected and disconnected pathways to care

	Quotes
Connected pathways to care	
Co-location	Cam's physiotherapist: "Usually it's actually in person because actually both of us [Occupational therapist] actually we- it's actually nice in a way that we actually both work in the same area. So we're both located in the outpatient department. So oftentimes it's that I will- because we are actually in the same- our agenda, we actually can see each other's work schedules."
Referral to multidiscipline services	Nadine: "My family physician also back in March 2015, aside from just sending me to the Pain clinic, she also referred me to the arthritis [clinic program]...And in July 2015 I was accepted into their outpatient day program so it was like a five-week program, so I kind of refer to that as my second team of doctors. Because I had an O.T.[occupational therapist], a physiotherapist, a social worker and an overseeing rheumatologist. Oh, and a nurse there. I had five people there..."
Listening	Kathy's counsellor: "People really listening to the patients. Number one thing is actually taking the time. I know sometimes people are pushed in for really short appointments that they don't get a lot of- a chance..." Cam's physiotherapist: "I guess one other thing that's important is also being a listener."
Communication	Amber physiotherapist: "I think communication is the biggest thing. I think, you know, it would be great if, like, we were able to have a meeting, like, face-to-face everyone or even through Skype these days, right. But, you know, just everyone kind of being, like, coming together and being- looking at her case and being, like, what is the treatment." Geoff's physiotherapist: "With this client I actually did have to- I sent- through the patient I asked the patient to go back and see his general practitioner regarding something that happened with his injection site. So that was actually through the patient himself."
Disconnected pathways to care	
Healthcare inequity	Lucy: "...[T]here's hardly any type of government-funded support programs for people with chronic illnesses. And it does affect my life more than I'd like to say...But I would like access to like, maybe, you know, some sponsored physiotherapy that's in the Regional Valley. Because that one in City is the only one in B.C [British Columbia]. And I think of all these people with chronic illnesses out there...But don't [access the service], because (a) they can't afford it or (b) it's not near them." Cam's family physician: "The only conflict I ever have is with Pharmacare when they start dictating what agents my patients might need to be funded for, particularly when they are unable to afford those agents. And the patients are then suffering ... on the basis of not getting the care that they require in terms of the funding that's necessary..."
Trialing medication	Helen: "I started out on cyclosporine and that did absolutely nothing. They made me stay on it longer for the sake of, I guess- for coverage for the government-I have to suffer more in order to be able to try the biologics. Which kind of was really frustrating. 'Cause it affected my life. I have a three-year-old and during that time my life was horrible 'cause I was in pain."
Physician attitude and knowledge	Brenda: "[C]ause my family doctor's not- doesn't seem super informed about inflammatory disease." Marie's spouse: "Dr. T. appeared to be more "old school" and have less regard for allied health such as PT and OT. I can't say for sure what he really thinks, but given his extremely brief encounters with Marie, this is the impression I got."
Appointment time pressures	Ingrid: "...[I]t's a function of time pressures...They [physicians] don't have the time. They absolutely- I mean, if they could spend half their day for each of their patients coordinating care, that would be great. So it's a systemic problem that's not going to get fixed." Danielle: "So I just felt like, okay, nobody's really listening to what I'm saying kind of thing and then the rheumatologist he kind of - he just seemed to want to push the biologics...he wouldn't listen to my- okay, this is what- it's my reasoning, whatever, and he kept trying to push the drugs."

primary care physicians due to physician retirement, practice closure, patient relocation, and lack of support for referral for tests or specialist consultation. Access to rehabilitation resources was also inconsistent. Some patients were referred to arthritis clinic programs by their rheumatologists. Despite requests for referral to these programs, other patients were not referred. These patients perceived that their rheumatologists lacked understanding of the benefits of rehabilitation. Scheduling difficulties, family commitments, and mobility challenges inhibited patient access to arthritis programs. For some, their financial situation and travel distance had prevented their access to these services. Socioeconomic status and medical insurance coverage also determined whether a patient could afford physiotherapy at private clinics as an alternative to arthritis clinic programs.

Access to the most effective pharmacological therapy was also disrupted. Participants referred to the necessity to "trial" different medications for specific periods of time to demonstrate their inefficacy and to conform to government prescription drug coverage requirements. This process was time-consuming; added to patients' frustration, anxiety, and life disruption; and further delayed effective treatment. In some instances, rheumatologists advocated on behalf of their patients directly with pharmaceutical companies for medication at reduced/no cost when a preferred treatment was not covered by either the publicly funded system or patients' extended health insurance (through employers or private plans). Kathy, who received the government disability allowance, had very limited access to resources: "One of the biggest things is access to, like, therapies that are not

covered. There's a bunch of medications that are inaccessible to me because they're not covered by my crappy [disability] coverage and if the medication's not covered I can't purchase it. I just— I don't have any money”.

Family physician unfamiliarity with IA also delayed access to rheumatology care. Patients reported instances of physician disbelief of symptoms and lack of understanding of the physical and psychological stress of IA contributing to delayed referrals. For instance, several female patients recounted how their family physicians had repeatedly ignored their descriptions of increasing joint pain and decreasing mobility, and refused referrals and IA testing. Instead, symptoms were variously attributed to carpal tunnel, pregnancy, and osteoarthritis or were dismissed as mental health issues. Terms such as “hysterical female diagnosis” and “because I was a woman” suggested that some women believed gender played a role in symptom dismissal and consequently delayed care.

Participants recognised physician time constraints which frequently resulted in brief consultations and, particularly prior to diagnosis, did not allow for listening to patients' complex illness experiences and assessment of patients' support needs. By the time some patients were diagnosed, they had experienced symptoms for months or even years. Patients felt that being listened to early on by their family physician could have accelerated their diagnosis and prevented years of pain and anxiety: “I had to fight for that diagnosis in the first part...I think that once I got diagnosed it was a huge relief because I think mentally it had been playing on me for years and years and years...” (Lucy). Furthermore, Kathy's counsellor commented that taking time to “really” listen to patients “before moving to prescriptive mode” would provide “everyone on the team” the opportunity to better understand patients' anxieties. These comments supported patients' concerns that physicians were often too quick to prescribe medication rather than identifying treatment that would encompass the needs of the whole person.

DISCUSSION

This work uniquely employed an ego-centred social network approach to explore IA care. It builds on previous research by exploring IA care networks identified by patients, rather than IA team care determined by a hospital or clinic (14,21). The study contributes to this body of work by illuminating the diverse nature of IA care and the need to develop linkages between network actors (patients and their IA network members). The orientation that relations and the patterns they form construct social life underpins a social network perspective (22). Relations that develop between individuals and groups are of interest rather than individual attributes (24). This perspective is a departure from more standard research approaches in IA care, which focus on individuals and attributes. For example, research approaches have interviewed multiple stakeholders but consider the

professional attributes (eg, skills specific to physiotherapy, nursing) individual actors bring to IA care delivery as discrete entities (22). A social network approach brings attention to the ways in which relational connections form between actors involved in IA care influence the social action of delivery of care. In particular, our findings illuminate how communication (information flow) and resource transfer and reachability (how easy it is to access IA care) intertwine within patients' health care networks. These relational aspects of networks interconnect with structural properties of networks, such as geographical distance, to influence social action (delivery of care) (24). Together with the broader health care system, these properties of social networks shape access to IA care.

Each network presented a different experience of care. However, dissimilarities in care were not unexpected given the heterogeneity of care networks. The provincial publicly funded universal health care insurance provides medically necessary care for all residents (29). This health care insurance is expected to cover all residents under the same terms and conditions (29). Thus, a surprising finding was the implication that access to appropriate care was, for some patients, delayed or out of reach because of their socioeconomic status, geographic location, or gender. This illustrates the potential for care inequities and poor disease outcomes. Nonetheless, participants expressed similar interprofessional (5) notions of IA care. However, although networks were multidisciplinary in composition, there was limited evidence to indicate that care was intentionally coordinated with goals and treatment objectives mutually shared between network actors. Perceptions of care did not match expectations. From a patient and informal care provider perspective, care did not always address the needs of the whole person. From a health provider perspective, various barriers impeded delivery of collaborative whole person care.

Information transfer throughout networks (26) and network connectedness (23) is critical for goal achievement (access to whole person care). However, information flow through electronic communication systems was not consistent throughout patients' health care networks. Inadequacies in these delivery modes—such as the exclusion of some health care providers from patient communiques—interrupted information flow and reachability between network actors. Moreover, the necessity for patients to act as communication pathways may, as our findings suggest, contribute to misinterpreted and filtered transfer of information through the network (30). Network connectedness is more difficult to achieve when network members are not co-located and directly involved in discussions (23). Our insights suggest that geographic closeness was important for communication. Interestingly, from a social network perspective, geographic closeness is not essential for the flow of information and resources (23).

Sporadic electronic communication and the absence of in-person communication may be overcome through development of strong relational ties (24). Our study identified relational

characteristics, such as trust, empathy, and willingness to listen to and believe in patients (Table 6 and Appendix 3), that appeared to contribute to information flow between patients and health care providers. Empathy and trust strengthen network relationships and dynamics and facilitate information flow between all network members (23,26,30). The process of listening is intrinsic to fostering whole person care (11,19,21,30). We have previously reported the consequences of not being listened to for the patients in this study (31). Not being listened to is a barrier to patient involvement in treatment negotiations, fractures communication ties, and can create tension in clinician–patient relationships (31). Insufficient physician and specialist consultation time restricts discussion of patients’ overall needs and is problematic for patients and health care providers (13,14,19,21). In our study, appointment time pressures were perceived to have inhibited listening, recounting, and discussion opportunities, potentially constraining information flow and access to care. Reachability also intertwined with resource transfer to influence access to care.

Our findings draw attention to the significance of family physicians’ role in network resource transfer (eg, knowledge and treatment therapies). Family physicians perform significant gatekeeper and supportive roles in patient care (21) and are positioned to promote or inadvertently constrain resource transfer and reachability. For instance, our findings corroborate literature that suggests family physician unfamiliarity with IA symptoms, treatment, and management may delay patient referral to rheumatology care (2,8,19–21) and thus influence patient outcomes. Furthermore, disbelief in (2,32) and misunderstandings of patients’ pain may prevent family physicians from attending to patients’ pain (11,12), contributing to poor pain management for some patients. Pain may also be ignored when physicians perceive women who report pain as complaining, hysterical, or exaggerating and do not believe or take reports of pain seriously (33). Our findings also imply that family physicians’ and rheumatologists’ attitudes toward rehabilitation and counselling may influence the reachability of these resources. Previous literature suggests that rheumatologist attitudes towards physical and occupational therapy vary (34) and that physician unfamiliarity with rehabilitation services (10) and specific arthritis programs (35) may impede referrals. There may be alternative explanations for lack of referrals not uncovered in this study, such as physician knowledge of long waitlists or patients not meeting priority criteria.

Lack of funding for rehabilitation is a barrier for referral (4). Variation in patients’ financial circumstances contributed to asymmetry and potential inequities in access to care by influencing both resource flow and reachability. Socioeconomic status impacts access to many aspects of IA care such as community rehabilitation services (35). For example, disability, employment status, gender, income, health care organization, and regional distribution of services can contribute to inequities (36). Our findings suggest that disability, gender, low income and associated health insurance, and distribution of services may have

contributed to inequities in access to care by influencing choice and ability to access services. Furthermore, nonreferral may have unfairly reduced opportunities to access services. Availability of resources, opportunities to access those resources, and the degree of choice in taking up those opportunities are significant factors for health equity (36).

Institutional factors may also constrain family physicians’ and rheumatologists’ efforts to transfer resources. Our findings, which mirror the literature (17,18), draw attention to the lengthy process of trialing medications to meet pharmaceutical funding criteria. This process perceivably curbed the flow of resources and constrained choice (preferred pharmacological therapy) but prolonged psychological stress for patients.

In summary, network structures and processes (communication pathways and relational ties) and physicians’ gatekeeper roles can promote or inhibit information and resource flow and reachability. This in turn may hamper equitable access to IA care and thus affect patient health outcomes.

Rather than exploring attributes of IA care individually, our approach considered how network actors were interconnected. By highlighting network structures and processes that have potential to promote information and resource flow, we broaden understanding of factors that contribute to timely and appropriate access to care. From a social network perspective, establishing effective communication pathways may accelerate access to whole person care. Robust and integrated communication between primary and secondary care is needed (19). Telehealth, for instance, increases patients’ and network actors’ reachability, particularly family physicians and specialists. Until recently, telehealth has received mixed responses in rheumatology care (37). Interestingly, the coronavirus disease 2019 pandemic has prompted an increase in the use of telehealth/telemedicine together with electronic visual communication pathways (37,38). Further research is needed to identify the benefits and disadvantages of telehealth and virtual communication pathways for patients and health care providers and whether they improve reachability and access to care.

An interoperable regional wide electronic health record system has significant potential to provide an efficient communication pathway to improve information flow and integration of patient care (39,40). Exploring the effectiveness of existing national/regional and international electronic health record systems from a social network perspective may inform future developments in this area. Electronic communication pathways may overcome geographic distance by facilitating reachability between network members, which can contribute to greater network collaboration.

Collaboration is a core competency area for health professional training (41). Increased collaboration between professional network members provides opportunities for members to learn from each other, expand their knowledge of the problem to be solved, and understand each others’ contributions (41). However, health care workplace systems and structures need

improvement to facilitate collaborative health care (19,41). For instance, addressing system structures that currently restrict opportunities (eg, time constraints due to administrative policy) to address patients' needs and collaborate with network members may develop and strengthen relational network dynamics. This may promote sharing of mutual values, objectives, and goals for care between network actors (shared decision-making). Physician workforce shortfalls contribute to disparate access to care (4,42). Addressing these shortfalls along with telehealth, integrated electronic health records, and opportunities for professional collaboration can contribute to improved access to care. However, it may not be sufficient to individually address these shortfalls of IA care. These factors should be considered properties of a landscape of IA care connected by relational ties that facilitate communication and resource transfer. There appears to be variation in whole person IA care. Thus, heterogeneous landscapes of whole person care can be expected. This suggests overarching institutional (eg, policy and guidelines) and organizational (electronic communication modes) health care system structures need to be flexible and adaptive to effectively address access inequities as part of improving patient health outcomes.

As with all qualitative research, study findings are context specific and may not be transferable to other IA populations. Findings may be unduly influenced by female patient perspectives relative to limited male perspectives. This may reflect disease epidemiology, as IA (especially RA) affects more women than men (8,10,34) and women report higher levels and different kinds of pain to men (43). Our analysis did not address perceptions of gender inequality around experiences of pain identified in the literature (33), and this is an area for future research. Although we interviewed rheumatologists, family physicians, physiotherapists, occupational therapists, counsellors, and family members, there were insufficient representatives to draw conclusions on specific issues for each group. Further research with each of these groups would provide a deeper understanding of specific needs. In particular, understanding family physicians' perspectives of IA care may be of significant importance given their "gatekeeper" role in patient care.

In conclusion, we explored the experiences of people with IA and their health care networks to gain a broader and richer understanding of how they perceive access to multidisciplinary care. Our findings suggest that the goal of whole person care was shared by participants, although care was seldom intentionally coordinated. Network communication and resource transfer potentially governed access to care. Communication pathways (eg, electronic) and relational ties (eg, empathy) inhibited or promoted the flow of information through networks. Various organizational structures blocked the flow of resources (eg, transfer of knowledge) through networks and limited access to care (eg, rehabilitation services). We propose the development of several organizational structures to support communication and resource transfer, which promote reachability and collaboration. This multi-layered network approach may facilitate more equitable access to whole person multidisciplinary care for people with IA.

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AUTHOR CONTRIBUTIONS

Hartford conceived and drafted the document. All authors were involved in critically revising the document for important intellectual content and approved the final version to be published. Dr. Nimmon had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Backman, Li, McQuitty, McKinnon, Kherani, Nimmon.

Acquisition of data. Hartford, Nimmon.

Analysis and interpretation of data. Hartford, Backman, Li, McQuitty, McKinnon, Kherani, Nimmon.

REFERENCES

1. British Columbia Ministry of Health, British Columbia Medical Association. Rheumatoid arthritis: diagnosis, management and monitoring. 2012. URL: <https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/rheumatoid-arthritis>.
2. Arthritis Alliance of Canada. Joint action on arthritis: a framework to improve arthritis prevention and care in Canada. 2012. URL: <http://www.arthritisalliance.ca/en/joint-action-on-arthritis>.
3. Combe B, Landewe R, Daien CI, Hua C, Aletaha D, Álvaro-Gracia JM, et al. 2016 update of the EULAR recommendations for the management of early arthritis. *Ann Rheum Dis* 2017;76:948–59.
4. Barber CE, Jewett L, Badley EM, Lacaille D, Cividino A, Ahluwalia V, et al. Stand up and be counted: measuring and mapping the rheumatology workforce in Canada. *J Rheumatol* 2017;44:240–57.
5. Chamberlain-Salaun J, Mills J, Usher K. Terminology used to describe health care teams: an integrative review of the literature. *J Multidiscip Healthc* 2013;6:65–74.
6. Ahlmén M, Nordenskiöld U, Archenholtz, Thyberg I, Rönqvist R, Lindén L, et al. Rheumatology outcomes: the patient's perspective. A multicentre focus group interview study of Swedish rheumatoid arthritis patients. *Rheumatology (Oxford)* 2005;44:105–10.
7. De Maria L, Acelajado MC, Luck J, Ta H, Chernoff D, Florentino, et al. Variations and practice in the care of patients with rheumatoid arthritis: quality and cost of care. *J Clin Rheumatol* 2014;20:79–86.
8. Widdifield J, Tu K, Thorne JC, Bombardier C, Paterson JM, Jaakkimainen L, et al. Patterns of care among patients referred to rheumatologists in Ontario, Canada. *Arthritis Care Res (Hoboken)* 2017;69:104–14.
9. Townsend A, Backman CL, Adam P, Li LC. Women's accounts of help seeking in early rheumatoid arthritis from symptom onset to diagnosis. *Chronic Illn* 2014;10:259–72.
10. Lacaille D, Anis AH, Guh DP, Esdaile JM. Gaps in care for rheumatoid arthritis: a population study. *Arthritis Rheum* 2005;53:241–8.
11. Ryan S, Lillie K, Thwaites C, Adams J. 'What I want clinicians to know'—experiences of people with arthritis. *Br J Nurs* 2013;22:808–12.

12. Cottrell E, Welsh V, Mallen C. Inflammatory arthritis: case review and primary care perspectives. *Clin Rheumatol* 2012;31:739–44.
13. Kjekouk I, Dagfinrud H, Mowinckel P, Uhlig T, Kvie, TK, Finset A. Rheumatology care: involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis Rheum* 2006;55:394–401.
14. Dures E, Almeida C, Caesley J, Peterson A, Ambler N, Morris M, et al. A survey of psychological support provision for people with inflammatory arthritis in secondary care in England. *Musculoskeletal Care* 2014;12:173–81.
15. Geenen JE, Newman S, Bossema ER, Vriezolk JE, Boelen PA. Psychological interventions for patients with rheumatic diseases and anxiety or depression. *Best Pract Res Clin Rheumatol* 2012;26:305–19.
16. Erwin J, Edwards K, Woolf A, Whitcombe S, Kitty S. Better arthritis care: patients' expectations and priorities, the competencies that community-based health professionals need to improve their care of people with arthritis? [Research Article]. *Musculoskeletal Care* 2018;16:60–6.
17. Guillemin F, Caruthers E, Li LC. Determinants of MSK health and disability—social determinants of inequities in MSK health. *Best Pract Res Clin Rheumatol* 2014;28:411–33.
18. Russell AS, Olszynski WP, Davison KS, Koehn C, Haraoui B. Leveling the field in the treatment of rheumatoid arthritis with biologic therapies: equal access for equal efficacy. *Clin Rheumatol* 2010;29:233–9.
19. Lempp H, Scott DL, Kingsley GH. Patients' views on the quality of health care for rheumatoid arthritis. *Rheumatol (Oxford)* 2006;45:1522–8.
20. Fary RE, Slater H, Chua J, Briggs AM. Translating policy into practice for community-based management of rheumatoid arthritis: targeting professional development needs among physiotherapists. *Intl J Rheumatol* 2012;2012:240689.
21. Pollard LC, Graves H, Scott DL, Kingsley GH, Lempp H. Perceived barriers to integrated care in rheumatoid arthritis: views of recipients and providers of care in an inner-city setting. *BMC Musculoskelet Disord* 2011;12:19.
22. Marin A, Wellman B. Social Network Analysis: An introduction. In: Scott J, Carrington PJ, editors. *The Sage Handbook of Social Network Analysis*. London: Sage Publications; 2014.
23. Daly AJ, editor. *Social network theory and educational change*. Cambridge (MA): Harvard Education Press; 2010.
24. Scott J. *Social network analysis*, 4th Edition. London: Sage Publications; 2017.
25. Nimmon L, Cristancho S. When I say...networks and systems. *Med Educ* 2019;53:331–4.
26. Westaby JD. *Dynamic Network theory: how social networks influence goal pursuit*. Washington (DC): American Psychological Association; 2012.
27. LaDonna KA, Bates J, Tait GR, McDougal A, Schulz V, Lingard L, et al. 'Who is on your health-care team?' Asking individuals with heart failure about care team membership and roles. *Health Expect* 2017;20:198–210.
28. Le Compte MD, Schensul JJ. *Designing and conducting ethnographic research*, 2nd Edition. Lanham (MA): Altamira Press; 2010.
29. Government of Canada. *Canada Health Act*. 2020. URL: <https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>.
30. Nimmon L, Regehr G. The complexity of patients' health communication social networks: a broadening of physician communication. *Teach Learn Med* 2018;30:4:352–66.
31. Hartford W, Backman C, Li LC, McKinnon A, Nimmon L. Appropriating and asserting power on inflammatory arthritis teams: a social network perspective. *Health Expect* 2020;23:813–24.
32. Kelly A, Tymms K, Tunnicliffe DJ, Sumpton D, Perera C, Fallon K, et al. Patients' attitudes and experiences of disease-modifying antirheumatic drugs in rheumatoid arthritis and spondyloarthritis: a qualitative synthesis. *Arthritis Care Res (Hoboken)* 2018;70:525–32.
33. Samulowitz A, Gremyr I, Eriksson E, Hensing G. "Brave men" and "emotional women": a theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Res Manag* 2018;2018:6358624.
34. Li LC, Bombardier C. Utilization of physiotherapy and occupational therapy by Ontario rheumatologists in managing rheumatoid arthritis: a survey. *Physiotherapy Canada* 2003;55:23–30.
35. Bain L, Sangar R, Bornstein C, Lukmanj S, Hapuhennedige S, Torne C, et al. Identifying real and perceived barriers to therapeutic education programs for individuals with inflammatory arthritis. *Clin Rheumatol* 2016;35:3217–26.
36. Whitehead M. The concepts and principles of equity and health. *Int J Health Serv* 1992;22:429–45.
37. López-Medina C, Escudero A, Collantes-Estevez E. COVID-19 pandemic: an opportunity to assess utility of telemedicine in patients with rheumatic diseases. *Ann Rheum Dis* 2021. E-pub ahead of print.
38. Howren A, Aviña-Zubieta JA, Rebić N, Dau H, Gastonguay L, Shonjania K, et al. Virtual rheumatology appointments during the COVID-19 pandemic: an international survey of perspectives of patients with rheumatic diseases. *Clin Rheumatol* 2020;39:3191–3.
39. Tharmalingam S, Hagens S, Zelmer J. The value of connected health information: perceptions of electronic health record users in Canada. *BMC Med Inform Decis Mak* 2016;16:93.
40. Canadian Institute for Health Information. *Chronic disease management in primary health care: a demonstration of EMR data for quality and health system monitoring*. 2014. URL: <https://www.cihi.ca/en>.
41. Paradis E, Whitehead CR. Beyond the lamppost: a proposal for a fourth wave of education for collaboration. *Acad Med* 2018;93:1457–63.
42. Canada Institute for Health Information. *Canada's doctor supply continues to grow faster than the population*. 2019. URL: <https://www.cihi.ca/en/physicians-in-canada>.
43. Lesuis N, Befrits R, Nyberg F, van Vollenhont RF. Gender and the treatment of immune-mediated chronic inflammatory diseases: rheumatoid arthritis, inflammatory bowel disease and psoriasis: an observational study. *BMC Medicine* 2012;10:82.

APPENDIX 1: INTERVIEW PROTOCOL DEVELOPMENT

The interview protocol was developed by LM with the help of WH, SM, AM, another patient research team member, and a research assistant. Interview questions from two previous studies (one with stroke survivors and one with patient with chronic obstructive pulmonary diseases) provided the foundation for developing the interview questions for this study. Three patient research team members provided valuable patient perspectives in further developing the questions. In line with social network analysis, patient participants were asked to complete a social network survey wherein they identified who they perceived to be in their inflammatory arthritis care network. WH and another research assistant performed a pilot interview with a female patient respondent who did not meet the inclusion criteria because of having been diagnosed with IA more than 10 years previously. The patient participant provided valuable critiques of the interview questions. Three different interview question formats were developed: patient, nonprofessional care provider, and professional care providers. The research group met regularly to discuss continued recruitment and data collection. Participant recruitment was determined completed after many unsuccessful attempts to recruit more male participants and identified healthcare providers.

Social network survey I. Name Generator:

Who do you perceive as being on your healthcare team? List as many individuals as you like, they can be health professionals or informal caregivers.

Name	Role	How long known each other?	How often do you communicate and how?	Contact Information
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Please list others if you would like to include more:

Information about the relationships/tie

- A. Out of these individuals you have listed which ones do you perceive to hold the **most influence** on your team and why?
- B. Out of the individuals listed which individuals' advice do you **trust the most** and why?
- C. Who are the **least** influential members of your team and why?

Patient interview questions

Our research team is interested in the patient experiences and perceptions of people living with inflammatory arthritis who (a) have been diagnosed within the last 2.5 years and (b) are provided care by a healthcare team.

In this study we define a healthcare team as including: (a) least two health professionals working together (e.g., nurse, GP, specialist physicians, occupational therapist, social worker etc.), (b) the patient and (c) informal caregivers (e.g., family, friends, those who help around the home, etc.).

You do not have to answer any questions that make you feel uncomfortable.

Patient Experience

- 1) Tell me about yourself, how long have you been diagnosed with inflammatory arthritis, what is your age, where were you born, do you work and what kind of work, etc.?
- 2) Who supports you in managing your condition (for example, family physician, specialists, occupational therapist, family members, friends, etc.)? What kind of care is available for arthritis patients?
- 3) What is your experience as a patient who is provided arthritis care by a variety of individuals?
- 4) Does the care you receive focus on your personal treatment goals and wishes?
- 5) Do you ask for what you need around your care from the individuals you have described as providing you with care? (e.g., do you ask questions, do you make your own health related decisions, do you make requests etc.)?
- 6) Do you believe that you are responsible for managing your own arthritis care? If so, what is that like for you?
- 7) Do you sometimes have to share information between these people? (Probe: How are providers kept up to date about the various treatments you receive, or test results; are family members/informal caregivers kept up to date too?)
- 8) The specialized language used by health professionals may not always be understood by patients and their informal caregivers. Have you ever had trouble understanding the specialized language health professionals' who provide you with arthritis care use? Do you ever use this specialized healthcare language in order to communicate and feel you are being taken seriously?
- 9) What are some ways in which your care can be improved or how do you feel you can be further supported?
- 10) What other sources/resources do you have access to for obtaining health information? Do you ever discuss those with the people you have described?

Health Care Network Dynamics

- 11) Do the people you have identified communicate between themselves about your care? If they do, have you ever noticed any communication problems?

12) Are there tensions between any of the people that you have described who provide you with care? Does this influence the care you receive? (How are these frictions dealt with or negotiated on the team?)

13) How do the people you've described use your experience, opinions, knowledge, and/or choices into your goals for care? Probe: Do you feel your voice is valued?

14) Do you see yourself as being a key member of your care team?

15) Do you see yourself as empowered or influential in terms of your health care decision making? Please explain.

16) Who is the most or least amount of influential person (including you) with respect to decisions around you care? Please explain.

17) Do you sometimes receive conflicting treatment plans or advice from your sources of information (i.e. from individuals or from other information sources)? (e.g., information about medications that do not interact well)? What do you do when this happens?

18) If you are unsatisfied or confused about the care you receive do you have somebody you can go to for help? Does this person then communicate with others on your care team on your behalf?

Interview Protocol for Caregivers

Our research team is interested the experiences and perceptions of inflammatory arthritis patients who (a) have been diagnosed within the last two years and (b) are provided care by a healthcare team.

You do not have to answer any questions that make you feel uncomfortable.

Caregiver Experience

- 1) Tell me about yourself, what is your age, where were you born, do you work and what kind of work, etc.?
- 2) Who is on ____'s healthcare team? What kind of care is available for arthritis patients? Do you see yourself as a member of the team?
- 3) What is your experience as a caregiver who has provided arthritis care?
- 4) What are your thoughts about the care he receives?
- 5) Do you advocate for his healthcare needs? (e.g., do you ask questions, take notes, speak up, do you make requests etc.)?
- 6) Does he manage his own arthritis care? Do you help?
- 7) How does the healthcare team communicate between themselves around his care? If they do, are there ever communications problems that happen on the team?
- 8) Do you sometimes have to share information about his care between healthcare providers? (e.g., Are providers kept up to date about the various care you receive?)
- 9) Do you ever need to express yourself using the terminology and language of each healthcare provider in order to have your voice heard? Please describe.
- 10) What are some ways in which his care can be improved or how you can be further supported?
- 11) What other sources/resources do you have access to for obtaining health information? Do you ever discuss those with your healthcare providers? (*him/her*)

Health Care Team Dynamics

- 12) Are there to be tensions between healthcare team members that influence the care he receive? How are these dealt with or negotiated on the team?

- 13) Is your voice held with value and weight in terms of how healthcare team members integrate your experience, opinions and/or suggestions?
- 14) Who holds the most or least amount of influence on the healthcare team? Please explain.
- 15) Do you see yourself as an empowered or influential member of the healthcare team? Please explain.
- 16) Does he sometimes receive conflicting treatment plans or advice from different healthcare providers? (e.g., medications that do not interact well)? What do you do when this happens?
- 17) If he/you are unsatisfied or confused about the care you receive do you have somebody on your healthcare team you can go to for help? Does this person then communicate with members of your healthcare team on your behalf?
- 18) How would you describe a supportive and well-functioning health care team in terms of managing X's inflammatory arthritis with the healthcare providers you have described? Where would you place yourself in this team?

Interview protocol for Healthcare Professionals

I am part of a team conducting a research project studying health service provision for patients within the first five years of being diagnosed with inflammatory arthritis. In particular, we are interested in understanding patients' and providers' experiences of team-based care in arthritis care.

One of your patients is a research participant in this study. This patient has identified you as an important healthcare professional involved in their care and that's why we're here to talk to you. Remember that you do not have to answer any questions that make you feel uncomfortable.

1. Describe to me this patient and your relationship with this patient in terms of providing care?

- 2. Who else provides healthcare support to this patient? What kind of role do you play within this group of healthcare providers/caregivers in helping this patient manage their health care?
- 3. What are some of the positive aspects and challenges of working with this patient's other healthcare providers/caregivers?
- 4. Are there ever conflicts in terms of your treatment recommendation being contested by another healthcare provider(s) or informal caregiver(s)? Please describe.
- 5. Who exchanges/passes information amongst these healthcare providers/caregivers? (This can include the patient)
- 6. How do you describe/enact patient centered care, and what does this look like in the context of providing care for this patient? (Probe: how do the other healthcare providers/caregivers enact patient centered care?)
- 7. What characteristics give people influence, or lack of influence on a healthcare team? (Probe: Do you consider you are a part of PATIENT X's health care team?)
- 8. Do patients ever draw on sources of information to educate themselves of their condition and then discuss what they have learned with you (please provide examples). In these cases, how have you responded to any treatment wishes or care requests they might come to you with?

Additional questions if there is time:

- 1. From your perspective as their [HEALTHCARE PROVIDER X], what are the treatment needs of [PATIENT X] as they deal with their inflammatory arthritis?
- 2. When was the patient diagnosed with inflammatory arthritis and have their needs changed since they were diagnosed?
- 3. If the patient is unsatisfied or confused about the care they receive do they have somebody among their healthcare providers/caregivers to go to for help? Does this person then communicate with other healthcare providers /caregivers on their behalf?

APPENDIX 2: RESEARCH TEAM AND CONTRIBUTIONS TO DATA COLLECTION AND ANALYSIS RIGOR

WH: Adult education (medical education)
 CB: Occupational therapy (scientist and clinician)
 LL: Physiotherapy (scientist and clinician)
 SM: Patient research team member
 AM: Patient research team member
 RK: Rheumatologist
 LN Social scientist

WH and NM, with the assistance of several research assistants, collected the data. All research team members were involved in the entire data analysis process from coding through to structural analysis. Early on in data collection, regular debriefing meetings were held to discuss recruitment methods (particularly recruiting male participants) and fine-tuning interview questions. Regular contact between research team members continued through meetings to discuss coding and identifying different aspects of IA care. The varied experiences of the research team were of particular importance here to bring different perspectives of IA care forward, identify different common understandings, validity of the data, and determine saturation.

Abbreviation: IA, inflammatory arthritis.

APPENDIX 3: ILLUSTRATIVE QUOTATIONS

Quotes	
<p>Holistic care networks: treating the whole person in their social context</p> <p>Whole person care</p>	<p>Marie: "And then over time with the physiotherapist and the occupational therapist and even kind of seeing like the counselor a bit, trying to work towards, you know, like, enjoying life and empowering and figuring out, like, you know, how to still be a person and not just a patient, I guess, with rheumatoid arthritis."</p> <p>Cam's rheumatologist: "Being able to access physical therapy, non-medication therapy was a positive thing I think seen by him 'cause he was trying to optimize things that were not related to medication if possible... So there's a patient support program that helps with the support for the biologic treatment that he's on,..."</p>

Quotes

- they've helped him with access to the medication, helping him navigate through and also been providing medication without cost to him. So that it was easier for him to get on to treatment and also be better with regards to the— his disease.”
- Amber's, physiotherapist: “I think it's definitely multifaceted. I think her rheumatologist is very important managing kind of her medications and everything like that and her biologics. I do think that physio does provide a nice role as well to help with any type of mechanical issues and then also guiding her on exercise. I think that massage does have some benefit as well, but I do feel like as she improves that hopefully she won't need to rely on, even from a physio standpoint, the manual therapy as much. I think counseling would be really helpful, just because dealing with pain, that's— I think that— I don't know if [name] sees a counselor but I think that that would be very helpful for her. But that as a physio is hard to recommend.”
- Jamie: “I'm doing another study which is looking at activity exercise, but more just activity. And a reduction of prolonged sitting time and so I just started doing that really recently. And that's great, actually. Just sort of having something formal set up and accountability in a way to an outside party has been a good motivator, I would say... So it's not really a medication, but it's still, you know, more holistic in that it's like a non-pharmaceutical factor.”
- Life stage and life context
- Brenda: “As a young mom I had lots of concerns. I had to go back to school, actually, after being diagnosed and start a whole new career....they were really good at supporting me and kind of giving me insight and helping me make little goals to help me to get to my big goal...my main goal was to find a career that would be good for me in the long run, wasn't so hard on my joints, and I saw a counselor as well through the arthritis clinic program. And she was really good at just helping me write down like mini-goals to help me get to my big goal.
- Erica: I physically have to go to school. It's really hard for me— it was really hard for me to get up 'cause— especially in the morning, I would feel stiffness in my body. So sometimes I couldn't get up. If I could, I have to take a hot shower for, say, like 10 minutes 'cause that kind of helps to ease pain. And even for, like, obviously psychologically it was really hard 'cause you kind of like, you know, you're basically— should I say it, you can't do much. You cannot move much, and just— there's too many restrictions if you're— if you have that.”
- Helen: “My fingers would go numb. My feet would go numb. And I couldn't even, like, eat with a fork. Like, I would drop everything. Make a big mess, and my husband's like just let me do it. And then I wasn't allowed to do the dishes anymore 'cause I'd drop knives. Like, I would be— I couldn't be in the kitchen with him 'cause I'd stab him... my husband would kick me out of the kitchen, because I would be trying to chop something and knives are flying everywhere because I have no hand to control— I don't have a grip. So it'd be kind of risky for us all to be in the kitchen. So I ended up getting kicked out...Because I always felt like I was always on the sidelines watching, because I— whenever I tried to participate it always ended badly.”
- Jamie: “...[L]ooking after a baby with arthritis it's so frustrating. Because everything is tiny and intricate and childproof and it's the worst— if you could put together the worst objects to have to manipulate with— if you had symptoms in your hands and wrists and arms which I have, you just couldn't come up with a worst list of things.”
- Jamie: “I made the phone calls, met with people. And then they come back and they're, like, actually, no. Your husband, sure. But you're actually uninsurable for these reasons. Come talk to us in a year.”
- Getting back to normal
- Kathy: “I guess my overall goal is to gain as much of my old functionality as I can while still being realistic about what I could actually get to.”
- Jamie: “I used to cycle a lot. And that's something I still haven't incorporated back into my routine. But, you know, like, getting back into that. I used to cycle to work and back in— I'm, like, a fair-weather cyclist so in the summer months and we're coming into winter now. But, yeah, that's something that I just haven't done now for a couple of years. And so that's— it's important to me and something I really enjoy and it's inexpensive and quick and all of those things.”
- Nadine: “I mean, my husband is a really big outdoors person. He's an expert skier and expert hiker and stuff. And so you lose that— when you can't do those types of activities together, it definitely weighed on our relationship. And so that was even more motivation for me to try to get better was 'cause I just wanted to be able to go back out and do these things that we love to do together.”
- Geoff's family physician: “Well, he needed to have his inflammation improved. He needed to be able to mobilize. He needed to be able to do activities of daily living.”
- Geoff: “So she was wanting me to get good enough that I could get back and ride. And then I can hook up again with the guys that I've trained with for, you know, years and years and years. There's a lot of retired guys that go to this gym I go to and we just socialize. And she figured that was very important... So I'm back and socializing.”
- Cam: “[I]f it was a question of taking more medication to get more mobility back then I would do that because I want— because of the activities I'd like to resume. So for me, you know, I really want to do what I can to— 'cause you know, my job was, you know, fairly physically demanding. So I know that I need to have quite a lot of recovery to be able to get back to doing what I was doing. And also with other stuff like fitness and just generally my health, keeping in shape...I miss the exercise, hiking, running and stuff like that. So that's really important part about life for me, so I definitely would, you know, say, make sacrifices in other areas if I could do that.”

Quotes	
<p>Connected network pathways to holistic IA care</p> <p>Co-location</p>	<p>Francois: “So yeah, the whole having my island close to me is extremely appealing. Just, I mean, logically, right. It makes sense to try to have your team closer if you can. So– I mean, that would be a big one, if I could– if that’s like– if you could have anything wish– I’d just like my folks closer to me so it’s not such an effort to get there.”</p> <p>Cam’s occupational therapist: “Well, I mean, the great thing is that we have a very tightknit team at City 2 Hospital I’m not sure that this exists everywhere else ‘cause I worked over at City 1 Arthritis Centre as well and I don’t have ongoing contact with their rheumatologist, at least not in person. So in City 2 Hospital we have– the great thing is with having our rheumatologist right across the road and that’s where we get a lot of our referrals from. So every five weeks or so we have rounds with the rheumatologist. So myself and physiotherapist and the rheumatologist will go through and talk about all the patients and sort of where their goals are, what they [inaudible] attained, any progresses, anything that is of a concern. So we bring that up and we reinforce that that way.”</p> <p>Cam’s physiotherapist: “In terms of the allied health section is that in City 2 Hospital we do have arthritis outpatient care team which is composed of physiotherapist and occupational therapist. So myself, I take upon the role of physiotherapist. We do have [O t 1], the occupational therapist.”</p> <p>Amber’s physiotherapist: “I like working in this facility with the massage therapist in-house because we can just have informal kind of communication in the office. And we can leave little notes for each other within kind of our database.”</p> <p>Geoff’s physiotherapist: “Okay, well, I obviously provide physiotherapy services, but I’m also able to liaise with his other team members. For instance, when he– he was actually referred to physiotherapy but upon seeing him it became very evident that he needed an occupational therapy referral. So I was able to just get that going for him so he was able to see occupational therapy, get the rheumatologist to refer him over for that. So I work in a very team kind of environment where physically we work very closely with the occupational therapists and the treating rheumatologist and the patient and family, of course.”</p>
<p>Referral to multidisciplinary services</p>	<p>Ingrid: “And I did go through the arthritis [clinic program] that was helpful.”</p> <p>Cam’s occupational therapist: “But at the same time there’s a whole lot of social issues that go on and that’s where you need to sort of relay them and refer them off to different support groups and different community supports that are available for them.”</p> <p>Brenda: “But I think a lot of it was mental at that point. I went from walking to not walking so besides the pain which I felt my healthcare team could really help me with, they referred me to the counselor at the arthritis centre which helped me with the other part of it.”</p>
<p>Listening</p>	<p>Kathy’s counsellor: “People really listening to the patients. Number one thing is actually taking the time. I know sometimes people are pushed in for really short appointments that they don’t get a lot of– a chance...”</p> <p>Cam’s physiotherapist: “I guess one other thing that’s important is also being a listener.”</p> <p>Kathy: “And, I mean, when you spend an hour with somebody every month you’re getting heard, or at least if they’re good you’re getting heard. And I feel like when I go in I’m able to voice all of my concerns that have come up over the past month and that she’s listening to what’s come up.”</p> <p>Marie: “I just feel like my family doctor’s just kind of like my best resource and he’s just really understanding and takes more of the time to listen to me. So I guess I feel like he’s doing a really good job at that and kind of just valuing my opinion in whatever it is.”</p> <p>Brenda: “And if it was having a really bad side effect on me I just told him [rheumatologist] I didn’t want it and he listened.”</p>
<p>Communication</p>	<p>Geoff’s physiotherapist: “And then we also have a very good relationship with his treating rheumatologist and we have rounds, regular rounds, about once a month where we can communicate and pass information between occupational therapists, the physiotherapists and the rheumatologist.”</p> <p>Geoff’s rheumatologist: “And also continuing to work with physio and O.T. and look at being able to have physio and O.T. help with providing me some information about updates between visits that I’ve had with him. Because the last time I saw him was in July, and so in August and September they provided updates about some of the things that were going on that he didn’t call me and tell me about.”</p> <p>Kathy: “I wish there was more communication between my people, but, like, they– like my specialist will send reports to my G.P. I don’t know how much information goes from my G.P. to my specialists. I think mostly it’s going in the other direction, like, from specialists to my G.P. She’s sort of the house for all of my medical information.”</p> <p>Geoff’s family physician: “Yes. It is usually [Geoff] who does it. Occasionally there is communication that comes back. Physicians have a tendency to be able to send a follow-up letter. But I’m not sure I’ve seen much from the rehab folks.”</p> <p>Amber: “My G.P. and my physio don’t communicate at all. Neither do massage therapist, or chiropractics– none of them are really interrelated which makes it a little more difficult ‘cause then sometimes I am having to remember, oh, my G.P. told me this or my rheumatologist told me that. And I need to relay that between</p>

Quotes

them which can kind of get a bit difficult, especially when my G.P. appointment can be six months away from, like, my rheumatologist appointment. And so trying to remember those things and then my physiotherapist, I see biweekly and I know he doesn't send reports back to anyone. And to be honest, if he did send reports back, I don't think they would read it."

Cam's family physician: "[I]nterestingly in the paper office I was sometimes able to copy multiple specialists fairly easy by just writing copy to, copy to, copy to on the individual consult that I would send out alerting the specialist to know that I was involving three or four specialists...ultimately were kept in the same loop. With electronic records- so cumbersome and onerous but to actually then copy to copy to copy to all the necessities and whatever it represents, quite frankly, I don't even think my EMR has that capability. Or if it does, my staff and I are so drowned in the paperwork, the faxes that we have to attach within the EMR or the faxes that come into the EMR- the efaxes and worse, paper mail that has to be scanned and then attached and put in. And then stored in and sent out to me to review to send back to the staff with further instructions as to how to they're going to handle it. Makes that style of operation almost now impossible."

Cam's family physician: "So while I might be conductor of the magnificent orchestra trying to create this great ensemble and make it sound really good, the odds of anyone in that orchestra ever getting back to me directly are very slim except where a direct consult to consult from physician to physician happens to take place. For the rest, yes, things'll float in from home nursing, but it's usually hours if not days after the fact which doesn't help the patients particularly. Because a discharge summary containing those elements usually arrives between a week and ten days later. By which time the patient's probably readmitted anyway. You might actually be a whole admission behind in terms of the information that actually flows to your EMR."

Francois: "All the time. That's the part I've been sort of- been disappointed at that I go somewhere for a test or a MRI or a- whatever it is I'm having. And either the results get dropped or the specialist doesn't get them ...and I feel like is this my job to make sure everyone's got the little bits of information that I thought was going on behind the scenes... and how I feel is like I've become a burden...But just making sure they've all got the information and so that when you do get your appointment finally you're not sitting there with someone going I don't know what you're talking about 'cause I didn't get anything. Which happened lots."

Network disconnect and
disrupted access to IA care
Healthcare inequity

Lucy: "I wish there was more support for inflammatory arthritis patients as regard to, like, physio and massage."

Amber: "[M]y physiotherapist who I see twice a week right now. He doesn't specialize in arthritis. But because in October I was in a second car accident, they [arthritis clinic] don't deal with car accidents so as a result, which was really frustrating, I had to find another physiotherapist. So instead of dealing with somebody who knows about the condition and knows how to treat it and could still work around the results from a car accident, it really sucks in terms of, like, I need to explain everything else. Luckily I knew this physiotherapist beforehand and he in the meantime...he encountered a few more ankylosing spondylitis patients and so he figured out- he did a lot more research. Figured out how to treat and work with it and so now he works with me to try and get it so that I can go back to sport stuff that was more access- you know, accessible."

Kathy: "The only reason that I have massage therapy is because I've found someone who will swap me. But if I had to pay for it, can't do it. The only reason I have physio is because I've now gotten into a place where physio is free. But it was completely inaccessible to me prior to that too."

Lucy: "And I'm, I would think, more well off than other people. Like, my husband makes pretty decent money and we have healthcare coverage and still I can't afford to go to physio or massage therapy on a regular basis."

Trialling and medication

Amber: "So working was a lot more difficult with school. I actually ended up taking four months off of school and work, just so that when we were trialing medications, I could see what worked and what didn't without the extra, like, stress influence from work and school."

Brenda: "But really it was in the beginning when we were running, like, we were testing all the different medications to see what worked for me. Like, I was supposed to try some medications for, like, five or six weeks before we could move onto another one."

Helen: "But I went to him with, like, I would really like to go HUMIRA. And he was, like, oh, you know, the government probably won't fund it 'cause you haven't tried any of the lower level ones yet. So he listened in the sense that he put me on cyclosporin to see how it goes and he's like, as soon as you've tried it, we know it's in your system, it's not working, then we can go a level up. But he didn't try HUMIRA. He tried Cimzia instead."

Danielle: "Medication-wise, like, okay, he tried the usual- went through all the NSAID's wouldn't work, wouldn't work, would work, ah, couldn't take it 'cause I'm a bleeder or whatever. So, okay, and then- but then he seemed to really just, whatever, push biologics. And I had a...I had a sample of one, a once-a-week injection and I had four. I didn't know at the time I was pregnant."

Marie's spouse: "When I have gone with Marie they have provided only very limited information on new medications, didn't confirm contraindications (such as pregnancy when taking the anti-inflammatory Arthrotec, even though Marie is a married woman in her early 30s)."

	Quotes
Physician attitude and knowledge	<p>Helen: “Yeah, I did a lot of research when I was diagnosed and– because we were trying to have a baby at the time. I would literally go to him and be, like, I can’t be on this one, I can’t be on this one. He’s, like, I really think we should put you on this one, which wasn’t safe for pregnancy. So it was something that I was very strict with, whatever he put me on, it needs to be something that is safe for pregnancy.”</p> <p>Geoff’s rheumatologist: “[W]hen we were starting medications and the medication side effects became a really important issue.”</p> <p>Geoff’s rheumatologist: “I think that sometimes there’s reluctance to go ahead with the medication but the reluctance is understandable. If you have trouble with the first medication that comes out of the box or off the prescription pad then you’re probably going to be trepidations about any other potential treatment, yeah.”</p> <p>Amber: “I’ve encountered some G.P.’s before I found this one who had no idea what ankylosing spondylitis was.”</p> <p>Patient Helen: “...[B]ecause my family doctor wouldn’t listen at the beginning. She kept saying, like, oh, it’s just carpal tunnel. I’m, like, well, why are my feet bothering me if it’s carpal tunnel. Why are my feet numb? And she kept putting it off. So it would be nice if family doctors kind of looked into things right away rather than kind of passing it off and, like, oh, I’ll see you in six months. I mean, six months is a big time for someone who can’t feel their feet or hands... So it took, I think, about two years, two and a half years, before they actually listened and sent me to a rheumatologist.”</p> <p>Lucy: “And they told me that it was probably to do with birth and labour and your ligaments get really sore because of hormones. And so that it wasn’t uncommon for this to happen with women, and that just go to physio and take some painkillers.”</p> <p>Marie: “Like I almost feel like my rheumatologist thinks that my symptoms aren’t bad enough, so he doesn’t really need to, like, I don’t know...I have a bad wrist and fingers and stuff like that. But, like, I feel like ‘cause it’s maybe a less severe rheumatoid arthritis, like, symptoms compared to some people I know, like...I don’t know. He just doesn’t take me seriously or something.”</p> <p>Marie’s spouse: “Yes, she [new rheumatologist] seems to have a slightly different risk tolerance with regards to medication and pregnancy, so has restarted Marie on disease modifying anti-rheumatic drugs (not just anti-inflammatory)...I think that Marie found this new rheumatologist more thorough and provided more explanations.”</p> <p>Patient Ingrid: “And I had superb medical care in the U.S. and when I came back to Canada I was with a rheumatologist who questioned the diagnosis, who– it was exceedingly challenging to work with this rheumatologist. I’m R.F. positive and anti-CCP positive and as with– the research shows, my CRP and ESR have always been in the normal range, no matter how inflamed– how much inflammation I’m dealing with. So that questioning of my diagnosis, which was ironclad, was exceptionally challenging.”</p> <p>Amber: “So, the pain’s real. The morning stiffness is real for, like, I can’t differentiate between what’s what. So it’s– I try and trust the doctor when– but when the doctor says, oh, it doesn’t exist, then you’re kind of hooped.”</p> <p>Kathy: “And I have had an enormous obstacle with trying to dissuade doctors that I’m depressed, like, I eventually developed depression because I went untreated for so long. And, like, when you’re in pain forever you’re probably not going to come out without some sort of mental health issues, like, pain is hard to deal with. But at the very beginning I was not depressed. I was in pain. And it was making me cry a lot, and trying to convince them that it was the chicken and not the egg was almost impossible. They were so willing to chalk it up to either depression or anxiety.”</p> <p>Lucy: “He actually offered me antidepressants ‘cause he thought I was depressed. And I said, I’m not depressed [inaudible] there’s something wrong with me, so I’m not going to– like I don’t– I was really offended that he actually even offered me antidepressants.”</p> <p>Jamie’s mother: “I don’t think [Jamie] went to any physio or to the arthritis clinic program. That wasn’t recommended to her which surprised me, because I immediately recommended that to her. But the rheumatologist didn’t feel that would be necessary at that time...”</p> <p>Marie: “[D]idn’t always refer me to the Arthritis Society. Like I had to ask him to do that, and I think he thought my arthritis wasn’t bad enough that I would need the support from the Arthritis Society.”</p> <p>Danielle: “The challenge was when I moved a couple different places and I changed G.P.’s...My G.P...new G.P. She has no clue about ankylosing spondylitis. And then a newer one that came to replace, right, so it was, like, someone replaced, someone replaced.”</p>
Appointment time pressures	<p>Amber: “...[S]ome healthcare practitioners don’t take the time– they might have all the experience in the world but they don’t take the time to really spend with the client. And so they don’t really– or they’re not hearing them. They’re not hearing their symptoms. Hearing kind of what they’re struggling with. And so they might come to a conclusion faster. And even though they have the experience they might not be taking into account that person.”</p> <p>Amber: “So I feel like some things that might have gotten missed because you’re in a very tight timeframe with your doctor...”</p>

Quotes

Physician shortfalls and switching physicians

- Kathy's counsellor: "People really listening to the patients. Number one thing is actually taking the time. I know sometimes people are pushed in for really short appointments..."
- Helen: "I feel like it maybe could have been prevented if someone had, I guess, listened and, I guess, took a different approach. But I do get that they're doctors and they don't have time."
- Brenda: "My family doctor I actually switched- to my new family doctor about a year ago....My family doctor, I'm not sure if he [inaudible] going through a rough time, but he delivered me 27 years ago. But he's just changed, like, his- how much he cares for his patients a lot and when I was actually going- when I first got diagnosed he was very uncompassionate."
- Helen: "I go back to my G.P. because you cannot get a family doctor unless you literally don't have one. And you have to, like, wait for one to all of a sudden like start practice. I mean, everyone leaps to them. You can't switch doctors. You don't have a choice, like, she was the one I picked when I was 16 and now I'm a lifer, like, it's the way it is. You can't switch family doctors because no other doctor will accept you if you have a family doctor. It doesn't matter if they're four hours away. You have a family doctor, too bad. I've tried. I've tried to get rid of her."
- Jamie: "I had to move to a new clinic 'cause that other one shut down completely."
- Kathy: "I spent over two years looking for a G.P. when I moved ... I mean. there's a G.P. shortage first of all, and second of all, when you have as many health problems as I do, like, any old G.P., it's just not going to cut it."
- Marie: "Lots of trial and error. Like the B.C. family doctor website doesn't necessarily keep up to date and doctors have filled their open spots- to find a family doctor...so trying to go to different offices and calling around... Eventually I heard of a doctor that was accepting new patients so I just went there right away...he's really good."
- Nadine: "And I know finding a family doctor is tough 'cause it took me a year to track one down initially. But you can do it, and it takes time, it takes energy, but you can do it."