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Everyday ethics and help-seeking in early rheumatoid arthritis

A. Townsend[1], **P. Adam**[2], **S.M. Cox**[3], and **L.C. Li**[4]

[1]CIHR Ethics of Health Research and Training Program, The W. Maurice Young Centre for Applied Ethics, University of British Columbia, 235–6356 Agricultural Road, Klinck Building, Vancouver, BC, V6T 1Z2, Canada

[2]Rheumatology Liaison, Mary Pack Arthritis Program, Vancouver Coastal Health Authority, Vancouver, British Columbia, Canada

[3]CIHR Ethics of Health Research Health and Training Program, The W. Maurice Young Centre for Applied Ethics, University of British Columbia, Vancouver, BC, Canada

[4]School of Rehabilitation Sciences, University of British Columbia, Vancouver, Canada

Abstract

Background—Sociological understandings of chronic illness have revealed tensions and complexities around help-seeking. Although ethics underpins healthcare, its application in the area of chronic illness is limited. Here we apply an ethical framework to interview accounts and identify ethical challenges in the early rheumatoid arthritis (RA) experience.

Methods—In-depth interviews were conducted with eight participants who had been diagnosed with RA in the 12 months prior to recruitment. Applying the concepts of autonomous decision-making and procedural justice highlighted ethical concerns which arose throughout the help-seeking process. Analysis was based on the constant-comparison approach.

Results—Individuals described decision-making, illness actions and the medical encounter. The process was complicated by inadequate knowledge about symptoms, common-sense understandings about the GP appointment, difficulties concerning access to specialists, and patient–practitioner interactions. Autonomous decision-making and procedural justice were compromised. The accounts revealed contradictions between the policy ideals of active self-management, patient-centred care and shared decision-making, and the everyday experiences of individuals.

Conclusions—For ethical healthcare there is a need for: public knowledge about early RA symptoms; more effective patient–practitioner communication; and increased support during the wait between primary and secondary care. Healthcare facilities and the government may consider different models to deliver services to people requiring rheumatology consults.

Keywords

Autonomous decision-making; Barriers; Diagnosis; Early RA; Ethics; Help-seeking; Procedural justice; Qualitative research; Self-management; Timely treatment

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Corresponding Author: A Townsend, [1]CIHR Ethics of Health Research and Training Program, The W. Maurice Young Centre for Applied Ethics, University of British Columbia, 235–6356 Agricultural Road, Klinck Building, Vancouver, BC, V6T 1Z2, Canada.

INTRODUCTION

Ethics underpins medicine, yet medical ethics has limited application in the 'everyday world' of healthcare; only 20% of practitioners describe the available ethics literature as helpful in practice [1]. Traditionally, medical ethics has centred on acute illness, not chronic conditions [2] and prioritized four principles: respect for autonomy, non-maleficence, beneficence and justice [3]. This framework was developed to assist medical practitioners identify practice-based moral problems, and aid medical decision-making [3]. Although still prominent, the principle-driven approach is increasingly regarded as inadequate for tackling the range of ethically complex situations arising in healthcare [4]. The last decade has seen a burgeoning 'ethics and healthcare' literature in medically based, health ethics and social science publications [5, 6] which address the patient–doctor relationship, [7,8] public health [9] and other diverse areas [10]. For example, Redman considers harms and benefits in chronic illness self-management *('patient ability to detect and manage symptoms, treatments and their consequences'*, p. 88), [2] claiming that individuals are encouraged to self-manage, but often ill-equipped to do so. Self-management education programmes have been developed for people with different chronic conditions including arthritis. Developing knowledge about rheumatoid arthritis (RA) and associated medications offers significant potential for preventing disease escalation. Issues of access to timely treatments, in the context of a shared decision-making model of care, make RA particularly fitting for ethical analysis.

Early diagnosis and treatment is crucial in RA [11] to avoid irreversible joint damage which may lead to permanent disability, increased personal suffering, and costly medications and surgery in already overburdened healthcare systems. RA affects about 1% of the population [12]. There is ample evidence to support initiating disease-modifying anti-rheumatic drugs (DMARDs) within 3 months of onset of RA to prevent joint damage [13]. However, evidence over the last decade shows there is a delay between symptom onset and DMARD use.[14,15] Recent research from Canada also reports a delay of 6–11 months between the onset of joint symptoms and the time of DMARD use [16]. This evidence suggests that maximum benefits of timely treatments are not being realized, whilst potential harm is endured. Patient delay in presentation to primary-care physicians has been identified as the main reason for the delay in seeing a rheumatologist, [17] while other evidence in the UK points to referral time from the general practitioner (GP) to the rheumatologist as a major source of the delay [15] RA has been investigated, producing sociological understandings of the 'lived experience' of chronic illness[18] which have informed self-management interventions [19] Yet, against the backdrop of potential for disease limitation, and the Expert Patient and Self-Management initiatives, little is known about people's decision-making and help-seeking in early RA.

The discipline of rheumatology, which attends to chronic musculoskeletal diseases, offers scant discussion of ethics [20–22]. Rom and colleagues [20] suggest that an ethical perspective to exploring barriers to timely treatment for RA would highlight issues of justice and equality. MacKenzie [22] echoes the need for ethical analysis in rheumatology, but criticises the four-principles framework as neglecting other moral concerns. He proposes a broader, contextual stance involving alternative ethical frameworks, for example, virtue ethics and care ethics, which prioritize traits such as compassion and trust. RA is fraught with ethical issues, regarding decision-making about care and treatment, patient–practitioner interaction, timely access to appropriate services, and opportunities to self-manage and live as full a life as possible. Here we apply an ethical framework to accounts of early RA help-seeking. We focus on autonomous decision-making with reference to onset and illness actions, and the medical encounter; and address procedural justice (PJ) in the medical encounter.

Autonomous Decision-making

The notion of individual autonomy is insufficient when investigating chronic illness and care where everyday experience and decision-making is critical [23]. Sherwin's conceptualisation of relational autonomy, [24] which focuses on self in a community, moral agency and autonomous decision-making (based on the availability of resources, e.g. information), has been proposed as an alternative [24, 25]. The concept of autonomous decision-making is helpful in assessing how far individuals have opportunities to make informed and meaningful decisions in the context of their healthcare and daily life. Alongside the rise of evidence-based medicine, [26] there is a growing public expectation that patients will be (or become) fully informed about their illness. In the policy context of the Expert Patient intervention in the UK27 and Self-Management programmes, [28] patients need information in order to assess, make decisions and take actions regarding their particular situation. However, patients may not have access to information required to enable them to make best decisions about their healthcare.26 Limited knowledge and resources may prevent individuals from taking effective actions, based on adequately informed decisions. Optimum health benefits may be denied, and health harms accrue [2].

The 'ideal' medical encounter comprising the passive patient and paternalistic health professional has shifted to a more symmetrical model of shared decision-making, or concordance [29]. Dialogue and cooperation between active patients, and enabling physicians, based on mutual support and information exchange is the new goal [29]. This collaborative approach allows for multiple perspectives, respects patients as experts, [27] and fosters the practice of autonomous decision-making. Secker describes this process as involving both independence and interconnectedness, whereby everything possible is done to ensure patients have access to, and are able to use resources (e.g., information) to make meaningful decisions [24]. However, there are very few empirical studies, which explore shared decision-making in RA, from an ethical perspective. Schildmann [30] provides a rare example in her analyses of RA patients' narratives about treatment decision-making, which revealed patients had inadequate knowledge of treatment alternatives. As Schildmann notes, ethically relevant challenges regarding treatment decision-making in clinical practice were exposed.

Procedural Justice

Both access to healthcare and decision-making in healthcare are justice concerns. Access to healthcare is a crucial good because illness and good health influences our happiness, self-confidence and self-respect. Health is of special moral importance *'because it contributes to* *the range of opportunities open to us. If, as a matter of justice we have social obligations to protect individual opportunity, promoting and restoring health is one component of fulfilling these obligations'* (Rid, p. 12) [31]. The concept of distributive justice (broadly, either the equal or equitable distribution of goods or services) has been criticized as insufficient when applied to chronic illness [32] An alternative is PJ, based on two values: (1) developing and exercising one's capacities and expressing one's experiences, the denial of which is oppression, and (2) participating in determining one's actions and the conditions of one's actions, the denial of which is domination (p. 352) [33].

Calling for more patient involvement in healthcare, Hughes and Larson [34] discuss decision-making using the framework of PJ. Drawing on the 'group value model', they outline the importance of the relationship between an individual (group member) and a group's authority figure, and identify three antecedents of PJ in decision-making: neutrality (fairness), trust, and standing (respected status). Participation in terms of voice (whether individuals have the opportunity to voice their preferences, based on appropriate information, clarification and options) increases perceptions of PJ, which in turn influences the response to any decisions made, even when there is an undesired outcome. In the healthcare setting, if an individual (as a patient group member) feels respected in the medical encounter, trusts the physician (the authority figure, e.g. with medical expertise and gate-keeping status) to be competent and fair, and participates (feels heard) throughout the decision-making process, he/she is more likely to accept negative consequences of any decisions made, and perhaps continue to pursue answers in the traditional healthcare setting. This is particularly salient in the case of early RA and medical consultations, where gaining an effective treatment plan is often an ongoing process of communication and decision-making, 'trial and error' and 'keeping at it'. From this perspective, PJ is not only integral to shared decision-making, but it also potentially informs illness actions, for example, medication use.

Focusing on ethical aspects in early RA offers a fresh perspective to rheumatology and builds on the growing trend of extending an ethical framework beyond the principle-based approach and acute medicine. This article draws on the discussion reported above and outlines issues of autonomous decision-making and PJ in the accounts of individuals with early RA as they discuss symptoms, decision-making, and illness actions from onset to early post-diagnosis.

PARTICIPANTS AND METHODS

In this pilot study, we interviewed eight participants about their RA experience from onset to early post-diagnosis. We purposively sampled [35] individuals who had received an RA diagnosis in the previous 12 months, lived in British Columbia (BC), and were English speakers. Participants were recruited through rheumatologists' offices in Vancouver, and GP practices in the province of BC, Canada. An enrollment period was set, a priori, at 4 weeks in order to assess the rate of participant recruitment.

In February 2007, we sent study documents to 163 GPs in BC who participated in The Arthritis Society *Points on Joints* initiative, a continuing medical education programme on arthritis diagnosis and management. Additionally, three rheumatologists from Vancouver agreed to forward the study information to patients who had a diagnosis of <12 months. Eight volunteers (three via their GP and five via the rheumatologist) contacted AT or PA for further information and all agreed to participate. This article draws on the accounts of these eight participants, a sample size considered adequate for exploratory study. Further, McCracken [36] states that a sample of eight participants is sufficient in most qualitative research because the critical factor is the 'way' the interview study is conducted, rather than the numbers interviewed. The open nature of the topic guide, the use of prompts and probes, the detailed field notes, the email contact (during recruitment), and second round of interviews (six phone follow-ups, two in person) generated extensive in-depth data for finely grained analysis.

We investigated the decision-making process and illness actions in help-seeking through in-depth interviews organized around three overlapping but distinct areas:

(1) onset and impact of symptoms pre-diagnosis; (2) experiences around the diagnosis, including medical encounters; and (3) post-diagnosis experiences of symptoms, medications and health professionals. The guide included probes and prompts for elaboration and clarification, and was developed from research team (researchers, patients/consumers, practitioners) discussions. Our goal was to elicit full responses from the participants about their early RA experiences and priorities. A second interview was conducted 3–5 months after the initial meeting, to gain further details, and to check emerging interviewer understandings. The interviewers [AT, PA] summarised the main points at the end of each interview to enhance validity. Comprehensive field-notes were recorded to aid analysis.

With informed consent, all tapes were fully transcribed and checked against the transcripts. Identifying information was removed. Two of the authors (AT and PA) conducted initial analysis independently. Transcripts were read to gain the 'gist' of the accounts and then re-read in a more fine-grained way, annotated line by line, and early codes and emerging themes identified and discussed with a third author (LL). Subsequent themes were identified and agreed upon through discussion and negotiation. AT and PA made constant comparisons within and between transcripts, and themes were added, revised, and refined. To aid analytic rigour, coherence and thematic consistency were checked, and both a range of experiences and similarities, were sought between and within transcripts.

Ethics approval was granted by the University of British Columbia, Behavioral Research Ethics Board (BREB) and Vancouver Acute, Mary Pack Arthritis Centre, Vancouver Coastal Health Authority (VCHA).

FINDINGS

All participants described: making sense of, and acting to manage early symptoms; consulting their GPs; at least one rheumatologist, and other healthcare providers prior to gaining an RA diagnosis. Below we apply an ethical framework of autonomous decision-making to onset and illness actions, and the medical encounter; we then focus on PJ and the medical encounter.

AUTONOMOUS DECISION-MAKING

Onset and Illness Actions

New resistant, severe, abnormal and debilitating symptoms which disrupted, or threatened to disrupt daily life, warranted a speedy GP visit: *'I just took some meds and about a week later I went (to the GP). I couldn't drive, it was so bad'* (Lyn, 50s). Diffuse, gradual or episodic symptoms signalled the need for a range of 'appropriate' illness actions. Participants conveyed how they normalized, accommodated and contained symptoms, and self-managed prior to a GP consultation. Individuals reported assessing their symptoms as not warranting a GP consultation, and taking both routine and complex illness actions. They 'made sense' of their symptoms and responses by drawing on their common-sense understandings of what was wrong and appropriate responses. In some cases, even when symptoms were severe and debilitating, their explanatory frameworks did not feature the possibility of RA and timely action. Some only realized their 'bodily changes' were symptoms in retrospect. Sarah accommodated her symptoms for months, without seeking medical advice although routine actions had become problematic:

> I didn't really notice that I had symptoms. I had a stiff shoulder and I had my daughter in to a family doctor….I had a heavy coat…I had trouble getting it on and off ….my daughter had helped me taking it off already but I needed to get it back on. So she had to help me with that and my doctor saw that…I would have gone to the doctor at some point in time, but I just thought that I had overdone it…strained something (Sarah, 50s).

This participant had not considered the stiffness (as well as pain and fatigue) she had experienced as requiring formal help, but rather accommodated it into her working and family life, pacing and undertaking self-management strategies to prevent disruption. Her lack of knowledge about RA and the need for speedy treatment is highlighted in her comments regarding subsequent advice (for a rheumatologist referral) from her GP, as she became increasingly incapacitated over several weeks: *'I am a lawyer, and I thought that rheumatologists are all kind of quacks and was really reluctant to do that (see a rheumatologist)'* (Sarah, 50s). For some of the participants, it was clear that their perception of the role of the GP consultation, combined with their interpretation of the symptoms, their proclivity to self-manage in daily life, their lack of knowledge about what early RA is and the need for timely treatment, played a significant role in delaying the GP meeting.

Illustrating this point further, a male participant describes how he 'made sense of' incapacitating symptoms (pain, stiffness, swelling) based on his knowledge of health conditions and the place of the GP consultation. He explains how, in his case, delay occurred:

> …I think I probably would have tolerated it for a while…I was trying to figure out what was going on because I had been seeing my physiotherapist on a regular basis and, I finally noticed myself one night that my legs seemed swollen, which kind of said to me, you know: 'Is there a blood pressure thing going on here, or what's going on here'?…I think…for the average male that they'd probably put that (the GP appointment) off for maybe six or eight months…And of course, now to

> understand RA, Wow! that's a long time…I knew enough about arthritis to some degree…because… my mother, and other people I knew…But (RA) itself, I wasn't tuned in to…I didn't see the value of accelerating the appointment…I was going anyway and I figured I am not dying so…(Ian, 60s).

This extract illustrates how Ian had knowledge about arthritis, but was not 'tuned in to' RA and the value of speedy treatment. He describes how he made sense of bodily changes, and took what he considered to be appropriate illness actions delaying the GP meeting; at the time he was making decisions about what to do, his explanatory framework did not include RA as a possibility or the *value of accelerating the appointment*. The significance of this missed opportunity to make a fully informed decision to gain optimum benefit is underlined by his words: '*And of course now to understand RA, Wow'*. His words suggest that lack of knowledge about RA and speedy treatment, rather than the ability and willingness to take actions, hampered his autonomous decision-making.

Several participants interpreted early symptoms as other conditions (one delayed the GP appointment for 5 months, despite experiencing sudden, severe, and debilitating symptoms thinking she had arthritis), getting older, 'overdoing it', or life occurrences 37 and described a range of self-management strategies, which as they indicated, may have delayed the referral process. RA did not figure in the 'explanatory frameworks' of this group of participants. Their accounts suggest that most were hampered, at some stage, in making effective and timely health-related decisions due, at least in part to a lack of knowledge about both rheumatologists and RA, for example, symptoms, susceptibility, course of the disease, and the importance of a prompt diagnosis and associated treatment.

The Medical Encounter

Another participant reflected how she felt under-equipped to make fully informed decisions about toxic medications at the time of diagnosis, when trying to decide: *'between a horrible thing* (escalation of the disease) *and a horrible thing'* (adverse effects of the treatments):

> (the rheumatologist) diagnosed me…and offered me a couple different routes of treatment…sent me on my way with another appointment in a month…or six weeks… In retrospect I wish that I could have been offered more options or some counseling…I think it (depression) was affecting my ability to make good decisions…. (Ruth, 40s).

This extract illustrates that decision-making not only requires adequate information in the way of options, but also should take into account the emotional needs of the newly diagnosed, and the subsequent need for support. It also highlights the process of decision-making. Others conveyed both obstacles to and opportunities for, autonomous decision-making which can be highlighted using PJ as a theoretical base.

PROCEDURAL JUSTICE

The Medical Encounter

Participants conveyed both high and low PJ in terms of perceptions of levels of fairness, trust and respect in medical encounters. PJ was fostered through teamwork, dialogue and shared information, and compromised when information, options and access to resources were sparse, and there was a feeling of 'not being listened to' (denoting 'low standing').

After a GP consultation, one participant described being 'in limbo' and feeling 'lost' with little knowledge of his condition, or advice about what he should or should not do. He described doing nothing, waiting for the rheumatologist's appointment for 2 months with little information, or medical contact during this period:

> 'And all they (GP) would say is just keep taking the pills, keep taking the pills. That really hasn't changed much. When I get into pain I'm still taking the pills. But for the fact you couldn't even see anybody for – they never even made an appointment for you to wait to see somebody. That bothered me. I said – geez I live in Canada. You should be able to talk to somebody or get some information or get fixed' (Stewart, 50s).

This participant felt he had too little information on which to base decisions and take actions, which would benefit his health. Obstacles to PJ are illustrated in several ways: he has no form in which to voice his experiences of feeling lost, and he indicates a lack of opportunity to determine his actions. He has no recourse for action, little information, and no support for this time period. He adds that he would like somebody to advise him on what actions to take beyond pills, (e.g. should he continue to fish, to drink alcohol?). In the absence of support and advice, he is *in limbo.*

In contrast, other participants pro-actively searched for information as they waited for the specialist appointment. However, this information-seeking could induce further anxiety about the disease, as individuals discovered the importance of, but an inability to gain, prompt treatment. This illustrates that, as active patients seeking information on which to base decisions and actions, it was not always possible to determine one's actions, and so PJ was compromised. This also echoes Redman's concerns about encouraging active self-management but not providing the resources to do so. Under these circumstances, one participant described *'feeling uncared for'* by a healthcare system, which, paradoxically, advised him to accept, though it did not offer, timely treatments. He recalled searching for a rheumatologist in order to receive treatment, limit damage, and ease symptoms:

> 'I found my rheumatologist on my own. I was told I had to call them (Dr X's office) to get my appointment: "If they don't call you in two weeks give them a call"…I gave them three weeks…a young lady told me: "Oh we've got a big pile of referrals…please be patient". Three weeks later I hadn't heard from them. So I started asking around. I asked my own doctor. I asked a pharmacist. I called four different rheumatologists about waitlists because you should be treated within three months of diagnosis to be truly successful and not to have joint damage…they're giving you contradictory messages really because you're told that it needs diagnosing, treating early on to prevent deterioration but then when it comes to it… I just don't understand why it had to be 6 months if I'd stuck with Dr X…. (Rick, 50s).

This participant seeks to overcome the barriers to a prompt rheumatologist meeting and gaining a treatment plan in order to limit damage. Despite conveying limited PJ (in terms of fairness, trust and respect), he works hard at gaining access to timely treatment.

Others who had experienced low levels of PJ in their interactions with healthcare professionals, described improved perceptions of PJ with a change in the healthcare practitioner, as in the following example. The participant describes resisting medications after being informed by her rheumatologist in an early meeting that she could get black blotches and go blind, but not to worry; she adds:

> …he just sat there with his prescription pad and wrote it out (prescription for Plaquinal), and handed it to me …I didn't really hit it off that good. I like to be able to sit and tell somebody not have them staring out the window, and you could see he was very uninterested; at least that's what it looked like (Iris).

Iris conveys a lack of trust and poor 'standing', as she details the meeting. However, she subsequently sees another rheumatologist, who prescribes her the same medication, but the reported meeting suggests high levels of PJ, patient involvement and the decision as process:

> and then she (rheumatologist) put me on Plaquinal. I wasn't too fussy but it was a much lower dose. Like the other doctor had me on 500, she had me on 2, and one pill and the other one was 3 times a day…And she'd say now if you've got trouble phone me…She's that good…It makes you feel that you have somebody who cares. And I think that's important especially in the medical line 'cos sometimes you think you are just a number…she makes you feel that you are just as important to her as any of the others down the line so that gives you more confidence…(Iris, 70s).

In this extract, Iris describes being 'put on' the medication, which she had previously refused, but there are subtle differences between this and the previous consultation; she is offered options, (both to take a lower dose, and to change her mind). This under-lines the decision as an ongoing negotiation, rather than an instruction. In contrast to her previous example, she indicates 'standing', has the opportunity to voice her experience after taking the medicine and trusts her new rheumatologist, so high levels of PJ are fostered, she accepts the decision, which she is not *too fussy about,* and perseveres, with confidence.

Another participant describes how he shares decisions about medications with his GP. In this extract, he emphasizes the importance of actively participating in team-work, denoting a symmetrical relationship and high standing in the 'medical community':

> it's called being proactive that's the great new word in the medical field… But you're being responsible to the physicians in the medical community who are trying to, to look after your care…I think we (GP) have got a good sharing relationship…What I have gotten off them is the impression I get they're very pleased that I'm involved in my treatment…(Ian).

Ian's experience with his healthcare team illustrates high levels of PJ. Ian's account shows that he continues to discuss issues with his health professionals even when the outcome of some decisions is negative; he is involved, has a voice and feels respected. The process, rather than the outcome, is central. He describes his GP as pivotal in the ongoing decision-making about medication regimens. Highlighting the importance of participation and voice in the decision-making process, Ian describes an initial appointment with a nurse, in which obstacles to PJ are conveyed in relation to decisions about injecting his medication:

> ‘it was just the way she presented it, there were no options. Cause I said to her: “… I’m in a state where they’re trying to figure out what to do, and when to do it, and there’s different medicines coming down the line, and you’re telling me I should inject myself right away”. And I’m saying: “Hold it now”…She had a rote she was following and I wasn’t fitting into the pattern quite well…she had this thought in her head that I will get an injection because (then) you won’t get any tummy problems but let me decide that…to my mind she…had a fixation, about an injection and I said well: “I read other information and so let me work with you on this”’. (Ian).

Ian subsequently negotiated a more symmetrical relationship with the nurse clinician who became part of his team. However, initially he decided not to re-contact her, and noted how as a direct result of the nurse’s attitude he exchanged information and knowledge with his GP as part of the decision-making process, and built a sharing relationship with him.

DISCUSSION

There are shortcomings in our study. It is a pilot project that has a relatively small number of participants, all of whom are RA patients. The knowledge would be enhanced by eliciting the accounts of rheumatologists and family practitioners as well as by undertaking observational research in medical settings. Nonetheless, its strength lies in the rich descriptions, the fine-grained analysis, and the open questions, thus allowing free talk of priorities and concerns of participants.

Participants in this study described decision-making from onset to early post-diagnosis. Their attempts to manage symptoms and limit the impact of the disease in their daily lives drove their behaviour. They made decisions and took actions based on their knowledge and common-sense understandings of the symptoms and appropriate actions. The rheumatology literature has identified patient delay in presentation to GPs as a major reason for the delay in seeing a rheumatologist, [17] along with the delay between primary and secondary care as being a major factor [15]. In line with research in the UK, which spans 26 years, [18,38] our Canadian data reveal that this group of patients often did not recognize the symptoms as needing a GP appointment and faced delays in gaining a diagnosis and an effective treatment plan in a number of ways.

An ethical framework of autonomous decision-making [25] and PJ [33,34] highlights how far participants had the relevant knowledge and support to make decisions, and take effective illness actions in daily life, particularly as patients with early RA. Ethical scrutiny reveals contradictions and tensions for this group of patients in a healthcare system, which increasingly supports the notion of ‘The Expert Patient’ taking responsibility for their healthcare, but often with inadequate knowledge and support to do so [2]. Revealed also are descriptions of medical encounters which feature both obstacles to and opportunities for PJ in decision-making about effective illness actions, gaining optimum benefits and avoiding disease progression [8].

As Redman notes, an ethical framework illuminates how unsupported self-management can limit the potential for benefits and lead to harm [39]. Inadequate information limits opportunities for individuals to make autonomous decisions about their health; it also becomes a (procedural) justice issue when the opportunity to develop and exercise one's capacities and express one's experiences is denied [39]. In the case of RA, and other chronic illnesses, when timely treatment is critical to limit disease progression and permanent harms, optimal benefits are diminished. Interventions should be seen to assist and enable individuals and limit disease as far as evidence allows.

If the aim of healthcare, in part, is to relieve pain and suffering and restore function, then effective healthcare should also promote the enhancement of well-being wherever possible. This is an ethical issue [20]. These findings reveal that even for the most resourceful, and pro-active amongst this group of patients, accessing timely care, treatment, support, and information was, at times, problematic. From the perspective of PJ, the participants not only risked avoidable disease damage, which potentially limited their prognosis and life opportunities, but also faced obstacles in the medical encounter regarding decision-making based on fairness, trust and respect. Based on these findings, the need for initiatives to more effectively transmit knowledge to the public, and during the medical consultation, about disease and self-management, is indicated. This may be particularly important given the emergence of the active and expert patient responsible for self-care, combined with research that spans decades, [40,41] which indicates that people with ongoing illness, and new symptoms, often delay seeking help. However, new practice or policy initiatives cannot be identified based on a pilot study; rather, more research is warranted to investigate what factors may encourage people to make timely GP appointments, and whether particular groups, or the general public be targeted in any advertising/awareness campaigns.

All participants described both positive and negative medical consultations. Some meetings were valued because of the characteristic of mutual respect in terms of shared tasks and a sense of working together, conveying a more symmetrical relationship, which involved participation and the ability to determine one's action [33]. More negative reports alluded to incidents and episodes when patients felt that they were not heard as individuals and were offered limited information about treatment options and side-effects. In these encounters, patients reported that their experience was downplayed and their opportunities to make fully informed decisions were diminished [24].

In this article we do not attempt a general moral theory, but suggest a selection of moral issues for further discussion and empirical investigation in the context of RA and chronic illness. The main purpose of an ethical framework is to clarify the moral justifications for healthcare and to provide a moral standard against which to evaluate interventions. Chronic illness ethics, like public health ethics, provides an analytical tool to help health professionals and policy-makers consider the ethical implications of proposed interventions, policy proposals, research initiatives, and programmes [9] For example, *'harms result when individuals do not believe that they are at risk for disease because they were never targeted* *in education campaigns… engaging in the steps of an ethics analysis makes us meticulous in our reasoning requirements when advocating interventions'* (Kass, p. 1782).

Where possible, the lay public need to be aware of the signs and symptoms of possible RA, know how to distinguish them from those of acute musculoskeletal conditions, and know the actions required. To this end, public education and social marketing strategies to improve arthritis awareness, and the use of screening tools may help improve early detection of RA [42]. Medical professionals, such as GPs and physiotherapists, also need to be more aware of early symptoms. There needs to be better communication in the consultation, which should aim to be based on informed collaborative alliance (or concordance). More guidance to support patients whilst they wait for a diagnosis is required, for example, patients could see a local arthritis nurse practitioner for pain management, support, and education, while they are waiting to see a rheumatologist. More early arthritis clinics (EAC) may be helpful. There is some evidence which indicates that they reduce waiting times for the first rheumatologist meeting, which is beneficial, and can prevent avoidable harms (www.health.gov.bc.ca/waitlist/index.html). People could have access to the information about the length of the waiting list of local rheumatologists so that they can make a decision on who they want to see (similar to the model of informing people about the length of orthopaedic surgical wait time in BC [42]. Although there is an increased focus by rheumatologists on diagnosing early RA and early RA clinics have been introduced for this purpose, evidence suggests policies or interventions need to be implemented more fully [42]. Also, healthcare facilitators, policy-makers, and healthcare decision-makers may consider different models to deliver services to people requiring rheumatology consults with a view to improve waiting times [42]. Detailed descriptions of early RA experiences regarding decision-making, access to information, and resources are, in this sense, a vital sources of input for empirically driven ethical analysis.

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