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A qualitative in-depth interview study of medication use from symptom onset to early post-diagnosis in patients newly diagnosed with rheumatoid arthritis.

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## Abstract

**Objective:** To examine accounts of medication use in participants with early rheumatoid arthritis (RA) from symptom onset to early post diagnosis in order to understand patient experience and improve outcome.

**Design:** Qualitative study with in-depth, personal interviews

**Participants:** 37 women and one man, aged 30s-70s, with a diagnosis of RA<12 months.

**Main outcome measure:** Participants' experiences and feelings of medication use in early RA.

**Setting:** British Columbia, Western Canada.

**Results:** Drugs were central to how people managed symptoms and disease. Several interacting themes were identified that hampered optimum medication use and delayed diagnosis and effective care: 1) Paradox of reliance on over the counter (OTC) medicines; 2) Contradictions and Internet use; 3) Complications of multi-morbidity. Tensions and complications arose in over the counter (OTC) and prescribed drug use. Paradoxically, 'effective' self-management with OTC drugs was detrimental to disease outcome as people relied on them extensively for pain relief and to maintain 'normal life' resulting in a delayed medical consultation, diagnosis and effective treatment; Internet use changed the dynamic and the outcome of the GP consultation e.g. some participants used Internet information to actively press for a speedy specialist appointment; Post-diagnosis, adherence was hindered by multi-morbidity and complications which added to the burden of using an already complex, combination therapy.

**Conclusions:** This study highlights how people/patients use medication in early RA which may transfer to other conditions. Given the shifting landscape of health care e.g. the drive towards active self-management, the emergence of the e-patient (engaged and web user) and rising multi-morbidity, in-depth understanding of how these interlocking factors impact patient experiences will help healthcare providers better support effective medication practices and identify gaps in care and support. The suggested extensive and prolonged reliance on OTC drugs needs investigating further when examining the health behaviours and outcomes of patient self-management.

## ARTICLE SUMMARY

### Article Focus

To understand the experiences of medication use in people with early RA from symptom onset to early post diagnosis.

### Key Messages

Our study suggests an over-reliance and extensive use of OTC medicines detrimental to health. People continue to self-medicate in the place of a GP consultation when symptoms are severe and debilitating but are masked by high and regular doses of OTC drugs.

Internet use can change the course of help seeking, patient-doctor dynamics and impact the timing of diagnosis and getting on prescribed medications.

Monitoring for co-morbidities is a significant burden for RA patients.

**Strengths and Limitations**

Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set offering the in-depth insight into how medication use was experienced for our participants. Their experiences could be transferred to other setting, depending on context. For example our findings may well reflect the experiences of people with other conditions who for example experience the complications of multi-morbidity and medication use, and who use the Internet for health reasons.

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**Introduction**

Medicines paradoxically promise both relief, and burden for those with chronic illness. In rheumatoid arthritis (RA) medicines ease symptoms and can limit disease progression, while often complex regimens can result in complications including causal co-morbidity<sup>1</sup>, adverse reactions and side effects. These combined factors can promote tensions and ambivalence around medication use and contribute to non-adherence to prescriptions, which can be detrimental to individuals and health care systems, thus a personal and public health issue: “Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources”<sup>2</sup> (p1). Given

that ultimately it is the decision of the patient whether or not to take medicines and how to take them, we need to better understand both over the counter (OTC) and prescription drug use in chronic illness and help-seeking.<sup>3-5</sup> In the context of the changing landscape of chronic illness care, e.g. the shift from the passive patient to the active partner,<sup>6</sup> the emergence of the ‘expert patient’<sup>7</sup> and e-patient, who seeks online guidance for ailments,<sup>8</sup> it is unsurprising that patients do not always take prescribed medicines as instructed. Neither is it surprising that people rely on OTC medicines to self-manage with no formal support. Our objective in this analysis was to understand medication use from the patient perspective and to identify barriers to optimum care from onset of symptoms to early post diagnosis. This information will be useful to both primary and secondary health care providers who work with patients to support adherence to prescribed medicines as a shared decision-making process. It will also offer information on the potential pitfalls of ‘effective’ but unsupported self-management through a reliance on over the counter (OTC) medicines, which may delay formal medical support and negatively impact outcome.

We used a qualitative approach<sup>9</sup> to investigate people’s experiences of early RA medication use in the context of their daily lives. In this paper we focus on: 1) The paradox of self-managing ‘effectively’ with OTC medications; 2) Internet use, contradictions and shared decision-making; 3) Complications of multi-morbidity. We then discuss how drug use was a core self-management strategy, and how it influenced help seeking, a timely diagnosis and effective treatment interventions. First we outline central characteristics of RA.

RA is a chronic illness, which necessitates combination drug therapy including OTC and prescribed medications. RA also shares features of other chronic diseases (pain and fatigue, early

symptoms with no visible signs, gradual and insidious progression). The experiences of those with early RA provide a rich source of qualitative data, which offer new and significant insights into medication use, which may be transferable to individuals experiencing other illness. RA symptoms include pain and inflammation, which may respond well to OTC medications (analgesics and anti-inflammatory drugs) prior to a GP (general practitioner) consultation. Prescription drugs used to treat RA include more powerful versions of the OTC medications to relieve pain, and non-steroidal anti-inflammatory drugs (NSAIDs), which relieve symptoms but do not impact the underlying disease, alter the course of the condition, or prevent damage to the joints or other organs.<sup>10</sup> However, effective and timely drug interventions can control disease progression and improve long-term outcomes. Current evidence supports the use of DMARDS within the first 3 months of symptoms appearing.<sup>11</sup> Delays in DMARD use are associated with worse disease control and have been reported across communities and at several stages of disease from onset to securing specialist treatment.<sup>12</sup> A study in the UK revealed that most patients with RA did not present to their GP until over 3 months after the onset of their symptoms<sup>12 13</sup>. Recent studies indicated a delay in DMARD use ranging from 6.5 months to 11.5 months in Canada, this was based on time between onset and prescription and assumes that the patient would start the drug immediately.<sup>14</sup> Combination therapy is standard care, which involves DMARDS, NSAIDs and analgesics. Corticosteroids (e.g. prednisone) are used as ‘bridging therapy’ (to relieve ‘flares’ or until the DMARD takes effect).<sup>15</sup>

**Participants and methods**

This analysis formed part of a wider study on the experience of help seeking in early rheumatoid arthritis, results of which have been published elsewhere<sup>16 17</sup> Help seeking was defined as

actions and use of formal and informal care among people who had been diagnosed within 12 months of study. Thirty-eight individuals (37 women, 1 man), aged 30s-70s participated in in-depth interviews between December 2007 and March 2009. All were English speaking and lived in the province of British Columbia, Canada.

## Recruitment

To aid our purposive sample range we recruited through patient organization Web sites, newsletters and information leaflets at local arthritis centers, as well as rheumatologist and family physician offices. In all settings potential participants contacted the research coordinator either by phone or e-mail, the study was discussed and those who agreed to participate were sent an informed consent document to be discussed and signed at interview. All eligible participants who made contact agreed to participate and gave written consent. One participant died prior to interview. Participants lived in a range of households and included individuals who were in paid employment, on disability, homemakers, and retirees. Participants lived in communities ranging from Vancouver a large city on the West coast to small mountain and rural communities in the North and East of BC. Participants were Caucasian, which does not reflect the diversity of parts of the lower mainland. All names are pseudonyms chosen by the participants. Ethical approval for the study was granted by the University of British Columbia's Behavioral Research Ethics Board and all participants gave written informed consent.

## Interviews

A topic guide was used to elicit in-depth accounts of participant experiences,<sup>18</sup> conducted at a time and place convenient to the participants, 30 in their home and 8 in hospital settings. The topic guide was organized around 3 separate but overlapping sections; 1) Symptoms/onset/impact including illness actions; 2) Consulting the GP and gaining a



diagnosis/health care system and professionals; 3) Post diagnosis experiences. Open questions were asked, and probes and prompts used for elaboration. The guide was formulated after discussion with the multi-disciplinary team including consumers (individuals with inflammatory arthritis). All participants agreed to a follow-up telephone interview for elaboration and clarification, where there was opportunity to check main results of the initial interview. The majority of the interviews were conducted by AT, research associate and PA outreach liaison worker at an arthritis clinic, experienced qualitative researchers. The remainder were conducted by members of the research team who were trained by AT. The topic guide had been tested in a pilot study.<sup>19</sup> Detailed field notes were taken to aid interpretation and validity of the data driven claims. Interviews lasted between 60-120 minutes. One participant was interviewed with spouse.. There was a summing up period at the end of interviews to give participants the opportunity to clarify and elaborate.

**Data analysis**

The audio-recorded interviews were transcribed verbatim. Analysis was iterative and informed by grounded theory; constant comparisons were made between and within transcripts and memos were written. We used paper-based methods in the initial stages and nVivo 7 was then used for storage and handling the extensive, detailed data. No apriori themes or codes were identified. AT and PA read and coded all transcripts independently and in stages to aid validity and reliability. Here we focus on how the participants discussed their medication use, from onset to post diagnosis. Transcripts were checked for accuracy against the recordings and identifying information removed. AT and PA annotated a selection of transcripts independently and devised preliminary codes for all data; all authors read a selection of transcripts and after discussion and negotiation preliminary codes were revised, agreed upon and major themes identified. AT and



PA then applied the codes to further transcripts and constantly compared themes. Early broad themes related to medication use were clear e.g. taking over the counter medications (OTC) as major self-management strategy; other themes emerged as analysis progressed such as OTC medicine use as paradox offering relief while causing harm (people who ‘effectively’ self-managed did not seek a GP appointment and diagnosis and effective treatment was delayed). All transcripts were reread as higher themes emerged; deviant cases were sought.

## Results

Both OTC and prescribed medicines were core to illness management from onset to post diagnosis. All participants experienced ‘trial and error,’ of a combination of drug regimens over time to gain efficacious treatment with minimum negative effects. All took a mix of medicines, most suffered side effects and adverse reactions to varying degrees and depended on medicines for symptom relief and to maintain function in daily life. Most conveyed medication as highly effective in easing severe and debilitating symptoms, and limiting the impact of the disease. Only a few reported medication use as unproblematic. The majority described ‘aggressive treatments’ and the risk of complications, which required monitoring and repeated medical appointments. Perhaps unsurprisingly participants relayed ambivalence around medications use; grateful for the significant benefits, whilst voicing concerns about the (potential for) harms either experienced as side effects (e.g. mood changing; extreme fatigue; diarrhoea) or symbolized by constant monitoring for adverse effects such as signs of liver or eye damage. Paradoxically, both *regular* and *efficacious* OTC medication use delayed diagnosis and timely treatment, important for optimum disease outcome.

**Paradox: Pre-diagnosis use of over the counter (OTC) medicines**

In the pre-diagnosis stages of illness, participants relied on OTC medications to control illness, maintain their roles and delay a GP consultation (Box 1). Many participants reported relying heavily on OTC analgesics for extended periods of time facilitating ‘normal’ life and fulfilling social roles and obligations. Although participants were recruited with <12 month diagnosis, many described taking OTC medicines for symptoms, years prior to their diagnosis. Most saw OTC analgesics as a way of controlling symptoms and ‘carrying on.’ One woman described negotiating symptoms and multiple roles (as a mother, student and employee) noting that over a period of a few years she was eventually “... *eating Ibuprofen like.... Smarties to try to keep the pain at bay*” (Box 1 Danielle).

**Box1: Paradox: Pre-diagnosis use of OTC medicines**

*Just took Tylenol and Ibuprofen and tried to keep it at bay... to try... to see a doctor... wasn't worth it with the hassle of... baby and work. It wasn't that urgent... I spent... up to 14 hours a day on my laptop... eating Ibuprofen like a box of Smarties to try to keep the pain under control (Danielle).*

*When you have two little kids you just keep going... I kept going to skating lessons... the pain of tying up those laces... undoing them... getting them in and out of car seats...I didn't pay a lot of attention to it because I just thought... that's life...you just keep going and you take Tylenol or Advil and that's the way it is... I was almost full-time work and I really loved my work... I was so stimulated... really enjoyed my kids... I just kept taking pain medication to function (Flossie).*

Over the counter (OTC) medicines were conveyed as core to daily life and central to managing symptoms at onset of RA, for time periods, which ranged from a few days to several years. Typically participants described using OTC medicines for several weeks, alongside other strategies, e.g. pacing and alternative therapists and treatments. Several expressed adapting to or pushing ‘*through the pain*’. Their priority to ‘*keep going*’ swamped any general aversion to medicines, or concerns about consuming large quantities of OTC analgesics routinely, for long

periods. Some who took the maximum dose as part of their daily routine, over a number of years expressed a reluctance to take them, but depended on them to function: *"Each day I ask myself: Now do I need them today?"* (Bonnie).

Significantly, consulting the GP did not *occur* to some, if they could 'carry on'; several took medicines routinely to function in full lives and maintain multiple roles. For them, OTC analgesics were an integral component of daily life, allowing them to keep busy, and 'push through' symptoms (Box 1 Flossie). Some conveyed consciously *avoiding* a GP appointment in the context of busy lives where a GP appointment was considered *a hassle*, and anticipated as being of little help. This involved however, 'trial and error' of OTC medicines to enable functioning across roles, e.g. parenting, working and studying. This could mean changing medications or varying the dose, balancing symptom relief against side effects. For example, Danielle favored OTC analgesics to those her GP had prescribed. She reported telling him that she was *"taking Ibuprofen... beyond the max per day on the bottle"* He prescribed something stronger. She notes: *I didn't like the effects of the other stronger stuff that was prescribed at the doctors because... I didn't have time for drowsiness in the program and then raising a child, drowsiness was just not in the equation so I just went back to the Ibuprofen.... Being drowsy does not help you fight the fatigue"* (Danielle). Others emphasized that they were reluctant to go to their GP *because* they strongly suspected they had RA and their knowledge of treatment options (via family members' experiences' or web-based information). They resisted an appointment for as long as possible and continued to self-medicate, in order to avoid anticipated RA treatment. Paradoxically, the more effectively participants self-managed symptoms (avoided disruption and maintained 'normal' life) the less likely they were to consult a GP. This hampered

a speedy diagnosis and prescribed treatments that could reduce disease damage.

**Contradictions: The e-patient, help-seeking and shared decision-making**

Internet use impacted help-seeking. Some discovered the importance of early treatment to limit disease, which prompted them to ask their GP for a (more speedy) specialist referral (Teresa Box 2).

**Box 2 Contradictions: The e-patient help-seeking and shared decision-making**

*I got on the Internet... and... concluded very quickly that this is RA.... I went back to my GP and I said I think I've got RA.... I 've got these symptoms. They match the diagnostic criteria.... I want the RA factor test.... she said: "...I'm going to refer you to a rheumatologist" (Teresa).*

*It's very confusing...to know that there's medications out there... nobody tells you this information.... The rheumatologist says: "Well I've got to put you on this, this is how you take it and this is what you can do and this is what you can't do, and you've got to go for a blood test once a month, don't drink, come back and see me in 10 weeks". And that's basically the way it was done, I mean, in my mind. So I go on the Internet and look up this medication and think: "Oh my God, this is terrible for what it does to your body, it's incredible". So my... GP said to me: Well, the choice is you either take the medication and... control it as you've been told or you go in a wheelchair and you take morphine". So what's the choice? So you have to do it (Alicia).*

*...letting patients decide... it's all very well on the one hand to let patients decide but then it's like can you go and decide but how much support are you getting making these decisions in terms of information? Or is it a case of?... Not much... a phone number, a website, a phone number of a drug company, a couple of websites. But we (rheumatologist appointment) had reached the end of our time. The cortisone shot had taken up five minutes out of the fifteen and there are people waiting in the waiting room. So he didn't review with me the differences between Humira and the Enbrel. Why one would work where the other had failed. He didn't review with me the side effects or the risk factors. That was for me to find out... (Teresa)*

Several expressed how the Internet information they gathered on medication options and side effects was not discussed in clinical consultations and conveyed a lack of genuine shared

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2  
3 decision-making in the GP and rheumatologist meeting ‘*So what’s the choice?*’ (Box 2 Alicia).  
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5 In this way there were contradictions around being an active and informed patient and the  
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7 opportunity to have a collaborative patient-doctor relationship (based on concordance and  
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9 mutuality rather than a compliant patient, adhering to prescribed drugs). Obstacles to discussing  
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11 options included a reported lack of time (in the consultation) (Box 2 Teresa).  
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### 15 16 17 **Complications and multi-morbidities**

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19 Post-diagnosis, participants described complex drug regimens comprising a combination of  
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21 analgesics, NSAIDS and DMARDS, and intermittently could include corticosteroids. Although  
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23 most participants conveyed a desire for prescription medications, they also described  
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25 complications. Treatment plans were characterized by ‘trial and error,’ multiple drugs, flexibility  
26  
27 of dosage, and forms of treatment (oral versus injection). The combination of uncertainty about  
28  
29 the particular risks and benefits for patients in the early stages of treatment plan meant that there  
30  
31 was a high degree of ‘trial and error’. This involved waiting for the results (of side effects to  
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33 cease and benefits to be felt) and required formal monitoring to avoid adverse effects such as  
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35 liver and eyes problems. For participants this meant regular blood tests, monitoring eye health  
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37 and taking supplements such as folinate. A few voiced concerns about delays to monitoring: “*I*  
38  
39 *still haven’t had my eyes checked... with this Plavix I am on. I have an appointment way in July*  
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41 *and I started the drug in December.... I was supposed to have a baseline.... So six months just*  
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43 *for your eye appointment*”(Marlain). The need for monitoring heightened awareness of the  
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45 potential toxicity of the drugs, alongside the side effects endured.  
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### 55 56 **Box 3 Complications and multi-morbidities**

*(Then) ... I was pretty much in perpetual pain I had the most awful week... my leg pain was so severe I was in tears and I was shaking... my neck swelled and I couldn't turn my head. I thought – oh my god this has gone through my neck, my knee... where is this going to end... I was tapering off Prednisone at that point... but in an act of desperation. I got up in the middle of the night and I took 20 mgs. of Prednisone. I was supposed to be on 2.5... But I had to have some relief..., next day... I went into... the locum... and asked for a cortisone shot in the knee... he wouldn't... He said you're on Humira, which raises your risk of infection. You've got RA which raises your risk of infection. He just didn't want to do it...I just didn't really know what to do. I went home. I went to bed. Yea. And I was icing, warming my knee and knee and using Celebrex. I didn't want to continue with the Prednisone because... the metabolic problems... it was probably one of the worst weeks of my life... I felt I that I had to make those decisions myself and I couldn't get to the rheumatologist... so I decided to go back on Methotrexate and I still had three pills from the pharmacy left knowing full well that the nodules would probably return and knowing about the liver damage... So I restarted Methotrexate... then I started to experience some relief (Teresa).*

There were examples of a lack of timely support when reactions to drug regimens developed. Some suffered severe side effects but found it difficult to access specialist help. Responses included: using a local emergency department; seeking an earlier consult with his/her GP, or suffering severe and debilitating side-effects while waiting for the scheduled specialist appointment. For example when one participant suffered an acute episode, gaps in care were revealed when she was unable to contact her rheumatologist, her GP refused to give her the relief she requested, and the emergency services at the local hospital she felt were unhelpful (Box 4 Teresa). She then made decisions about medications pending her specialist appointment.

For many participants the already complex RA combined therapy treatment was exacerbated by multi-morbidity (separate illness conditions) and associated multiple medication use. For some the RA medications had adverse effects on pre-existing conditions. At times a lack of formal support and options offered, lack of communication between physicians, and confusion in a medical system not organized to care for multiple conditions and drug regimens heightened



suffering, frustrations and uncertainties and delayed RA treatment was a *'stumbling block'* (Shari). Adverse affects were exacerbated when there was inadequate information offered by formal services and/or a lack of support in making medication-based decisions and offering relief. For several, early symptoms were mistaken for an already diagnosed condition, combined with a fear for medications due to multiple intake and previous medical history and complications with previous drug regimens and seeing a series of physicians *"terrified of the medication... I had a medication years ago that's... why I have kidney problems..."* (Sherry). Some indicated difficulties in making decisions about medications, as they weighed up multiple risks relating to age, medical history and drug interactions. Uncertainty was amplified for others by what they perceived to be inadequate, burdensome and conflicting information from diverse sources.

## Discussion

Contradictions and complications emerged around medication use in the accounts of our study participants, newly diagnosed with RA. Participants commonly reported OTC medication use as an effective self-management strategy, which for many ultimately delayed diagnosis and effective treatment. Paradoxically, the more 'successful' self-managers risked longer delays and more harmful outcomes. Participants described Internet use which for some, altered the patient-doctor dynamic, in some instances, changing the role of GP as 'keeper of knowledge' as engaged patients learned about their symptoms and treatments and requested a specialist referral.

Significantly, Internet use also revealed contradictions in care, as web searches indicated a need for prompt treatment, while facing waits for a specialist meeting. Post-diagnosis, although most participants conveyed a desire for prescription medications, they also described complications of



side effects and adverse reactions, which were particularly burdensome for those with multi-morbidities and associated complex drug regimens.

Our study has limitations. Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set. The participants recruited could have been more inclined to be active self-managers or help-seekers.<sup>20</sup> They could also have been more prone than others to have problems, complex trajectories and experience tensions around help-seeking and medication use than others. We recruited just one man, and all participants were Caucasian so the sample was of limited scope. Nevertheless the in-depth analysis gave insight into how medication use was experienced over time for our newly diagnosed participants taking account of the changing context in which people manage chronic illness, which may well reflect the experiences of people with other conditions who for example experience the complications of multi-morbidity and medication use, and who may well use the Internet for health reasons.

Reflecting literature spanning 50 years<sup>21 22</sup> participants commonly reported delaying a GP consultation. We also found evidence that it simply did not occur to people to consult their GP or other as long as OTC medicines masked symptoms for prolonged periods. This attitude towards managing symptoms oneself could be encouraged by policy over the last decade about responsibility to self-manage and inappropriate use of overburdened resources and may illustrate the importance of identifying the negative consequences of relying on OTC medicines in particular circumstances. The delays in obtaining prescribed medication (for some) reflected experiences of patients in a study 40 years ago.<sup>23</sup> We found however that the participants could

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3 reduce delay in care by securing a more speedy rheumatologist appointment, diagnosis and  
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5 efficacious treatment plan via the Internet. In some examples, the participant was the gatekeeper  
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7 of knowledge, who took Internet information to their GP and requested (and got) a specialist  
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9 referral. This illustrated how the Internet has the potential to alter the patient-doctor dynamic and  
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11 perhaps accelerate not only a diagnosis but also the emergence of an engaged and empowered e-  
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13 patient. In several cases, however there seemed to be little opportunity to operate as an expert or  
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15 e-patient and take part in shared and informed decision-making in the consultation when Internet  
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17 knowledge was not shared. Most did not convey a sense that consultations were a ‘meetings  
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19 between experts’<sup>24, 7</sup>. Participants who described complications of multi-morbidities also reported  
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21 feeling unsupported when making decisions about medications in times of crisis (when acute  
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23 side effects were experienced, sometimes due to multiple medicine regimens) and as part of a  
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25 routine but ‘aggressive’ treatment plan. This brings to the surface a disconnect between policy  
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27 and practice and prompts more research on support for expert patients who self-manage with  
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29 little or no formal support, but also highlights the complications and lack of support when  
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31 experiencing multimorbidity related complications. For our participants, being effective self-  
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33 managers (self-medicated) could be bad for their health and being ‘expert patients’ engaged and  
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35 involved rarely translated into the consulting room, especially when the expert was a specialist,  
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37 rather than a GP. Some discussion points need highlighting.  
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48 These results have implications for policy and practice. First, the concept of self-management as  
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50 an education program in which patients are taught skills, or more recently acknowledged as  
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52 support for patients, needs to be clearly differentiated from the work of self-managing that  
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54 people undertake in daily life. Medications occupy a central place in people’s lives as they self-  
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manage, *prior to* seeking formal help; the long established concept of the ‘iceberg of illness’<sup>25</sup> bears witness to this extensive activity long before policy extolled the version of an expert patient who is to be encouraged to self-manage.<sup>7</sup> People do not take OTC medications in a cultural vacuum; established cultural attitudes of stoicism, more recent notions of over burdened health systems and taking responsibility for one’s health combine to encourage self-managing and avoidance of GP consults. As such it is unsurprising that people self-medicated for long periods of time and used maximum dosage drugs to help contain symptoms, *even when* they were ongoing, severe and debilitating, (especially when gradual, intermittent and insidious). Second, in the context of the notion of the expert patient and the rapidly emerging e-patient, and the new technologies of health, it is unsurprising that people seek information. But for our patients, there was often not the support in the consultation for discussion for a range of reasons.<sup>19</sup> It seems that although expectations are placed upon patients to be pro-active, to self-manage, to pursue information when outside of the consulting room, for many of our participants, bringing that knowledge and increasing expertise into the consultation is not encouraged. Third, a mix of potent drugs which work well but also have negative effects, build on the cultural ambivalence and aversion to medications which people often already have.<sup>4</sup> The ‘cocktail of drugs’ offered as ‘aggressive treatment’ is complicated further by the existence of multi-morbidity, associated polypharmacy and drug interactions, or fears of such. These findings re-emphasize that to construct patient medication behaviour as adherent or non-adherent does not engage with the patient experience of drug use, and their priorities but recycles a medical view of the patient in a binary oppositional way that is unhelpful and non-patient centred.

**Conclusions**

Our research re-emphasizes the role of and tensions around medication use in a changing health care environment. It suggests that one key challenge facing interventions to improve a timely RA diagnosis is to redress the public health message of appropriate help-seeking and individuals' responsibility to self-manage. Unless 'mixed messages' are clarified, people may well continue to use OTC medicines extensively and inappropriately to mask severe symptoms and maintain function in their daily lives. Interventions also need to acknowledge how the role of the Internet is likely to accelerate the emergence of e-patients, and how this will impact patient-doctor and other health professional; interactions, as well as recognize the complications of multi-morbidity and how these separate but often interlinking factors impact adherence. More evidence is required to understand what these factors mean for help-seeking, changing dynamics in consultations and the use of health services, as well as to examine potential burden for patients, people and professionals.

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#### Statements

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**Competing Interests:** All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) AT, PA, CB, LL have support from University of British Columbia, and Vancouver Coastal Health for the submitted work; (2) AT, PA, CB, LL have no relationships

with companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AT, PA, CB, LL have no non-financial interests that may be relevant to the submitted work.

**Contributorship:** Anne Townsend PhD– contributed to the conception and design of the study, conducted interviews, analysis and interpretation, led writing all drafts, guarantor of the study

Paul Adam – contributed to the conception and design of the study, conducted interviews, analysis and interpretation, commented on all drafts,

Catherine Backman PhD- contributed to the conception and design of the study, analysis and interpretation, commented on all drafts

Linda Li PhD- led study design and conception, conducted interview, analysis and interpretation, commented on all drafts.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

**Data Sharing:** Currently there is no further data available.

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# Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1. included in text	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2. identified	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
3. identified AT and PA	Occupation	What was their occupation at the time of the study?
4. identified	Gender	Was the researcher male or female?
5. included in text	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
8. reference to validity and reliability and independent checks in text	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
<b>Domain 2: study design</b>		
Theoretical framework		
9. identified	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
10. identified	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11. identified	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12. identified	Sample size	How many participants were in the

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		study?
13. identified	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14. identified	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>
15. identified	Presence of non-participants	Was anyone else present besides the participants and researchers?
16. identified	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>
Data collection		
17. identified	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18. identified	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19. identified	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20. identified	Field notes	Were field notes made during and/or after the interview or focus group?
21. identified	Duration	What was the duration of the interviews or focus group?
22. identified	Data saturation	Was data saturation discussed?
23. identified	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
<b>Domain 3: analysis and findings</b>		
Data analysis		
24. identified	Number of data coders	How many data coders coded the data?
25. identified	Description of the coding tree	Did authors provide a description of the coding tree?
26. identified	Derivation of themes	Were themes identified in advance or derived from the data?
27. identified	Software	What software, if applicable, was used to manage the data?
28. identified	Participant checking	Did participants provide feedback on the findings?
Reporting		
29. identified	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>e.g. participant number</i>
30. checked	Data and findings consistent	Was there consistency between the data presented and the findings?
31. checked	Clarity of major themes	Were major themes clearly presented in the findings?

32. identified e.g. only  
a few described  
medication use as  
unproblematic.

Clarity of minor themes

Is there a description of diverse cases or  
discussion of minor themes?

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## Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

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## Abstract

**Objective:** To examine accounts of medication use in participants with early rheumatoid arthritis (RA) from symptom onset to early post diagnosis.

**Design:** Qualitative study with in-depth, personal interviews

**Participants:** 37 women and one man, aged 30s-70s, with a diagnosis of RA<12 months.

**Main outcome measure:** Participants' experiences and feelings of medicine use in early RA.

**Setting:** British Columbia, Canada.

**Results:** Medications were central to how people managed symptoms and disease. Predominant themes were identified that hampered optimum medication use and delayed diagnosis and effective care: 1) Paradox of reliance on over the counter (OTC) medications; 2). Ambivalence around post-diagnosis prescribed medication use. Paradoxically, 'effective' self-management with OTC is potentially detrimental to disease outcome as people relied on them extensively for pain relief and to maintain 'normal life' resulting in a delayed medical consultation, diagnosis and effective treatment. Post-diagnosis, adherence was hindered by ambivalence towards medications in general.

**Conclusions:** This study highlights how people use in early RA, and contributes to a better understanding of medication use issues that may transfer to other conditions. Given the drive toward active self-management in health care, and the ambivalence about using strong medic, in-depth understanding of how these intertwined factors impact patient experiences will help healthcare providers support effective medic practices. The reported extensive and prolonged reliance on OTC may speak to a care gap and needs further investigation in the context of health behaviors and outcomes of patient self-management.

## ARTICLE SUMMARY

### Article Focus

To understand the experiences of medication use in people with early RA from symptom onset to early post diagnosis.

### Key Messages

Our study suggests an over-reliance and extensive use of OTC medications detrimental to health. People continued to self-medicate in the place of a GP consultation when symptoms were severe and debilitating but were masked by high and regular doses of OTC medications.

Ambivalence about medication use suggests that we need to understand patient priorities and experiences better in order to support adherence

### Strengths and Limitations

Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set offering insight into our participants'

experiences of medication use. Their experiences may be transferable to other settings, with individuals who have similar characteristics.

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**Introduction**

Medicines paradoxically promise both relief and burden for those with chronic illness. In rheumatoid arthritis (RA) medicines ease symptoms and can limit disease progression, while often complex regimens can result in complications including causal co-morbidity, adverse reactions and side effects<sup>1</sup>. These combined factors can promote tensions and ambivalence around medication use and contribute to non-adherence to prescriptions, which can be detrimental to individuals and health care systems, thus creating a personal and public health issue: “Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources”<sup>2</sup> (p1). Given that it is ultimately the patient’s decision whether or not to take medications and how to take them, we need to better understand both over the counter (OTC)<sup>3</sup> and prescription use in chronic illness and help-seeking.<sup>4-5</sup> Qualitative research is designed to explore, interpret and gain a deeper understanding of social phenomena, and therefore is a useful approach to apply to patient experiences and use of medications. The shift in



chronic illness care from passive patient to active partner, and policy support for shared-decision-making and self-managing<sup>6-8</sup> makes this topic particularly important. Our objective in this analysis was to understand medication use from the patient perspective and identify barriers to optimum care from onset of symptoms to early post diagnosis. This information will be useful to health care providers who work with patients to support adherence to prescribed medicines as a shared decision-making process. It also offers information on the potential pitfalls of well-intentioned but unsupported self-management through a reliance on OTC medications, which may delay formal medical support and negatively impact outcome.

We used a qualitative approach<sup>9</sup> to investigate people's experiences of early RA medication use in the context of their daily lives. In this paper we focus on two predominant themes, which emerged from interviews: 1) The paradox of self-managing 'effectively' with OTC medication; 2) Ambivalence and tensions around taking prescribed medication. We then discuss how medication use was a core self-management strategy, and how it influenced help seeking, a timely diagnosis and effective treatment interventions. The experiences of those with early RA provided a rich source of qualitative data, offering new and significant insights into medication use, which may be transferable to individuals experiencing onset of similar conditions characterized by pain, debility and concerns about unpredictable symptoms, uncertainties about the course of the illness and what to do about it. Different conditions impact *functional* ability, that is, the nature and levels of incapacity and attempts to minimize it, fundamentally affect daily life and provoke various opinions around medication use.<sup>5</sup>

Because the goals of RA are to ease pain, reduce inflammation and prevent joint damage,

combinations of medications are required; disease modifying anti-rheumatic drugs (DMARDS), biologics, non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics are treatments that include both OTC and prescribed medications.<sup>10</sup> As well as combinations of medications, current evidence shows that DMARD interventions control disease progression and improve long-term outcomes within the first 3 months of symptoms appearing.<sup>11</sup> Delays in DMARD use are associated with poorer disease control and have been reported across communities and at several stages of disease from onset to securing specialist treatment. A delay in DMARD use ranging from 6.5 months to 11.5 months was reported in a Canadian study, which assumed that patients started the drug immediately upon prescription.<sup>12</sup> A UK study concluded that for their participants “the majority of the delay in assessing patients with RA in secondary care lay at the level of the patient seeking medical advice” (p3)<sup>13</sup> And qualitative research in the UK identified a combination of factors influenced decisions to consult in early RA patients, including the nature of symptoms, knowledge of RA and attitudes towards health care providers.<sup>14</sup> Other research about women’s decision-making around prescribed medications for RA identified it as a complex and multi-faceted process.<sup>15</sup> Overall, we know little about the factors impacting decision-making in over the counter and prescribed medication use in early RA, from onset to diagnosis. This study extends this knowledge by comparing OTC and prescribed medications use.

**Participants and methods**

This analysis formed part of a wider study on the experience of help-seeking in early rheumatoid arthritis from onset of symptom to early post diagnosis<sup>16</sup>. The overarching aim was to better understand the patient experience of early illness in the context of their daily lives and to identify

delays along the care pathway. The original aim then was not to investigate medication use, but to understand the priorities and the experiences of the participants. Perhaps unsurprisingly medication use emerged as an important theme. Other results have been published elsewhere.<sup>16,</sup>

<sup>17</sup>

## Recruitment

A purposive sample was recruited through patient organization Web sites, newsletters and information leaflets at local arthritis centers, as well as clinician offices. To be eligible, volunteers were to be adults, with a (self-reported) RA diagnosis within the previous 12 months, and able to converse in English (See Table 1). In all settings potential participants contacted the research coordinator either by phone or e-mail, the study was described and volunteers were sent an informed consent document to be discussed and signed at interview. All eligible participants who made contact agreed to participate and gave written consent. One person who agreed to participate died prior to interview. They lived in a range of households in British Columbia (BC) and included individuals who were in paid employment, on disability, homemakers, and retirees; people who lived in communities ranging from Vancouver, a large city on the West coast, to small mountain and rural communities in the North and East of BC. Participants were Caucasian, which does not reflect the diversity of parts of the Vancouver metropolitan area. All names are pseudonyms chosen by the participants. The University of British Columbia's Behavioral Research Ethics Board granted ethical approval for the study and all participants gave written informed consent.

## Interviews

A topic guide was used to elicit in-depth accounts of participant experiences,<sup>18</sup> conducted at a time and place convenient to the participants, 30 in their home and 8 in a health research centre.

The topic guide was organized around 3 separate but overlapping sections; 1) Symptoms/onset/impact including illness actions; 2) Consulting the general practitioner (GP) and gaining a diagnosis/health care system and professionals; 3) Post diagnosis experiences. Open questions were asked, and probes and prompts used for elaboration. The guide was formulated after discussion with the multi-disciplinary team including consumers (individuals with inflammatory arthritis) and rheumatologists. The topic guide was tested in a pilot study.<sup>19</sup> A follow-up telephone interview allowed for elaboration and clarification, and to check main results of the initial interview (18 phone and one e-mail follow-up were conducted). Nineteen interviews were conducted by AT (n=19), research associate and PA (n=5), outreach liaison worker at an arthritis clinic, LL (n=1), a trained research coordinator (n=8), and three students supervised by PA (n=5). Both AT and PA are experienced qualitative researchers. Prior to data collection, AT conducted a training session. Field notes were taken to aid interpretation and validity of the data driven claims. Most interviews lasted between 60 and 90 minutes. One participant was interviewed with spouse present.

**Data analysis**

The audio-recorded interviews were transcribed verbatim. Transcripts were checked for accuracy against the recordings and identifying information removed. Analysis was iterative, and thematic guided by a constant comparative approach.<sup>20</sup> We used paper-based methods in the initial stages and nVivo 7 was then used for storage and handling the extensive, detailed data. No pre-selected codes were identified prior to data analysis. AT and PA annotated a selection of transcripts independently and devised preliminary codes for all data; all authors read a selection of transcripts and after discussion and negotiation preliminary codes were revised, agreed upon and

major themes identified. AT and PA then applied the codes to further transcripts and constantly compared themes. Early broad themes related to medication use were clear, e.g., taking over the counter medications (OTC) as a major self-management strategy; other themes emerged as analysis progressed such as OTC medicine use as paradox offering relief while causing harm (people who 'effectively' self-managed pain with OTC medication did not seek a GP appointment and diagnosis and evidence-based treatment was delayed). All transcripts were reread as higher themes emerged. Deviant cases were sought and analyses and interpretations were discussed with a medical sociologist experienced in qualitative research as a form of peer checking. The multi-disciplinary author team also offered differing perspectives to aid validity of the data driven claims.

## Results

Both OTC and prescribed medications were core to illness management from onset to post diagnosis. All participants experienced 'trial and error' with a combination of drug regimens over time to gain efficacious treatment with minimum negative effects. All took a mix of medications, most reported side effects and adverse reactions to varying degrees, and depended on medicines for symptom relief and to maintain function in daily life. Most conveyed medication as highly effective in easing severe and debilitating symptoms, and limiting the impact of the disease. Only a few reported medication use as unproblematic. The majority described concerns and anxieties about *aggressive treatments* and the risk of complications, which required monitoring and repeated medical appointments. Perhaps unsurprisingly participants relayed ambivalence around medications use; grateful for the significant benefits, whilst voicing concerns about actual or potential harms such as side effects (e.g. mood changing;

extreme fatigue; diarrhea) or symbolized by constant monitoring for adverse effects such as signs of liver or eye damage. Paradoxically, both regular and efficacious OTC medication use delayed diagnosis and timely physician-directed treatment, important for optimum disease outcome. Below we discuss two predominant themes from the interviews.

**Paradox: Pre-diagnosis use of over the counter (OTC) medicines**

OTC medicines were conveyed as core to daily life and central to managing symptoms at onset of RA, for time periods that ranged from a few days to several years. Typically participants described using OTC medicines for several weeks, alongside other strategies like pacing and alternative therapists and treatments. Several expressed adapting to or pushing *through the pain*. Their priority to *keep going* swamped any general aversion to medicines, or concerns about consuming large quantities of OTC analgesics routinely, for long periods.

Prior to diagnosis participants relied on OTC medications to relieve pain so they could function in everyday life (Box1 Alicia), using OTC analgesics to alleviate symptoms for extended periods of time facilitating ‘normal’ life. For example, OTC medications enabled social roles and obligations including family roles (Box 1 Flossie) and paid work (Box 1 Julie). Although participants were recruited within 12 months of diagnosis, many described taking OTC medicines for years prior to their diagnosis, the early RA diagnosis be questionable. One participant described negotiating symptoms and multiple roles (as a mother, student and employee) noting that over a period of a few years she was *relying on Ibuprofen* (Box 1 Danielle). For participants, OTC analgesics were an integral component of daily life, allowing them to keep busy, and *push through* symptoms. Consequently, negotiating symptoms around

daily life by relying on OTC medications meant delaying a GP consultation while they continued to self-manage. In the context of busy lives a GP appointment considered *a hassle* significantly, consulting the GP did not *occur* to some, if they could *carry on*. It was only when the OTC medicines failed to control the pain and people could no longer function in their roles that they made an appointment to see their family doctor (Box 1 Nicole).

***Box1: Paradox: Pre-diagnosis use of OTC medicines to function***

**Self-assessing symptoms and regulating OTC medicine intake**

Participants continued to self-regulate with OTC medicines after seeing their family doctors and prior to a diagnosis. This could mean changing medications or varying the dose, balancing symptom relief against side effects, doing a self-assessment check to gauge how many OTC meds would be required (Box 2 Bonnie). Danielle favored OTC analgesics to those her GP had prescribed (Box 2 Danielle). The more participants were able to avoid activity disruption by self-managing symptoms with OTC medications, the less likely they were to consult a GP. This hampered a speedy diagnosis and prescribed treatments that could reduce disease damage. Another participant took OTC medications, as well as prescription anti-inflammatory medications, for another condition (Box 2 Charlize). Others continued to take OTC medications and to see their family doctor. Martha relied on both OTC and prescription painkillers over a period of years when she made several visits to her doctor with escalating symptoms of pain (Box 2 Martha). The quotes in this second section speak to the ways people self-managed their symptoms in daily life via OTC medications: doing a self-assessment check to gauge how many OTC meds would be required (Bonnie), increasing OTC medications when required (Charlize), choosing to take OTC medications to avoid side effects (drowsiness) from prescription drugs



(Danielle). Although the majority relied on OTC medicines to control symptoms and maintain daily life a minority of participants explicitly noted a clear aversion to OTC medicines (Box 2 Marlain, Nora).

**Box 2: Self-assessing symptoms and regulating OTC medicine intake**

**Ambivalence: Post-diagnosis prescribed medication use**

In the face of debilitating, severe and unpredictable symptoms and uncertainties about disease prognosis, participants were relieved to see a specialist and to be prescribed RA medications designed to limit the disease process, improve function and reduce pain. An RA diagnosis, however, was treated with ambivalence. First, there was relief about a diagnosis but concern about having to live with a long-term condition. Second, there were descriptions of how participants relied on multiple prescription medications, but voiced a desire to come off them or reduce them because of concerns about potential toxicity and side effects.

Most participants were familiar with analgesics and anti-inflammatory drugs (both OTC and GP prescribed) and had been taking them to relieve symptoms and function in daily life, prior to RA diagnosis (Boxes 1, 2). Prescribed medications were perceived differently. Participants reported they were faced with *aggressive treatment* (Ruth) and *drug cocktails* (Jane-2), for which they were grateful but also had misgivings about. Ambivalence was expressed most clearly around taking DMARDs. For example, although desiring treatment, some participants delayed initiating or filling prescriptions. A few delayed taking DMARDs because they anticipated disruption at work or to holidays (Box 3 Cynthia). One participant described a combination of reasons, which put her off methotrexate; a lack of information from her rheumatologist, having to inject it, and that it was a cancer drug, all meant that Bianca delayed taking methotrexate until she could

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3 discuss it with her family doctor (Box 3 Bianca). Another participant was reluctant to take  
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5 prescribed DMARDS because she initially wanted to manage the RA herself along with her other  
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7 chronic conditions and limit her multiple medication intake (Box 3 Nicole).  
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11 ***Box 3: Ambivalence: a need for and an aversion to prescribed medications***

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13 ***Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications***

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19 Nearly all of the participants described side effects. Most participants, keen to reduce the impact  
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21 of RA strove to find a combination of prescription medications that suited them. This meant that  
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23 finding the right combination of drugs was a matter of trial and error, because for several the side  
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25 effects were extreme, and outweighed the benefits (Box 4 Flossie). Several noted they wanted to  
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27 reduce the level/frequency of their medications (Box 4 Debbie). Yet only one person reported  
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29 that they had stopped taking their prescription medicines and this was with the knowledge of her  
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31 family doctor and rheumatologist (Box 4 Sharon).  
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38 A few did not report side effects, and they were prepared to endure potential adverse effects to  
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40 their system, if it meant that they could function (Box 4 Sherry). noted how she tolerated an  
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42 aversion to DMARD but a need for it (Box 4 Nora). In this example, an anti- attitude, combined  
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44 with knowledge of the potential toxicity of , is outweighed by the benefits (of symptom relief  
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46 and functional ability) gained.  
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53 The tensions underpinning aggressive treatment (as described by participants) as care was clear  
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55 in the accounts. The powerful medications needed to effectively treat the disease resulted in  
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57 finely balancing the risks and benefits (Box 4 Charlize). Another contradiction voiced by many  
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was the use of prednisone, a drug, which offered relief but also side effects and could only be taken for limited periods of time (Box 4 Jessie). Overall ambivalence around taking effective and intensive treatments were amplified by information gained from multiple sources (e.g., the Internet, family members' experiences), combined with a reported lack of opportunity to meaningfully discuss risks, benefits and options in the specialist consultation.

**Discussion**

Paradox and ambivalence arose around medicine use in the accounts of study participants, recently diagnosed with RA. Participants commonly reported OTC medication use as an effective self-management strategy prior to seeking medical attention, which for many ultimately delayed diagnosis and effective treatment. Paradoxically, the more 'successful' self-managers risked longer delays and more harmful outcomes. Post-diagnosis, although most participants conveyed a desire for prescription medicines, they also described an aversion to them and concerns with complications. Understanding patient perceptions may inform several elements of practice, including effective patient-provider communication.

Our study has limitations. Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set. The participants recruited could have been more inclined to be active self-managers or help-seekers.<sup>21</sup> They could also have been more prone to have problems, complex trajectories and experience tensions around help-seeking and medicine use than others with RA. Despite purposive approaches, we recruited just one man, and all participants were Caucasian, so the sample is limited.

Trainee/multiple interviewers may have affected the quality in a minority of the interviews,

though this was taken into account in the analysis. Nevertheless the in-depth analysis gave insight into how medicine use was experienced over time, taking account of the changing context in which people manage chronic illness from symptom onset to diagnosis, which may reflect the experiences of people with similar chronic conditions Both MS and RA are autoimmune conditions; they are systemic, episodic illnesses, with no cure. Persistent yet fluctuating pain and fatigue contribute to negative experiences with activity disruption and participation in valued life roles.<sup>16</sup>

Consistent with literature spanning 50 years<sup>22,23</sup> participants commonly reported delaying a GP consultation. We also found evidence that it simply did not occur to people to consult their GP or other health professional as long as OTC medicines masked symptoms for prolonged periods. Use of OTC medicines to manage early RA symptoms and delay a medical appointment has been identified in other research.<sup>12</sup> This attitude towards managing symptoms oneself and prolonged use of OTC medicines could be unintentionally encouraged by policy messages about responsibility to self-manage and inappropriate use of over burdened health systems; this may illustrate the importance of better informing the public about the negative consequences of relying on OTC medicines in particular circumstances<sup>3,8</sup>. The delays in obtaining prescribed medication (for some), however, reflected experiences of patients with chronic illness in a study 40 years ago.<sup>24</sup> The accounts revealed reluctance to go on prescribed medicines, and a desire to reduce or come off them, to avoid side effects. Another significant finding was that although participants were concerned about the risks of prescription medicines, consistent with other populations<sup>25</sup> they largely reported little concern about using OTC medications because they perceived them as less harmful compared to recommended prescription medicines. This mirrors what others have identified in terms of encouraging a more active and empowered patient, which

may increase OTC medicine use and underplay the harms involved.<sup>3,8</sup> Findings also indicate how patients assess risk when making decisions about medication use.

Consequently, these findings have implications for policy and practice. First, the ambivalence which was conveyed by so many of the participants supports the need for concordance, which involves clinician and patient discussion around patient concerns, experiences, perspectives,<sup>5, 19</sup> risks and benefits associated with both prescribed medications<sup>26</sup> and OTC medicines. In this way, interventions are needed that incorporate patient perspectives<sup>26</sup> in meaningful ways. Second, medications occupy a central place in people's lives as they self-manage, *prior to* seeking formal help; the long established concept of the 'iceberg of illness'<sup>27</sup> bears witness to this extensive activity long before policy extolled the version of an expert patient who is to be encouraged to self-manage.<sup>7</sup> People do not take OTC medications in a cultural vacuum; established cultural attitudes of stoicism, more recent notions of over-burdened health systems and taking responsibility for one's health combine to encourage OTC medicine use and avoidance of GP consultations. As such it is perhaps unsurprising that people self-medicated for long periods of time and used maximum dosage drugs to help contain symptoms, even when symptoms were persistent and severe. Third, a mix of potent drugs which work well but also have negative effects, build on the cultural ambivalence and aversion to medications which people often already have.<sup>5</sup> The 'cocktail of drugs' offered as 'aggressive treatment' is complicated further by the existence of multi-morbidity, associated poly-pharmacy and drug interactions, or fears of such. These factors need to be considered as part of the patient experience of medication use, which informs decision-making and issues of risk.

## Conclusions

Our research re-emphasizes the role of and tensions around medication use in a changing health care environment. It suggests that one key challenge facing interventions to improve a timely RA diagnosis is to redress the public health message of appropriate help-seeking and individuals' responsibility to self-manage. Unless 'mixed messages' are clarified, people may well continue to use OTC medicines extensively and inappropriately to mask severe symptoms and maintain function in their daily lives. Interventions also need to acknowledge how the patient and clinician roles are changing, as well as recognize the complications of multi-morbidity and how these separate but often interlinking factors impact adherence. Interventions need to better communicate the need to gain treatment, the ramifications of having a chronic, systemic disease. RA is more than just joint pain, which many people feel comfortable in self-treating (with what may often be damaging levels of OTC medicines) rather than gaining a diagnosis. The risks and benefits of OTC medicines compared to prescription medicines need to be clarified in ways that support more informed decision-making in RA.

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## Statements

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) AT, PA, CB, LL have support from University of British Columbia, and Vancouver Coastal Health for the submitted work; (2) AT, PA, CB, LL have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AT, PA, CB, LL have no non-financial interests that may be relevant to the submitted work.

Anne Townsend PhD– contributed to the conception and design of the study, conducted interviews, analysis and interpretation, led writing all drafts, guarantor of the study

Paul Adam – contributed to the conception and design of the study, conducted interviews, analysis and interpretation, commented on all drafts,

Catherine Backman PhD- contributed to the conception and design of the study, analysis and interpretation, commented on all drafts

Linda Li PhD- led study design and conception, conducted interview, analysis and interpretation, commented on all drafts.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Further data are available relating to quotes around OTC medication use and ambivalence of prescribed medications.

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## Boxed Quotes

### Box1: Paradox: Pre-diagnosis use of OTC medicines to function

*I was just taking regular Tylenol and I mean I was sucking those back because I mean the pain was excruciating (Alicia)*

*When you have two little kids you just keep going... I kept going to skating lessons... the pain of tying up those laces... undoing them... getting them in and out of car seats...I didn't pay a lot of attention to it because I just thought... that's life...you just keep going and you take Tylenol or Advil and that's the way it is... I was almost full-time work and I really loved my work... I was so stimulated... really enjoyed my kids... I just kept taking pain medication to function (Flossie).*

*My husband had to help me to get a T-shirt on because everything was so stiff. I couldn't move and it was very painful... all these Tylenol / I would take up to 4 tablets of 650 mgs., by 11:00 the pain would go down to the point where I felt like I was happy to be at work. I could function fairly good. But the morning was a really tough time... At that point I had only taken occasionally more than six tablets a day to keep on going to work... it would go up to over 4,000 mgs. a day (Julie).*

*Just took Tylenol and Ibuprofen and tried to keep it at bay... to try... to see a doctor... wasn't worth it with the hassle of... baby and work. It wasn't that urgent... I spent... up to 14 hours a day on my laptop... eating Ibuprofen like a box of Smarties to try to keep the pain under control (Danielle).*

*I could hardly do anything... and when I started missing work I knew that that wasn't right... I tried the normal you know Tylenol or Aspirin or whatever to try and help as far as the pain went and nothing really worked. Nothing helped. So that's – again I decided – OK I can't go on like this on my own obviously. So again I decided – I made it clear that I had to go to the doctor and see what was wrong (Nicole).*

**Box 2: Self-assessing symptoms and regulating OTC medicine intake**

*Every morning, I take Tylenol for arthritis. Some days, I take two every morning. Some times I take a lot more.... I also take two at dinnertime. So a minimum of 4 a day. Sometimes more ... Each day I ask myself: Now do I need them today? (Bonnie).*

*I didn't like the effects of the other stronger stuff that was prescribed at the doctors because... I didn't have time for drowsiness in the program and then raising a child, drowsiness was just not in the equation so I just went back to the Ibuprofen.... Being drowsy does not help you fight the fatigue (Danielle).*

*Interviewer: Where there any other things that you were doing besides the ice to manage it at that early point?*

*There were things I probably shouldn't have been doing but because... I already was on some inflammatory medications... I sort of upped the dose, not the dosage of the prescription medication but I would use 'over-the-counter' anti-inflammatories as well and by that I mean I would take extra doses of Aspirin... with codeine and caffeine, which would get me through some of the times (Charlize).*

*[I kept going to the doctor] because they (pains) were getting worse and because I was taking Tylenol and you know Tylenol 3 and everything and it wasn't helping (Martha)*

*I am not one to take pills. I hate even taking Tylenol for a headache (Marlain)*

*I am just afraid to take medication. I don't even have Tylenol in the house. I take maybe, I don't know, through my whole life I might have taken three Tylenols or something (Nora).*

**Box 3: Ambivalence: a need for and an aversion to prescribed medications**

*The truth is... that right after my (specialist) appointment (Husband) and I were planning to go to Edmonton and I didn't want to be starting on a new medication (DMARD) when I was on a trip...I waited to see my GP (Cynthia).*

*Since he didn't give me a lot of information, the specialist, about Methotrexate I had to do a lot of reading on my own about it and I was very reluctant, to use it... So it was probably a month after I was prescribed it to when I actually started taking it... It was... injectible... it's a little bit more of a hassle to take... when the drugs are so strong you'd like to know a little bit more information than if it was... take an antibiotic and you're going to feel better. It's... take this drug and maybe in six months you'll feel better... Well Methotrexate was also used to treat cancer so it's a very, very strong drug. ... (Bianca).*

*We talked a little bit about... treatment and things that might help and he (rheumatologist) asked me how I felt about medications... because I struggle with other health issues and I take so many different medications already I asked if we might be able just to try managing things on our own (GP and me) before we got into a big treatment sort of plan and he said that was fine. He did prescribe a pain killer that was a little bit more than what my family physician had given me and he said:... "See how you do and if you need to come back before, call me but otherwise we'll see you in two months."... but things didn't get a lot better and I still missed the odd day of work... So when I went back to the (rheumatologist) I said... I need help.... So then we started talking about treatment options... He put me on a treatment program (DMARDS).... the medication has been a good thing because I tried to go without it and I couldn't (Nicole).*

**Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications**

*The Methotrexate cleared all the symptoms of rheumatoid... right away. Like eventually, it was just the side effects I couldn't tolerate... It created a whole host of other symptoms that were not weighing up the benefits... it... alters your psyche... it's harder to dig your happy self out of that (Flossie).*

*After my first shot (a biologic) I was able to get off the chair without any help... by the third shot I think I was almost back to normal....I am going to ask Dr. X. if I can take my [biologic] If I can not do it once a week maybe every 10 days. Just slowly and see how my body reacts to that. Because when I get my shot the first two days now I don't feel that well. I'm feeling a little bit agitated (Debbie).*

*The Methotrexate and Sulfasalazine so changed my personality. I was miserable. When I think back on the nine months it's like a blur. It's like something I don't really want to remember. I just quit the medication and then I went back to see [the rheumatologist] and he said: "Well you had a reaction". And he kept pooh, poohing me off... He's very dedicated. But he just needs to crawl into his patients' shoes sometimes (Sharon).*

*I have been on Methotrexate for just over a month. And it seems to be working ... But it terrifies me (Sherry).*

*I just have to take it. I don't think my attitude has changed. If I have to I have to... It will still be hard to do because I know I am destroying other parts of my body with the medications. ...I wouldn't take it if I didn't have to (Nora).*

*So either way you're treated there is a negative side effect... you try not to kill yourself with the treatment and still manage your daily life (Charlize).*

*I would like to get off the Prednisone as soon as possible... it's almost weird... Prednisone is a magic drug until you find out the side effects... It's almost cruel to give it to people because it works so well (Jessie).*

Table 1

	Age range	Sex (M/F)	Recruited via	Symptom onset to seeing Rx	Seeking medical help for symptoms leading to a diagnosis/ RA test	Referral wait time to see a rheumatologist	Diagnosis
Alicia	60s	Female	Unknown	1 year	3 months	6-8 weeks	Uncertain but treated for RA
Barbara Anne	40s	Female	Family doctor's office	10 years	1 year	6 months	Diagnosed
Bianca	30s	Female	Rheumatologist office	2 years 3 months	7 months	2 months	Diagnosed
Bonnie	60s	Female	Arthritis Newsletter	40 years	20 years	No referral	Not diagnosed
Charlize	50s	Female	Arthritis Newsletter	4 months	Less than 1 week	3 months	Diagnosed
Cynthia	60s-70s	Female	Arthritis Newsletter	1 year	5 months	2 mths	Diagnosed
Danielle	30s-50s	Female	Rheumatologist Office	8 years	3 years	2-3 months	Uncertain but treated for RA
Debbie	50-60s	Female	Rheumatologist office	2 years 4 months	2years 4 months	3 months	Diagnosed
Dodi	50s-70s (estimated)	Female	Rheumatologist office	5-6 months	2-3 weeks	10 months	Diagnosed
Dorothy	30s	Female	Rheumatologist office	1 year 10 months	2 months	2 months	Diagnosed
Flossie	50s	Female	Arthritis Newsletter	24 years	unknown	6 weeks	Diagnosed
Jackie	40s	Female	Arthritis Newsletter	8 months	3 months	9 months	Uncertain but treated for RA
Jane	60s	Female	Arthritis Newsletter	8-9 months	5 months	1 month	Diagnosed
Jane 2	50s	Female	Arthritis Newsletter	4 months	1 month	6-8 weeks	Diagnosed
Jean	50s	Female	Arthritis Newsletter	19 years	8 years	2 months	Diagnosed
Jessie	50s-60s	Female	Rheumatologist office	3-4 months	3-4 weeks	6 weeks	Diagnosed
Julie	50s-60s	Female	Physiotherapist office	3 months	3-4 weeks	1 month	Diagnosed
June	50s	Female	Arthritis Newsletter	3 months	unknown	6 weeks	Diagnosed
Kerry	30s	Female	Arthritis Newsletter	3 months	No delay	10 days	Diagnosed
Lee	40s	Female	Family doctor office	14 years	Unknown	Unknown	No diagnosis (has complex



							multi-morbidities tests ongoing)
Laurie	60s	Female	Arthritis Newsletter	1-2 years	1-2 years	At regular rheumatologist regular appointment	Diagnosed
Maple	40s	Female	Arthritis Newsletter	2 months	6 -7 weeks	1 day	Diagnosed
Marie	60s	Female	Rheumatologist office	3 weeks	2 weeks	1 week	Diagnosed
Marlain	50s-60s	Female	Rheumatologist office	4-5 years	2-3 years	< 6 months	Diagnosed
Martha	70s	Female	Unknown	9 years	6-8 years	1 year	Diagnosed
Nicole	30s	Female	Arthritis Newsletter	1 month	2 weeks	2 weeks	Diagnosed
Nicolette	50s	Female	Rheumatologist office	12 months	11 months	1 month	Diagnosed
Nora	50s	Female	Rheumatologist office	11 months	1 month	3 months	Diagnosed
Rain	40s-50s	Mail	Arthritis Website	4 years	11 months	10 months	Diagnosed
Rosie	60s	Female	Arthritis Newsletter	26 years	26 years	1 month	Diagnosed
Sally	50s	Female	Arthritis Newsletter	1 year	2 months	1 month	Diagnosed
Sarah	50s	Female	Arthritis Newsletter	3 years	16 months	1 month	Diagnosed
Shari	60s	Female	Unknown	6 months	unknown	No referral family doctor diagnosis	Diagnosed
Sharon	60s	Female	Family doctor office	7 years	unknown	2 months	Diagnosed
Sherry	40s	Female	Rheumatologist office	9-10 years	5 years	6 months	Diagnosed
Smokie Jean	50-60s	Female	Rheumatologist	40 years	4 years	3 weeks	Diagnosed
Teresa	50s	Female	Unknown	11 months	9 months	5 months	Diagnosed
Yoda	50s	Female	Rheumatologist office	3 years 6 months	1-2 weeks	6 months	Diagnosed

Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

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Abstract

Objective: To examine accounts of medication use in participants with early rheumatoid arthritis (RA) from symptom onset to early post diagnosis.

Design: Qualitative study with in-depth, personal interviews

Participants: 37 women and one man, aged 30s-70s, with a diagnosis of RA<12 months.

Main outcome measure: Participants' experiences and feelings of medicine use in early RA.

Setting: British Columbia, Canada.

Results: Medications were central to how people managed symptoms and disease. Predominant themes were identified that hampered optimum medication use and delayed diagnosis and effective care: 1) Paradox of reliance on over the counter (OTC) medications; 2). Ambivalence around post-diagnosis prescribed medication use. Paradoxically, 'effective' self-management with OTC is potentially detrimental to disease outcome as people relied on them extensively for pain relief and to maintain 'normal life' resulting in a delayed medical consultation, diagnosis and effective treatment. Post-diagnosis, adherence was hindered by ambivalence towards medications in general.

Conclusions: This study highlights how people use in early RA, and contributes to a better understanding of medication use issues that may transfer to other conditions. Given the drive toward active self-management in health care, and the ambivalence about using strong medic, in-depth understanding of how these intertwined factors impact patient experiences will help healthcare providers support effective medic practices. The reported extensive and prolonged reliance on OTC may speak to a care gap and needs further investigation in the context of health behaviors and outcomes of patient self-management.

ARTICLE SUMMARY

Article Focus

To understand the experiences of medication use in people with early RA from symptom onset to early post diagnosis.

Key Messages

Our study suggests an over-reliance and extensive use of OTC medications detrimental to health. People continued to self-medicate in the place of a GP consultation when symptoms were severe and debilitating but were masked by high and regular doses of OTC medications.

Ambivalence about medication use suggests that we need to understand patient priorities and experiences better in order to support adherence

Strengths and Limitations

Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set offering insight into our participants'

experiences of medication use. Their experiences may be transferable to other settings, with individuals who have similar characteristics.

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Researchers independent from funders

## Introduction

Medicines paradoxically promise both relief and burden for those with chronic illness. In rheumatoid arthritis (RA) medicines ease symptoms and can limit disease progression, while often complex regimens can result in complications including causal co-morbidity, adverse reactions and side effects<sup>1</sup>. These combined factors can promote tensions and ambivalence around medication use and contribute to non-adherence to prescriptions, which can be detrimental to individuals and health care systems, thus creating a personal and public health issue: “Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources”<sup>2</sup> (p1). Given that it is ultimately the patient’s decision whether or not to take medications and how to take them, we need to better understand both over the counter (OTC)<sup>3</sup> and prescription use in chronic illness and help-seeking.<sup>4-5</sup> Qualitative research is designed to explore, interpret and gain a deeper understanding of social phenomena, and therefore is a useful approach to apply to patient experiences and use of medications. The shift in

chronic illness care from passive patient to active partner, and policy support for shared-decision-making and self-managing<sup>6-8</sup> makes this topic particularly important. Our objective in this analysis was to understand medication use from the patient perspective and identify barriers to optimum care from onset of symptoms to early post diagnosis. This information will be useful to health care providers who work with patients to support adherence to prescribed medicines as a shared decision-making process. It also offers information on the potential pitfalls of well-intentioned but unsupported self-management through a reliance on OTC medications, which may delay formal medical support and negatively impact outcome.

We used a qualitative approach<sup>9</sup> to investigate people’s experiences of early RA medication use in the context of their daily lives. In this paper we focus on two predominant themes, which emerged from interviews: 1) The paradox of self-managing ‘effectively’ with OTC medication; 2) Ambivalence and tensions around taking prescribed medication. We then discuss how medication use was a core self-management strategy, and how it influenced help seeking, a timely diagnosis and effective treatment interventions. The experiences of those with early RA provided a rich source of qualitative data, offering new and significant insights into medication use, which may be transferable to individuals experiencing onset of similar conditions characterized by pain, debility and concerns about unpredictable symptoms, uncertainties about the course of the illness and what to do about it. Different conditions impact functional ability, that is, the nature and levels of incapacity and attempts to minimize it, fundamentally affect daily life and provoke various opinions around medication use.<sup>5</sup>

Because the goals of RA are to ease pain, reduce inflammation and prevent joint damage,

combinations of medications are required; disease modifying anti-rheumatic drugs (DMARDs), biologics, non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics are treatments that include both OTC and prescribed medications.<sup>10</sup> As well as combinations of medications, current evidence shows that DMARD interventions control disease progression and improve long-term outcomes within the first 3 months of symptoms appearing.<sup>11</sup> Delays in DMARD use are associated with poorer disease control and have been reported across communities and at several stages of disease from onset to securing specialist treatment. A delay in DMARD use ranging from 6.5 months to 11.5 months was reported in a Canadian study, which assumed that patients started the drug immediately upon prescription.<sup>12</sup> A UK study concluded that for their participants “the majority of the delay in assessing patients with RA in secondary care lay at the level of the patient seeking medical advice” (p3)<sup>13</sup> And qualitative research in the UK identified a combination of factors influenced decisions to consult in early RA patients, including the nature of symptoms, knowledge of RA and attitudes towards health care providers.<sup>14</sup> Other research about women’s decision-making around prescribed medications for RA identified it as a complex and multi-faceted process.<sup>15</sup> Overall, we know little about the factors impacting decision-making in over the counter and prescribed medication use in early RA, from onset to diagnosis. This study extends this knowledge by comparing OTC and prescribed medications use.

## Participants and methods

This analysis formed part of a wider study on the experience of help-seeking in early rheumatoid arthritis from onset of symptom to early post diagnosis<sup>16</sup>. The overarching aim was to better understand the patient experience of early illness in the context of their daily lives and to identify

delays along the care pathway. The original aim then was not to investigate medication use, but to understand the priorities and the experiences of the participants. Perhaps unsurprisingly medication use emerged as an important theme. Other results have been published elsewhere.<sup>16, 17</sup>

**Recruitment**

A purposive sample was recruited through patient organization Web sites, newsletters and information leaflets at local arthritis centers, as well as clinician offices. To be eligible, volunteers were to be adults, with a (self-reported) RA diagnosis within the previous 12 months, and able to converse in English (See Table 1). In all settings potential participants contacted the research coordinator either by phone or e-mail, the study was described and volunteers were sent an informed consent document to be discussed and signed at interview. All eligible participants who made contact agreed to participate and gave written consent. One person who agreed to participate died prior to interview. They lived in a range of households in British Columbia (BC) and included individuals who were in paid employment, on disability, homemakers, and retirees; people who lived in communities ranging from Vancouver, a large city on the West coast, to small mountain and rural communities in the North and East of BC. Participants were Caucasian, which does not reflect the diversity of parts of the Vancouver metropolitan area. All names are pseudonyms chosen by the participants. The University of British Columbia’s Behavioral Research Ethics Board granted ethical approval for the study and all participants gave written informed consent.

**Interviews**

A topic guide was used to elicit in-depth accounts of participant experiences,<sup>18</sup> conducted at a time and place convenient to the participants, 30 in their home and 8 in a health research centre.



The topic guide was organized around 3 separate but overlapping sections; 1) Symptoms/onset/impact including illness actions; 2) Consulting the general practitioner (GP) and gaining a diagnosis/health care system and professionals; 3) Post diagnosis experiences. Open questions were asked, and probes and prompts used for elaboration. The guide was formulated after discussion with the multi-disciplinary team including consumers (individuals with inflammatory arthritis) and rheumatologists. The topic guide was tested in a pilot study.<sup>19</sup> A follow-up telephone interview allowed for elaboration and clarification, and to check main results of the initial interview (18 phone and one e-mail follow-up were conducted). Nineteen interviews were conducted by AT (n=19), research associate and PA (n=5), outreach liaison worker at an arthritis clinic, LL (n=1), a trained research coordinator (n=8), and three students supervised by PA (n=5). Both AT and PA are experienced qualitative researchers. Prior to data collection, AT conducted a training session. Field notes were taken to aid interpretation and validity of the data driven claims. Most interviews lasted between 60 and 90 minutes. One participant was interviewed with spouse present.

## Data analysis

The audio-recorded interviews were transcribed verbatim. Transcripts were checked for accuracy against the recordings and identifying information removed. Analysis was iterative, and thematic guided by a constant comparative approach.<sup>20</sup> We used paper-based methods in the initial stages and nVivo 7 was then used for storage and handling the extensive, detailed data. No pre-selected codes were identified prior to data analysis. AT and PA annotated a selection of transcripts independently and devised preliminary codes for all data; all authors read a selection of transcripts and after discussion and negotiation preliminary codes were revised, agreed upon and

major themes identified. AT and PA then applied the codes to further transcripts and constantly compared themes. Early broad themes related to medication use were clear, e.g., taking over the counter medications (OTC) as a major self-management strategy; other themes emerged as analysis progressed such as OTC medicine use as paradox offering relief while causing harm (people who ‘effectively’ self-managed pain with OTC medication did not seek a GP appointment and diagnosis and evidence-based treatment was delayed). All transcripts were reread as higher themes emerged. Deviant cases were sought and analyses and interpretations were discussed with a medical sociologist experienced in qualitative research as a form of peer checking. The multi-disciplinary author team also offered differing perspectives to aid validity of the data driven claims.

Results

Both OTC and prescribed medications were core to illness management from onset to post diagnosis. All participants experienced ‘trial and error’ with a combination of drug regimens over time to gain efficacious treatment with minimum negative effects. All took a mix of medications, most reported side effects and adverse reactions to varying degrees, and depended on medicines for symptom relief and to maintain function in daily life. Most conveyed medication as highly effective in easing severe and debilitating symptoms, and limiting the impact of the disease. Only a few reported medication use as unproblematic. The majority described concerns and anxieties about *aggressive treatments* and the risk of complications, which required monitoring and repeated medical appointments. Perhaps unsurprisingly participants relayed ambivalence around medications use; grateful for the significant benefits, whilst voicing concerns about actual or potential harms such as side effects (e.g. mood changing;

extreme fatigue; **diarrhea**) or symbolized by constant monitoring for adverse effects such as signs of liver or eye damage. Paradoxically, both regular and efficacious OTC medication use delayed diagnosis and timely physician-directed treatment, important for optimum disease outcome.

Below we discuss two predominant themes from the interviews.

### **Paradox: Pre-diagnosis use of over the counter (OTC) medicines**

OTC medicines were conveyed as core to daily life and central to managing symptoms at onset of RA, for time periods that ranged from a few days to several years. Typically participants described using OTC medicines for several weeks, alongside other strategies like pacing and alternative therapists and treatments. Several expressed adapting to or pushing *through the pain*. Their priority to *keep going* swamped any general aversion to medicines, or concerns about consuming large quantities of OTC analgesics routinely, for long periods.

Prior to diagnosis participants relied on OTC medications to relieve pain so they could function in everyday life (Box1 Alicia), using OTC analgesics to alleviate symptoms for extended periods of time facilitating 'normal' life. For example, OTC medications enabled social roles and obligations including family roles (Box 1 Flossie) and paid work (Box 1 Julie). Although participants were recruited within 12 months of diagnosis, many described taking OTC medicines for years prior to their diagnosis, the early RA diagnosis be questionable. One participant described negotiating symptoms and multiple roles (as a mother, student and employee) noting that over a period of a few years she was *relying on Ibuprofen* (Box 1 Danielle). For participants, OTC analgesics were an integral component of daily life, allowing them to keep busy, and *push through* symptoms. Consequently, negotiating symptoms around

daily life by relying on OTC medications meant delaying a GP consultation while they continued to self-manage. In the context of busy lives a GP appointment considered *a hassle* significantly, consulting the GP did not *occur* to some, if they could *carry on*. It was only when the OTC medicines failed to control the pain and people could no longer function in their roles that they made an appointment to see their family doctor (Box 1 Nicole).

***Box1: Paradox: Pre-diagnosis use of OTC medicines to function***

**Self-assessing symptoms and regulating OTC medicine intake**

Participants continued to self-regulat with OTC medicines after seeing their family doctors and prior to a diagnosis. This could mean changing medications or varying the dose, balancing symptom relief against side effects, doing a self-assessment check to gauge how many OTC meds would be required (Box 2 Bonnie). Danielle favored OTC analgesics to those her GP had prescribed (Box 2 Danielle). The more participants were able to avoid activity disruption by self-managing symptoms with OTC medications, the less likely they were to consult a GP. This hampered a speedy diagnosis and prescribed treatments that could reduce disease damage. Another participant took OTC medications, as well as prescription anti-inflammatory medications, for another condition (Box 2 Charlize). Others continued to take OTC medications and to see their family doctor. Martha relied on both OTC and prescription painkillers over a period of years when she made several visits to her doctor with escalating symptoms of pain (Box 2 Martha). The quotes in this second section speak to the ways people self-managed their symptoms in daily life via OTC medications: doing a self-assessment check to gauge how many OTC meds would be required (Bonnie), increasing OTC medications when required (Charlize), choosing to take OTC medications to avoid side effects (drowsiness) from prescription drugs

(Danielle). Although the majority relied on OTC medicines to control symptoms and maintain daily life a minority of participants explicitly noted a clear aversion to OTC medicines (Box 2 Marlain, Nora).

### ***Box 2: Self-assessing symptoms and regulating OTC medicine intake***

#### **Ambivalence: Post-diagnosis prescribed medication use**

In the face of debilitating, severe and unpredictable symptoms and uncertainties about disease prognosis, participants were relieved to see a specialist and to be prescribed RA medications designed to limit the disease process, improve function and reduce pain. An RA diagnosis, however, was treated with ambivalence. First, there was relief about a diagnosis but concern about having to live with a long-term condition. Second, there were descriptions of how participants relied on multiple prescription medications, but voiced a desire to come off them or reduce them because of concerns about potential toxicity and side effects.

Most participants were familiar with analgesics and anti-inflammatory drugs (both OTC and GP prescribed) and had been taking them to relieve symptoms and function in daily life, prior to RA diagnosis (Boxes 1, 2). Prescribed medications were perceived differently. Participants reported they were faced with *aggressive treatment* (Ruth) and *drug cocktails* (Jane-2), for which they were grateful but also had misgivings about. Ambivalence was expressed most clearly around taking DMARDs. For example, although desiring treatment, some participants delayed initiating or filling prescriptions. A few delayed taking DMARDs because they anticipated disruption at work or to holidays (Box 3 Cynthia). One participant described a combination of reasons, which put her off methotrexate; a lack of information from her rheumatologist, having to inject it, and that it was a cancer drug, all meant that Bianca delayed taking methotrexate until she could

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3 discuss it with her family doctor (Box 3 Bianca). Another participant was reluctant to take  
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5 prescribed DMARDS because she initially wanted to manage the RA herself along with her other  
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7 chronic conditions and limit her multiple medication intake (Box 3 Nicole).  
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11 ***Box 3: Ambivalence: a need for and an aversion to prescribed medications***

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13 ***Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications***

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19 Nearly all of the participants described side effects. Most participants, keen to reduce the impact  
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21 of RA strove to find a combination of prescription medications that suited them. This meant that  
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23 finding the right combination of drugs was a matter of trial and error, because for several the side  
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25 effects were extreme, and outweighed the benefits (Box 4 Flossie). Several noted they wanted to  
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27 reduce the level/frequency of their medications (Box 4 Debbie). Yet only one person reported  
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29 that they had stopped taking their prescription medicines and this was with the knowledge of her  
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31 family doctor and rheumatologist (Box 4 Sharon).  
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38 A few did not report side effects, and they were prepared to endure potential adverse effects to  
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40 their system, if it meant that they could function (Box 4 Sherry). noted how she tolerated an  
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42 aversion to DMARD but a need for it (Box 4 Nora). In this example, an anti- attitude, combined  
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44 with knowledge of the potential toxicity of , is outweighed by the benefits (of symptom relief  
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46 and functional ability) gained.  
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53 The tensions underpinning aggressive treatment (as described by participants) as care was clear  
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55 in the accounts. The powerful medications needed to effectively treat the disease resulted in  
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57 finely balancing the risks and benefits (Box 4 Charlize). Another contradiction voiced by many  
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was the use of prednisone, a drug, which offered relief but also side effects and could only be taken for limited periods of time (Box 4 Jessie). Overall ambivalence around taking effective and intensive treatments were amplified by information gained from multiple sources (e.g., the Internet, family members' experiences), combined with a reported lack of opportunity to meaningfully discuss risks, benefits and options in the specialist consultation.

## Discussion

Paradox and ambivalence arose around medicine use in the accounts of study participants, recently diagnosed with RA. Participants commonly reported OTC medication use as an effective self-management strategy prior to seeking medical attention, which for many ultimately delayed diagnosis and effective treatment. Paradoxically, the more 'successful' self-managers risked longer delays and more harmful outcomes. Post-diagnosis, although most participants conveyed a desire for prescription medicines, they also described an aversion to them and concerns with complications. Understanding patient perceptions may inform several elements of practice, including effective patient-provider communication.

Our study has limitations. Like all qualitative research we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set. The participants recruited could have been more inclined to be active self-managers or help-seekers.<sup>21</sup> They could also have been more prone to have problems, complex trajectories and experience tensions around help-seeking and medicine use than others with RA. Despite purposive approaches, we recruited just one man, and all participants were Caucasian, so the sample is limited. Trainee/multiple interviewers may have affected the quality in a minority of the interviews,



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though this was taken into account in the analysis. Nevertheless the in-depth analysis gave insight into how medicine use was experienced over time, taking account of the changing context in which people manage chronic illness from symptom onset to diagnosis, which may reflect the experiences of people with similar chronic conditions Both MS and RA are autoimmune conditions; they are systemic, episodic illnesses, with no cure. Persistent yet fluctuating pain and fatigue contribute to negative experiences with activity disruption and participation in valued life roles.<sup>16</sup>

Consistent with literature spanning 50 years<sup>22,23</sup> participants commonly reported delaying a GP consultation. We also found evidence that it simply did not occur to people to consult their GP or other health professional as long as OTC medicines masked symptoms for prolonged periods.

Use of OTC medicines to manage early RA symptoms and delay a medical appointment has been identified in other research.<sup>12</sup> This attitude towards managing symptoms oneself and prolonged use of OTC medicines could be unintentionally encouraged by policy messages about responsibility to self-manage and inappropriate use of over burdened health systems; this may illustrate the importance of better informing the public about the negative consequences of relying on OTC medicines in particular circumstances<sup>3,8</sup>. The delays in obtaining prescribed medication (for some), however, reflected experiences of patients with chronic illness in a study 40 years ago.<sup>24</sup> The accounts revealed reluctance to go on prescribed medicines, and a desire to reduce or come off them, to avoid side effects. Another significant finding was that although participants were concerned about the risks of prescription medicines, consistent with other populations<sup>25</sup> they largely reported little concern about using OTC medications because they perceived them as less harmful compared to recommended prescription medicines. This mirrors what others have identified in terms of encouraging a more active and empowered patient, which

may increase OTC medicine use and underplay the harms involved.<sup>3,8</sup> Findings also indicate how patients assess risk when making decisions about medication use.

Consequently, these findings have implications for policy and practice. First, the ambivalence which was conveyed by so many of the participants supports the need for concordance, which involves clinician and patient discussion around patient concerns, experiences, perspectives,<sup>5, 19</sup> risks and benefits associated with both prescribed medications<sup>26</sup> and OTC medicines. In this way, interventions are needed that incorporate patient perspectives<sup>26</sup> in meaningful ways.

Second, medications occupy a central place in people's lives as they self-manage, *prior to* seeking formal help; the long established concept of the 'iceberg of illness'<sup>27</sup> bears witness to this extensive activity long before policy extolled the version of an expert patient who is to be encouraged to self-manage.<sup>7</sup> People do not take OTC medications in a cultural vacuum; established cultural attitudes of stoicism, more recent notions of over-burdened health systems and taking responsibility for one's health combine to encourage OTC medicine use and avoidance of GP consultations. As such it is perhaps unsurprising that people self-medicated for long periods of time and used maximum dosage drugs to help contain symptoms, even when symptoms were persistent and severe. Third, a mix of potent drugs which work well but also have negative effects, build on the cultural ambivalence and aversion to medications which people often already have.<sup>5</sup> The 'cocktail of drugs' offered as 'aggressive treatment' is complicated further by the existence of multi-morbidity, associated poly-pharmacy and drug interactions, or fears of such. These factors need to be considered as part of the patient experience of medication use, which informs decision-making and issues of risk.

Conclusions

Our research re-emphasizes the role of and tensions around medication use in a changing health care environment. It suggests that one key challenge facing interventions to improve a timely RA diagnosis is to redress the public health message of appropriate help-seeking and individuals' responsibility to self-manage. Unless 'mixed messages' are clarified, people may well continue to use OTC medicines extensively and inappropriately to mask severe symptoms and maintain function in their daily lives. Interventions also need to acknowledge how the patient and clinician roles are changing, as well as recognize the complications of multi-morbidity and how these separate but often interlinking factors impact adherence. Interventions need to better communicate the need to gain treatment, the ramifications of having a chronic, systemic disease. RA is more than just joint pain, which many people feel comfortable in self-treating (with what may often be damaging levels of OTC medicines) rather than gaining a diagnosis. The risks and benefits of OTC medicines compared to prescription medicines need to be clarified in ways that support more informed decision-making in RA.

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Statements

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) AT, PA, CB, LL have support from University of British Columbia, and Vancouver Coastal Health for the submitted work; (2) AT, PA, CB, LL have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AT, PA, CB, LL have no non-financial interests that may be relevant to the submitted work.

Anne Townsend PhD— contributed to the conception and design of the study, conducted interviews, analysis and interpretation, led writing all drafts, guarantor of the study

Paul Adam – contributed to the conception and design of the study, conducted interviews, analysis and interpretation, commented on all drafts,

Catherine Backman PhD- contributed to the conception and design of the study, analysis and interpretation, commented on all drafts

Linda Li PhD- led study design and conception, conducted interview, analysis and interpretation, commented on all drafts.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Further data are available relating to quotes around OTC medication use and ambivalence of prescribed medications.

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**Boxed Quotes**

**Box1: Paradox: Pre-diagnosis use of OTC medicines to function**

*I was just taking regular Tylenol and I mean I was sucking those back because I mean the pain was excruciating (Alicia)*

*When you have two little kids you just keep going... I kept going to skating lessons... the pain of tying up those laces... undoing them... getting them in and out of car seats...I didn't pay a lot of attention to it because I just thought... that's life...you just keep going and you take Tylenol or Advil and that's the way it is... I was almost full-time work and I really loved my work... I was so stimulated... really enjoyed my kids... I just kept taking pain medication to function (Flossie).*

*My husband had to help me to get a T-shirt on because everything was so stiff. I couldn't move and it was very painful... all these Tylenol / I would take up to 4 tablets of 650 mgs., by 11:00 the pain would go down to the point where I felt like I was happy to be at work. I could function fairly good. But the morning was a really tough time... At that point I had only taken occasionally more than six tablets a day to keep on going to work... it would go up to over 4,000 mgs. a day (Julie).*

*Just took Tylenol and Ibuprofen and tried to keep it at bay... to try... to see a doctor... wasn't worth it with the hassle of... baby and work. It wasn't that urgent... I spent... up to 14 hours a day on my laptop... eating Ibuprofen like a box of Smarties to try to keep the pain under control (Danielle).*

*I could hardly do anything... and when I started missing work I knew that that wasn't right... I tried the normal you know Tylenol or Aspirin or whatever to try and help as far as the pain went and nothing really worked. Nothing helped. So that's – again I decided – OK I can't go on like this on my own obviously. So again I decided – I made it clear that I had to go to the doctor and see what was wrong (Nicole).*



**Box 2: Self-assessing symptoms and regulating OTC medicine intake**

*Every morning, I take Tylenol for arthritis. Some days, I take two every morning. Some times I take a lot more.... I also take two at dinnertime. So a minimum of 4 a day. Sometimes more ... Each day I ask myself: Now do I need them today? (Bonnie).*

*I didn't like the effects of the other stronger stuff that was prescribed at the doctors because... I didn't have time for drowsiness in the program and then raising a child, drowsiness was just not in the equation so I just went back to the Ibuprofen.... Being drowsy does not help you fight the fatigue (Danielle).*

*Interviewer: Where there any other things that you were doing besides the ice to manage it at that early point?*

*There were things I probably shouldn't have been doing but because... I already was on some inflammatory medications... I sort of upped the dose, not the dosage of the prescription medication but I would use 'over-the-counter' anti-inflammatories as well and by that I mean I would take extra doses of Aspirin... with codeine and caffeine, which would get me through some of the times (Charlize).*

*[I kept going to the doctor] because they (pains) were getting worse and because I was taking Tylenol and you know Tylenol 3 and everything and it wasn't helping (Martha)*

*I am not one to take pills. I hate even taking Tylenol for a headache (Marlain)*

*I am just afraid to take medication. I don't even have Tylenol in the house. I take maybe, I don't know, through my whole life I might have taken three Tylenols or something (Nora).*

**Box 3: Ambivalence: a need for and an aversion to prescribed medications**

*The truth is... that right after my (specialist) appointment (Husband) and I were planning to go to Edmonton and I didn't want to be starting on a new medication (DMARD) when I was on a trip...I waited to see my GP (Cynthia).*

*Since he didn't give me a lot of information, the specialist, about Methotrexate I had to do a lot of reading on my own about it and I was very reluctant, to use it... So it was probably a month after I was prescribed it to when I actually started taking it... It was... injectible... it's a little bit more of a hassle to take... when the drugs are so strong you'd like to know a little bit more information than if it was... take an antibiotic and you're going to feel better. It's... take this drug and maybe in six months you'll feel better... Well Methotrexate was also used to treat cancer so it's a very, very strong drug. ... (Bianca).*

*We talked a little bit about... treatment and things that might help and he (rheumatologist) asked me how I felt about medications... because I struggle with other health issues and I take so many different medications already I asked if we might be able just to try managing things on our own (GP and me) before we got into a big treatment sort of plan and he said that was fine. He did prescribe a pain killer that was a little bit more than what my family physician had given me and he said: ... "See how you do and if you need to come back before, call me but otherwise we'll see you in two months." ... but things didn't get a lot better and I still missed the odd day of work... So when I went back to the (rheumatologist) I said... I need help.... So then we started talking about treatment options... He put me on a treatment program (DMARDS).... the medication has been a good thing because I tried to go without it and I couldn't (Nicole).*

**Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications**

*The Methotrexate cleared all the symptoms of rheumatoid... right away. Like eventually, it was just the side effects I couldn't tolerate... It created a whole host of other symptoms that were not weighing up the benefits... it... alters your psyche... it's harder to dig your happy self out of that (Flossie).*

*After my first shot (a biologic) I was able to get off the chair without any help... by the third shot I think I was almost back to normal....I am going to ask Dr. X. if I can take my [biologic] If I can not do it once a week maybe every 10 days. Just slowly and see how my body reacts to that. Because when I get my shot the first two days now I don't feel that well. I'm feeling a little bit agitated (Debbie).*

*The Methotrexate and Sulfasalazine so changed my personality. I was miserable. When I think back on the nine months it's like a blur. It's like something I don't really want to remember. I just quit the medication and then I went back to see [the rheumatologist] and he said: "Well you had a reaction". And he kept pooh, poohing me off... He's very dedicated. But he just needs to crawl into his patients' shoes sometimes (Sharon).*

*I have been on Methotrexate for just over a month. And it seems to be working ... But it terrifies me (Sherry).*

*I just have to take it. I don't think my attitude has changed. If I have to I have to... It will still be hard to do because I know I am destroying other parts of my body with the medications. ...I wouldn't take it if I didn't have to (Nora).*

*So either way you're treated there is a negative side effect... you try not to kill yourself with the treatment and still manage your daily life (Charlize).*

*I would like to get off the Prednisone as soon as possible... it's almost weird... Prednisone is a magic drug until you find out the side effects... It's almost cruel to give it to people because it works so well (Jessie).*

Table 1

	Age range	Sex (M/F)	Recruited via	Symptom onset to seeing Rx	Seeking medical help for symptoms leading to a diagnosis/ RA test	Referral wait time to see a rheumatologist	Diagnosis
Alicia	60s	Female	Unknown	1 year	3 months	6-8 weeks	Uncertain but treated for RA
Barbara Anne	40s	Female	Family doctor's office	10 years	1 year	6 months	Diagnosed
Bianca	30s	Female	Rheumatologist office	2 years 3 months	7 months	2 months	Diagnosed
Bonnie	60s	Female	Arthritis Newsletter	40 years	20 years	No referral	Not diagnosed
Charlize	50s	Female	Arthritis Newsletter	4 months	Less than 1 week	3 months	Diagnosed
Cynthia	60s-70s	Female	Arthritis Newsletter	1 year	5 months	2 mths	Diagnosed
Danielle	30s-50s	Female	Rheumatologist Office	8 years	3 years	2-3 months	Uncertain but treated for RA
Debbie	50-60s	Female	Rheumatologist office	2 years 4 months	2years 4 months	3 months	Diagnosed
Dodi	50s-70s (estimated)	Female	Rheumatologist office	5-6 months	2-3 weeks	10 months	Diagnosed
Dorothy	30s	Female	Rheumatologist office	1 year 10 months	2 months	2 months	Diagnosed
Flossie	50s	Female	Arthritis Newsletter	24 years	unknown	6 weeks	Diagnosed
Jackie	40s	Female	Arthritis Newsletter	8 months	3 months	9 months	Uncertain but treated for RA
Jane	60s	Female	Arthritis Newsletter	8-9 months	5 months	1 month	Diagnosed
Jane 2	50s	Female	Arthritis Newsletter	4 months	1 month	6-8 weeks	Diagnosed
Jean	50s	Female	Arthritis Newsletter	19 years	8 years	2 months	Diagnosed
Jessie	50s-60s	Female	Rheumatologist office	3-4 months	3-4 weeks	6 weeks	Diagnosed
Julie	50s-60s	Female	Physiotherapist office	3 months	3-4 weeks	1 month	Diagnosed
June	50s	Female	Arthritis Newsletter	3 months	unknown	6 weeks	Diagnosed
Kerry	30s	Female	Arthritis Newsletter	3 months	No delay	10 days	Diagnosed
Lee	40s	Female	Family doctor office	14 years	Unknown	Unknown	No diagnosis (has complex

							multi-morbidities tests ongoing)
Laurie	60s	Female	Arthritis Newsletter	1-2 years	1-2 years	At regular rheumatologist regular appointment	Diagnosed
Maple	40s	Female	Arthritis Newsletter	2 months	6 -7 weeks	1 day	Diagnosed
Marie	60s	Female	Rheumatologist office	3 weeks	2 weeks	1 week	Diagnosed
Marlain	50s-60s	Female	Rheumatologist office	4-5 years	2-3 years	< 6 months	Diagnosed
Martha	70s	Female	Unknown	9 years	6-8 years	1 year	Diagnosed
Nicole	30s	Female	Arthritis Newsletter	1 month	2 weeks	2 weeks	Diagnosed
Nicolette	50s	Female	Rheumatologist office	12 months	11 months	1 month	Diagnosed
Nora	50s	Female	Rheumatologist office	11 months	1 month	3 months	Diagnosed
Rain	40s-50s	Mail	Arthritis Website	4 years	11 months	10 months	Diagnosed
Rosie	60s	Female	Arthritis Newsletter	26 years	26 years	1 month	Diagnosed
Sally	50s	Female	Arthritis Newsletter	1 year	2 months	1 month	Diagnosed
Sarah	50s	Female	Arthritis Newsletter	3 years	16 months	1 month	Diagnosed
Shari	60s	Female	Unknown	6 months	unknown	No referral family doctor diagnosis	Diagnosed
Sharon	60s	Female	Family doctor office	7 years	unknown	2 months	Diagnosed
Sherry	40s	Female	Rheumatologist office	9-10 years	5 years	6 months	Diagnosed
Smokie Jean	50-60s	Female	Rheumatologist	40 years	4 years	3 weeks	Diagnosed
Teresa	50s	Female	Unknown	11 months	9 months	5 months	Diagnosed
Yoda	50s	Female	Rheumatologist office	3 years 6 months	1-2 weeks	6 months	Diagnosed

# Participant Interview Guide

**Preamble:**

Thanks so much for agreeing to take part in this study. What I really want to hear from you today is your experience of RA, in your own words, from when you first noticed any signs of illness, right up to now; e.g. how it has affected you, and what you have been able to do about it, and what happened around the time of diagnosis.

**Ice-breaker:** To start with, can you tell me what a typical week is like for you?

**1. Can you tell me about your arthritis, starting from when you first noticed anything?**

*Probes: (only if appropriate)*

- What about when you first noticed any aches/pain/stiffness in joints or general tiredness?
- How did your symptoms affect your day-to-day life? (Work / leisure / family)
- What helped? Medication / treatments / equipment.
- Health professionals/alternative practitioners?
- What sorts of information did you have / find?
- What about people you know, like friends and family (with arthritis or others).
- Anything else you can think of?

**2. Can you tell me what happened leading up to, and around the time of diagnosis?**

*Probes: (only if appropriate)*

- From when you first noticed anything was wrong, about how long was it before you saw your doctor, or another health worker?
- Can you remember the last thing that happened before making the appointment to see the doctor?
- About how long was it from when you saw your doctor (or other) to when the RA was diagnosed?
- Was anybody particularly helpful or unhelpful at that time?
- How did receiving the diagnosis make you feel?
- Did you see anybody else or do anything else during that time which helped your symptoms?
- Can you remember how your symptoms were affecting your day-to-day life at around that time?
- Anything else you can think of?

### 3. What about since the diagnosis?

*Probes: (Only if appropriate)*

- How are things now? Symptoms / impact / anything else
- Many people say there are times when they feel they have no control over their RA, what's been your experience? What helps at times like this?
- What helps best now? Can you say a little more about that?
- Can you tell me about your experience with medications?
- Could you tell me about a time when your current GP / rheumatologist was most helpful to you? What about a time when he or she was least helpful?
- Can you think of any time when you expressed dissatisfaction to your health professional, or perhaps that you wish you had?
- Can you give an example of when things might have been done better or gone smoother?
- What health professionals have you seen/do you see in relation to your RA?
- What about alternative practitioners?
- Anything else?

**If required/time – summing up:**

**4. Overall:** (section getting at most salient points before interview close)

#### a) What/Who has been the most helpful to you in managing your arthritis?

*Probes: (If appropriate)*

- Information / health professionals / friends and family / yourself / medication / alternative treatments/practitioners
- How important is your attitude? Can you tell me a bit more about that?
- How important is past experience, e.g. previous/other illness or past use of health services?
- How satisfied are you/have you been with the information you have received / found?
- Can you suggest anything else that would be, or would have been helpful to you in managing your arthritis?

#### b). Bottom line / in a nutshell; What would you say was the main reason you went to see your family doctor?

#### c). And briefly, what would you say was the main thing that stopped you from making that appointment till then?

- Have you any advice or tips you could give others about RA?
- Is there anything else that you would like to talk about?
- Just before we finish, can you tell me about why you chose to take part in this interview?



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Thanks very much for your time, and telling me about your experiences.

For peer review only

# Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1. included in text	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2. identified	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
3. identified AT and PA	Occupation	What was their occupation at the time of the study?
4. identified	Gender	Was the researcher male or female?
5. included in text	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
8. reference to validity and reliability and independent checks in text	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
<b>Domain 2: study design</b>		
Theoretical framework		
9. identified	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
10. identified	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11. identified	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12. identified	Sample size	How many participants were in the

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		study?
13. identified	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14. identified	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>
15. identified	Presence of non-participants	Was anyone else present besides the participants and researchers?
16. identified	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>
Data collection		
17. identified	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18. identified	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19. identified	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20. identified	Field notes	Were field notes made during and/or after the interview or focus group?
21. identified	Duration	What was the duration of the interviews or focus group?
22. identified	Data saturation	Was data saturation discussed?
23. identified	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findings		
Data analysis		
24. identified	Number of data coders	How many data coders coded the data?
25. identified	Description of the coding tree	Did authors provide a description of the coding tree?
26. identified	Derivation of themes	Were themes identified in advance or derived from the data?
27. identified	Software	What software, if applicable, was used to manage the data?
28. identified	Participant checking	Did participants provide feedback on the findings?
Reporting		
29. identified	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>
30. checked	Data and findings consistent	Was there consistency between the data presented and the findings?
31. checked	Clarity of major themes	Were major themes clearly presented in the findings?

32. identified e.g. only  
a few described  
medication use as  
unproblematic.

Clarity of minor themes

Is there a description of diverse cases or  
discussion of minor themes?

For peer review only



## Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

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Manuscripts

Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

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## Abstract

**Objective:** To examine accounts of medication use in participants with early rheumatoid arthritis (RA) from symptom onset to early post diagnosis.

**Design:** Qualitative study with in-depth, personal interviews.

**Participants:** 37 women and one man, aged 30s-70s, with a diagnosis of RA <12 months.

**Main outcome measure:** Participants' experiences and feelings of medication use in early RA.

**Setting:** British Columbia, Canada.

**Results:** Medications were central to how people managed symptoms and disease. Two main themes were identified, showing that optimum medication use was hampered, and how this related to delayed diagnosis and effective care. The first theme, 'paradox of pre-diagnosis reliance on over the counter (OTC) medications', describes how people's self-management with OTC medications was 'effective.' Participants relied extensively on OTC medications for pain relief and to maintain 'normal life.' However, as this contributed to delayed medical consultation, diagnosis and effective treatment, OTC medication was also potentially detrimental to disease outcome. The second theme, 'ambivalence around prescription medications post diagnosis,' describes how adherence was hindered by patient beliefs, priorities and ambivalence towards medications.

**Conclusions:** This study highlights how people use medications in early RA and contributes to a better understanding of medication use that may transfer to other conditions. Given the drive toward active self-management in health care and patients' ambivalence about using strong medications, in-depth understanding of how these combined factors impact patient experiences will help health care providers to support effective medication practices. The reported extensive reliance on OTC medications may speak to a care gap needing further investigation in the context of health behaviours and outcomes of patient self-management

## ARTICLE SUMMARY

### Article Focus

To understand the experiences of medication use in people with early RA from symptom onset to early post diagnosis.

### Key Messages

Our study suggests an over-reliance and extensive use of OTC medications detrimental to health. People continued to self-medicate in place of a general practitioner (GP) consultation when symptoms were severe and debilitating but masked by high and regular doses of OTC medications.

Ambivalence about medication use suggests that we need to understand patient priorities and experiences better in order to support adherence.

### Strengths and Limitations



This is an in-depth analysis of a relatively large qualitative dataset, offering insight into our participants’ experiences of medication use. However, given the nature of qualitative research, we do not claim generalization to other populations. Experiences may be transferable to other settings with individuals who have similar characteristics.

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**Introduction**

Medications paradoxically promise both relief and burden for people with chronic illness. In rheumatoid arthritis (RA), medications ease symptoms and can limit disease progression, but often complex regimens can exacerbate adverse reactions and side effects.<sup>1</sup> These combined factors can promote tensions and ambivalence around medication use and foster non-adherence detrimental to individuals and healthcare systems: “Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources”.<sup>2</sup> (p1) Given it is the patient who decides whether and how to take medications, we need to better understand over the counter (OTC)<sup>3</sup> and prescription use in chronic illness.<sup>4-5</sup> Qualitative research is designed to explore, interpret and gain a deeper understanding of social phenomena, and is well-suited to examine participants’ experiences and use of medications. The shift in chronic illness care from passive

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3 patient to active partner coupled with policy support for shared decision-making and self-  
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5 managing<sup>6-8</sup> makes this topic particularly important. Our objective in this analysis was to  
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7 understand medication use from the patient perspective and identify barriers to optimum care  
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9 from onset of symptoms to early post diagnosis. This information will be useful to health care  
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11 providers who work with patients to improve adherence and who support shared decision-  
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13 making. Our findings also highlight the potential pitfalls of unsupported self-management  
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15 through a reliance on OTC medications, which may delay diagnosis and negatively impact  
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17 outcome.  
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22 We used a qualitative approach<sup>9</sup> to investigate people's early RA medication use in the context  
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24 of their daily lives. In this paper, we focus on two predominant themes, which emerged from  
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26 interviews: 1) The paradox of self-managing 'effectively' with OTC medication; 2) Ambivalence  
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28 and tensions around taking prescribed medication. We then discuss how medication use was a  
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30 core self-management strategy for our participants, and how it influenced help-seeking, a timely  
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32 diagnosis and effective treatment interventions. The accounts of people with early RA provided a  
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34 rich source of qualitative data. The interviews offered insights into medication use, which may  
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36 be transferable to others with similar illness experiences characterized by pain, unpredictable  
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38 symptoms and concerns about the course of the illness and what to do about it. Other qualitative  
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40 research shows that, like RA, various long-term conditions impact *functional* ability and daily  
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42 life, and reveals how patient attempts to minimize incapacity provoke various decisions around  
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44 medication use.<sup>5</sup>  
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55 As the goals of RA treatment are to ease pain, reduce inflammation and prevent joint damage,  
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combinations of medications are required. Disease modifying anti-rheumatic drugs (DMARDS), biologics, non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics are treatments that include both OTC and prescribed medications.<sup>10</sup> As well as combinations of medications, current evidence shows that DMARD therapy controls disease progression and improves long-term outcomes when initiated within the first three months of symptoms appearing.<sup>11</sup> Delays in DMARD use are associated with poorer disease control and have been reported across communities and at several stages of disease from onset to securing specialist visits. A delay in DMARD use ranging from 6.5 months to 11.5 months was reported in a Canadian study, which assumed that patients started the drug immediately upon prescription.<sup>12</sup> A UK study concluded that for their participants “the majority of the delay in assessing patients with RA in secondary care lay at the level of the patient seeking medical advice.” (p3)<sup>13</sup> Other qualitative research in the UK identified how multiple factors, e.g. the nature of symptoms, knowledge of RA and attitudes towards health care providers, influenced when to consult in early RA patients.<sup>14</sup> A study examining women’s use of prescribed RA medications identified the decision-making process as complex and multi-faceted.<sup>15</sup> Further research investigating the experience of medication use in women and men with long-term multi-morbidity (including RA) identified the central role of medication and patient ambivalence around taking different types of medicines.<sup>5</sup> We know little about the factors impacting decision-making and medication use in early RA from onset to diagnosis. Our study extends this knowledge by comparing OTC and prescribed medications use.

**Participants and methods**

This analysis formed part of a wider study on the experience of help-seeking in early RA from onset of symptoms to early post diagnosis.<sup>16</sup> The overarching aim was to better understand the patient experience of early illness in the context of their daily lives and to identify delays along the care pathway. The original aim then was not to investigate medication use, but to understand the priorities and the experiences of the participants. Perhaps unsurprisingly, medication use emerged as an important theme. Other results have been published elsewhere.<sup>16, 17</sup>

## Recruitment

A purposive sample was recruited through patient organization websites, newsletters and information leaflets at local arthritis centres, as well as clinician offices. To be eligible, volunteers had to be adults with a self-reported RA diagnosis within the previous 12 months, and be able to converse in English (see Table 1). Potential participants contacted the research coordinator either by phone or e-mail, the study was described and volunteers were sent an informed consent document to be discussed and signed at interview. All eligible participants who made contact agreed to participate and gave written consent. One person who agreed to participate died prior to interview. Participants lived in a range of households in British Columbia (BC) and comprised individuals who were in paid employment, those receiving disability benefits, homemakers, and retirees. The participants lived in communities ranging from Vancouver, a large city on the West coast, to small, mountain and rural communities in the North and East of BC. Participants were Caucasian, which does not reflect the diversity of parts of the Vancouver metropolitan area. All names are pseudonyms chosen by the participants. The University of British Columbia's Behavioral Research Ethics Board granted ethical approval for the study and all participants gave written informed consent.

**Interviews**

A topic guide was used to elicit in-depth accounts of participant experiences<sup>18</sup> conducted at a time and place convenient to the participants (30 in their home and eight in a research centre). The topic guide was organized around three separate but overlapping sections: 1) Symptoms/onset/impact including illness actions; 2) Consulting the general practitioner (GP) and gaining a diagnosis/healthcare system and professionals; 3) Post diagnosis experiences. Open questions were asked, and probes and prompts used for elaboration. The guide was formulated after discussion with the multi-disciplinary team including consumers (individuals with inflammatory arthritis) and rheumatologists. The topic guide was tested in a pilot study (eight participants) and the main format was unchanged.<sup>19</sup> A follow-up telephone interview allowed for further elaboration and clarification, and to check main results of the initial interview (18 phone and one e-mail follow-up were conducted). Interviews were conducted by AT research associate (n=19), PA outreach coordinator at an arthritis clinic (n=5) and LL (n=1). The remaining interviews were conducted by a research coordinator (n=8) and three students supervised by PA (n=5). AT and PA are both experienced qualitative researchers. Prior to data collection, AT conducted a field-work/interviewing training session. Field notes were taken to aid interpretation and validity of the data driven claims. Most interviews lasted between 60 and 90 minutes. One participant was interviewed with spouse present.

**Data analysis**

The audio-recorded interviews were transcribed verbatim. Transcripts were checked for accuracy against the recordings and identifying information removed. Analysis was iterative and thematic, guided by a constant comparative approach.<sup>20</sup> We used paper-based methods in the initial stages

and nVivo 7 was then used for storage and handling the extensive dataset. No pre-selected codes were identified prior to data analysis. AT and PA annotated a selection of transcripts independently and devised preliminary codes for all data. All authors read a selection of transcripts and, after discussion and negotiation, preliminary codes were revised, agreed upon and major themes identified. AT and PA then applied the codes to further transcripts and constantly compared themes. Early broad themes related to medication use were clear, e.g., taking OTC medicines as a major self-management strategy. Other themes emerged as analysis progressed such as OTC medicine use as paradox (the more ‘effectively’ people self-managed with OTC medication, the less likely they were to seek medical help, gain a diagnosis and be prescribed RA treatments). All transcripts were re-read as higher themes emerged. Deviant cases were sought and analyses and interpretations were discussed with a medical sociologist experienced in qualitative research as a form of peer-checking. The multi-disciplinary author team also offered differing perspectives to aid validity of the data driven claims. Statements made by participants are indicated by italics.

## Results

Both OTC and prescribed medication was core to illness management from onset to post diagnosis. All participants experienced *trial and error* with a combination of drug regimens over time to gain efficacious treatment with minimum negative effects. All took a mix of medications, most reported side effects and adverse reactions to varying degrees, and depended on medicines for symptom relief and to maintain function in daily life. Most conveyed medication as highly effective in easing severe and debilitating symptoms, and limiting the impact of the disease. Only a few reported medication use as unproblematic. The majority described concerns and anxieties

about *aggressive treatments* and the risk of complications, which required monitoring and repeated medical appointments. Perhaps unsurprisingly, participants relayed ambivalence around medications use, grateful for the significant benefits whilst voicing concerns about actual or potential harms such as side effects (e.g., mood changing, extreme fatigue, diarrhea) or adverse effects that required long-term monitoring (e.g., for liver or eye damage). Paradoxically, the more ‘effectively’ participants used OTC medications the more likely was a delayed diagnosis and prescribed treatment, key to optimum disease outcome. Below we discuss two predominant themes from the interviews.

**Paradox: Pre-diagnosis use of over the counter (OTC) medicines**

OTC medicines were conveyed as core to daily life and central to managing symptoms at onset of RA, for time periods that ranged from a few days to several years. Typically participants described using OTC medicines for several weeks alongside other strategies, e.g., pacing activities and turning to alternative therapists and treatments. Several participants expressed adapting to or *pushing through the pain*. Their priority to *keep going* swamped any general aversion to medication, or concerns about consuming large quantities of OTC analgesics, both routinely and for long periods.

Prior to diagnosis, participants relied on OTC medications for extended periods of time (see Box1 Alicia), using OTC analgesics to alleviate symptoms of pain, maintain function and facilitate *normal life*. For example, OTC medications enabled people to fulfill social roles and obligations, e.g., in the family (see Box 1 Flossie) and paid work (see Box 1 Julie). Although participants were recruited within 12 months of diagnosis, many described taking OTC



medicines for months/years prior to their reported diagnosis of RA. One participant described negotiating symptoms and multiple roles (as a mother, student and employee) noting that over a period of a few years she was *relying on Ibuprofen* (see Box 1 Danielle). OTC analgesics were an integral component of daily life, allowing participants to keep busy and *push through* symptoms. Consequently, negotiating symptoms around daily life by relying on OTC medications meant delaying a GP consultation while they continued to self-manage. Significantly, in the context of busy lives, consulting the GP did not occur to some if they could *carry on*. For many, it was only when the OTC medicines failed to control pain and people could no longer function in core roles that they consulted their family doctor (see Box 1 Nicole).

***INSERT HERE Box1: Paradox: Pre-diagnosis use of OTC medications to function***

**Self-assessing symptoms and regulating OTC medication intake**

Participants continued to self-regulate with OTC medicines after seeing their family doctors and prior to a diagnosis. This could mean changing medications or varying the dose, balancing symptom relief against side effects, or doing a self-assessment check to gauge how many OTC medications would be required (see Box 2 Bonnie). Danielle favoured OTC analgesics to those her GP had prescribed, to which she attributed significant side effects (see Box 2 Danielle). Another participant took OTC medications together with anti-inflammatory medications prescribed for another condition (see Box 2 Charlize). Martha relied on both OTC and prescription painkillers over a period of years when she made several visits to her doctor with escalating symptoms of pain (see Box 2 Martha). The quotes in this second section illustrate how people self-managed their symptoms in daily life by self-regulating OTC medications: doing a self-assessment check to gauge how many OTC meds would be required (Bonnie), increasing

OTC medications when required (Charlize), choosing to take OTC medications to avoid side effects (drowsiness) from prescription drugs (Danielle). Although the majority relied on OTC medicines to control symptoms and function in daily life, a small minority of participants explicitly noted a clear aversion to OTC medicines (see Box 2 Marlain, Nora). Self-regulating OTC medications was a core self-management strategy, which for many meant avoiding a GP consultation. This ‘effective’ self-management hampered a speedy diagnosis and prescribed treatments that could reduce disease damage.

*INSERT HERE Box 2: Self-assessing symptoms and regulating OTC medicine intake*

**Ambivalence: Post-diagnosis prescribed medication use**

In the face of debilitating, severe and unpredictable symptoms and uncertainties about disease prognosis, participants were relieved to see a specialist and to be prescribed medications designed to control disease activity and improve symptoms. An RA diagnosis, however, was treated with ambivalence. First, participants described relief at being diagnosed but concern about having to live with a long-term condition. Second, participants came to rely on multiple prescription medications, but voiced a desire to come off/reduce them due to experiencing side-effects and concerns about potential toxicity and adverse effects.

Most participants were familiar with analgesics and anti-inflammatory drugs (both OTC and GP prescribed) and had been taking them to relieve symptoms and function in daily life, prior to RA diagnosis (see Boxes 1, 2). Prescribed medications were perceived differently. Participants reported they were faced with *aggressive treatment* (Ruth) and *drug cocktails* (Jane-2), for which they were grateful but also had misgivings about. Ambivalence was expressed most clearly

around taking DMARDS. For example, although desiring treatment, some participants delayed initiating or filling prescriptions. A few delayed taking DMARDS because they anticipated disruption at work or on holidays (see Box 3 Cynthia). One participant described a combination of reasons, which put her off methotrexate: a lack of information from her rheumatologist; having to inject it, and recognizing that it was a cancer treatment all meant that Bianca delayed taking methotrexate until she could discuss it with her family doctor (see Box 3 Bianca). Another participant was reluctant to take prescribed DMARDS because she initially wanted to manage the RA herself along with her other chronic conditions and limit her multiple medication intake (see Box 3 Nicole).

***INSERT HERE Box 3: Ambivalence: a need for and an aversion to prescribed medications***

Nearly all of the participants described side effects. Most participants sought optimum symptom relief, disease control and minimum side effects, which meant finding a combination of prescription medications which suited them. For many, this was a process of trial and error, as the side effects were sometimes extreme and outweighed the benefits (see Box 4 Flossie). Several noted they continued to take, but were keen to reduce the level/frequency of their medications because of their aversion to them (see Box 4 Debbie). Yet only one person noted that she had stopped taking all prescription medications and this was reportedly with the knowledge of her family doctor and rheumatologist (see Box 4 Sharon).

***INSERT HERE Box 4: Ambivalence: weighing up the benefits and potential harms of prescribed medications***

A few did not report side effects and they were prepared to endure potential adverse effects to their system, if it meant that they could function (see Box 4 Sherry). Nora noted how she tolerated an aversion to DMARDS but had a need for it (see Box 4 Nora). In this example, an anti-medication attitude combined with knowledge of the potential toxicity of DMARDS is outweighed by the benefits (of symptom relief and functional ability) gained.

The tensions underpinning *aggressive* treatment as care (as described by participants) were clear in the accounts. Participants balanced the risks (of toxicity and adverse effects) and benefits (effective treatment of disease) of prescribed RA medications (see Box 4 Charlize). Another contradiction voiced by many was the use of prednisone, a drug that offered relief but also side effects and could only be taken for limited periods of time (see Box 4 Jessie). Overall, ambivalence around taking effective and intensive treatments was amplified by information gathered from multiple sources (e.g., the Internet, family members' experiences) combined with a reported lack of opportunity to meaningfully discuss risks, benefits and options in the specialist consultation.

**Discussion**

Paradox and ambivalence arose around medicine use in the accounts of study participants, recently diagnosed with RA. Participants commonly reported OTC medication use as an 'effective' self-management strategy prior to seeking medical attention, which for many participants ultimately delayed diagnosis and effective treatment. Paradoxically, the more 'successful' self-managers risked longer delays and more harmful outcomes. Post-diagnosis, although most participants conveyed a strong desire for prescription medicines, they also

described an aversion to them and concerns with complications of both side effects and adverse effects. Understanding patient perceptions and priorities can inform several elements of practice and care, fostering effective patient-provider communication and shared decision-making.

Ultimately, this may lead to more prompt diagnosis and higher levels of adherence.

Our study has limitations. Given the nature of qualitative research, we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set. The participants recruited could have been more inclined than others to be active self-managers or help-seekers.<sup>21</sup> They could also have been more prone to have problems, complex trajectories and experience tensions around help-seeking and medicine use than others with RA. Despite purposive approaches, we recruited just one man and all participants were Caucasian, so the sample is limited. Trainee/multiple interviewers may have affected the quality in a minority of the interviews, though this was taken into account in the analysis. Nevertheless, the in-depth analysis gave insight into how medication use was experienced over time, taking account of the changing context in which people manage chronic illness from symptom onset to diagnosis. It is possible that people with similar chronic conditions may have similar experiences. For example, there are similarities between RA and multiple sclerosis (MS). Both are chronic, systemic, autoimmune conditions with fluctuating pain and fatigue disrupting life roles.<sup>16</sup> Given that symptoms and activity disruption drove some of the pre-diagnosis medication decisions in the present study, there may be questions to explore in MS and other similar conditions.

Consistent with literature spanning 50 years,<sup>22,23</sup> participants commonly reported delaying a GP consultation. A significant finding was that it simply did not occur to people to consult their GP

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or other health professional, as long as OTC medicines masked symptoms for prolonged periods. The delays some participants reported in obtaining prescribed medication reflected experiences of patients with chronic illness in a study 40 years ago.<sup>24</sup> More recent research has revealed how people's use of OTC medications to manage early RA symptoms contributes to delays in seeking a medical appointment.<sup>12</sup> This may point to a need to increase public awareness about the symptoms of inflammatory types of arthritis and importance of early intervention for optimal outcomes. The attitude towards managing symptoms oneself and prolonged use of OTC medicines could be unintentionally encouraged by policy messages about inappropriate use of overburdened health systems and the need for self-management.<sup>3,8</sup> The accounts revealed reluctance to go on prescribed medicines, and a desire to reduce or come off them to avoid side effects. Another significant finding was that although participants were concerned about the risks of prescription medicines, consistent with other populations,<sup>25</sup> they largely reported little concern about using OTC medications because they perceived them as less harmful compared to recommended prescription medicines. This mirrors what others have identified in terms of encouraging a more active and empowered patient, which may increase OTC medicine use and underplay the harms involved.<sup>3,8</sup> Findings also show patients assess risk when making decisions about medication use in ways that may not be consistent with advice from health professionals.

Consequently, these findings have implications for policy and practice. First, the ambivalence that was conveyed by so many of the participants supports the need for concordance, which involves clinician and patient discussion around patient concerns, experiences, perspectives,<sup>5,19</sup> risks and benefits associated with both prescribed medications<sup>26</sup> and OTC medicines. In this way, interventions are needed that incorporate patient perspectives<sup>26</sup> and priorities in meaningful

ways. Second, medications occupy a central place in people's lives as they self-manage *prior to* seeking formal help. The long established concept of the 'iceberg of illness'<sup>27</sup> bears witness to this extensive activity long before policy extolled the version of an expert patient who is to be encouraged to self-manage.<sup>7</sup> People do not take OTC medications in a cultural vacuum. Established cultural attitudes of stoicism, more recent notions of overburdened health systems and taking responsibility for one's health combine to encourage OTC medicine use and avoidance of GP consultations. As such, it is perhaps unsurprising that people self-medicated for long periods of time and used maximum dosage drugs to help contain symptoms, even when symptoms were persistent and severe. Third, a mix of potent drugs that work well but also have negative effects build on the cultural ambivalence and aversion to medications, which people often already have.<sup>5</sup> The *cocktail of drugs* offered as *aggressive treatment* is complicated further by the existence of multi-morbidity, associated poly-pharmacy and drug interactions, or fears of such. These factors need to be considered as part of the patient experience of medication use, which informs decision-making.

## Conclusions

Our research re-emphasizes the role of and tensions around medication use in a changing health care environment. It suggests that one key challenge facing interventions to improve a timely RA diagnosis is to redress the public health message of appropriate help-seeking and individuals' responsibility to self-manage. Unless mixed messages are clarified, people may well continue to use OTC medicines extensively and inappropriately to mask severe symptoms and maintain function in their daily lives. Interventions also need to acknowledge how the patient and clinician roles are changing, as well as recognize the complications of multi-morbidity and how these



separate but often interlinking factors impact adherence. Interventions need to better communicate the need to gain treatment and the ramifications of having a chronic, systemic disease. RA is more than just joint pain, which many people feel comfortable in self-treating rather than gaining a diagnosis. Finally, the risks and benefits of OTC medications compared to prescription medications need to be clarified in ways that support more informed decision-making in RA.

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Statements

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) AT, PA, CB, LL have support from University of British Columbia, and Vancouver Coastal Health for the submitted work; (2) AT, PA, CB, LL have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AT, PA, CB, LL have no non-financial interests that may be relevant to the submitted work.

Anne Townsend PhD– contributed to the conception and design of the study, conducted interviews, analysis and interpretation, led writing of all drafts, guarantor of the study.

Paul Adam – contributed to the conception and design of the study, conducted interviews, co-led analysis and interpretation, commented on all drafts.

Catherine Backman PhD- contributed to the conception and design of the study, analysis and interpretation, commented on all drafts.

Linda Li PhD- led study design and conception, conducted interview, analysis and interpretation, commented on all drafts.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Further data are available relating to quotes around OTC medication use and ambivalence of prescribed medications.

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## Boxed Quotes

### **Box1: Paradox: Pre-diagnosis use of OTC medicines to function**

*I was just taking regular Tylenol and I mean I was sucking those back because I mean the pain was excruciating (Alicia)*

*When you have two little kids you just keep going... I kept going to skating lessons... the pain of tying up those laces... undoing them... getting them in and out of car seats...I didn't pay a lot of attention to it because I just thought... that's life...you just keep going and you take Tylenol or Advil and that's the way it is... I was almost full-time work and I really loved my work... I was so stimulated... really enjoyed my kids... I just kept taking pain medication to function (Flossie).*

*My husband had to help me to get a T-shirt on because everything was so stiff. I couldn't move and it was very painful... all these Tylenol / I would take up to 4 tablets of 650 mgs... by 11:00 the pain would go down to the point where I felt like I was happy to be at work. I could function fairly good. But the morning was a really tough time... At that point I had only taken occasionally more than six tablets a day to keep on going to work... it would go up to over 4,000 mgs. a day (Julie).*

*Just took Tylenol and Ibuprofen and tried to keep it at bay... to try... to see a doctor... wasn't worth it with the hassle of... baby and work. It wasn't that urgent... I spent... up to 14 hours a day on my laptop... eating Ibuprofen like a box of Smarties to try to keep the pain under control (Danielle).*

*I could hardly do anything... and when I started missing work I knew that that wasn't right... I tried the normal you know Tylenol or Aspirin or whatever to try and help as far as the pain went and nothing really worked. Nothing helped. So that's – again I decided – OK I can't go on like this on my own obviously. So again I decided – I made it clear that I had to go to the doctor and see what was wrong (Nicole).*

**Box 2: Self-assessing symptoms and regulating OTC medicine intake**

*Every morning, I take Tylenol for arthritis. Some days, I take two every morning. Some times I take a lot more.... I also take two at dinnertime. So a minimum of 4 a day. Sometimes more ... Each day I ask myself: Now do I need them today? (Bonnie).*

*I didn't like the effects of the other stronger stuff that was prescribed at the doctor's because... I didn't have time for drowsiness in the program and then raising a child, drowsiness was just not in the equation so I just went back to the Ibuprofen.... Being drowsy does not help you fight the fatigue (Danielle).*

*Interviewer: Where there any other things that you were doing besides the ice to manage it at that early point?*

*There were things I probably shouldn't have been doing but because... I already was on some inflammatory medications... I sort of upped the dose, not the dosage of the prescription medication but I would use 'over-the-counter' anti-inflammatories as well and by that I mean I would take extra doses of Aspirin... with codeine and caffeine, which would get me through some of the times (Charlize).*

*[I kept going to the doctor] because they (pains) were getting worse and because I was taking Tylenol and you know Tylenol 3 and everything and it wasn't helping (Martha)*

*I am not one to take pills. I hate even taking Tylenol for a headache (Marlain)*

*I am just afraid to take medication. I don't even have Tylenol in the house. I take maybe, I don't know, through my whole life I might have taken three Tylenols or something (Nora).*

**Box 3: Ambivalence: a need for and an aversion to prescribed medications**

*The truth is... that right after my (specialist) appointment (Husband) and I were planning to go to Edmonton and I didn't want to be starting on a new medication (DMARD) when I was on a trip...I waited to see my GP (Cynthia).*

*Since he didn't give me a lot of information, the specialist, about Methotrexate I had to do a lot of reading on my own about it and I was very reluctant, to use it... So it was probably a month after I was prescribed it to when I actually started taking it... It was... injectible... it's a little bit more of a hassle to take... when the drugs are so strong you'd like to know a little bit more information than if it was... take an antibiotic and you're going to feel better. It's... take this drug and maybe in six months you'll feel better... Well Methotrexate was also used to treat cancer so it's a very, very strong drug. ... (Bianca).*

*We talked a little bit about... treatment and things that might help and he (rheumatologist) asked me how I felt about medications... because I struggle with other health issues and I take so many different medications already I asked if we might be able just to try managing things on our own (GP and me) before we got into a big treatment sort of plan and he said that was fine. He did prescribe a pain killer that was a little bit more than what my family physician had given me and he said: ... "See how you do and if you need to come back before, call me but otherwise we'll see you in two months." ... but things didn't get a lot better and I still missed the odd day of work... So when I went back to the (rheumatologist) I said... I need help.... So then we started talking about treatment options... He put me on a treatment program (DMARDS).... the medication has been a good thing because I tried to go without it and I couldn't (Nicole).*



**Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications**

*The Methotrexate cleared all the symptoms of rheumatoid... right away. Like eventually, it was just the side effects I couldn't tolerate... It created a whole host of other symptoms that were not weighing up the benefits... it... alters your psyche... it's harder to dig your happy self out of that (Flossie).*

*After my first shot (a biologic) I was able to get off the chair without any help... by the third shot I think I was almost back to normal....I am going to ask Dr. X. if I can take my [biologic] If I can not do it once a week maybe every 10 days. Just slowly and see how my body reacts to that. Because when I get my shot the first two days now I don't feel that well. I'm feeling a little bit agitated (Debbie).*

*The Methotrexate and Sulfasalazine so changed my personality. I was miserable. When I think back on the nine months it's like a blur. It's like something I don't really want to remember. I just quit the medication and then I went back to see [the rheumatologist] and he said: "Well you had a reaction". And he kept pooh, poohing me off... He's very dedicated. But he just needs to crawl into his patients' shoes sometimes (Sharon).*

*I have been on Methotrexate for just over a month. And it seems to be working ... But it terrifies me (Sherry).*

*I just have to take it. I don't think my attitude has changed. If I have to I have to... It will still be hard to do because I know I am destroying other parts of my body with the medications. ...I wouldn't take it if I didn't have to (Nora).*

*So either way you're treated there is a negative side effect... you try not to kill yourself with the treatment and still manage your daily life (Charlize).*

*I would like to get off the Prednisone as soon as possible... it's almost weird... Prednisone is a magic drug until you find out the side effects... It's almost cruel to give it to people because it works so well (Jessie).*



**Table 1 Participant characteristics (self-reported at time of initial interview) \***

	Age range	Sex (M/F)	Recruited via	Symptom onset to seeing Rx	Seeking medical help for symptoms leading to a diagnosis/ RA test	Referral wait time to see a rheumatologist	Diagnosis
Alicia	60s	Female	Unknown	1 year	3 months	6-8 weeks	Uncertain but treated for RA
Barbara Anne	40s	Female	Family doctor's office	10 years	1 year	6 months	Diagnosed
Bianca	30s	Female	Rheumatologist office	2 years 3 months	7 months	2 months	Diagnosed
Bonnie	60s	Female	Arthritis Newsletter	40 years	20 years	No referral	Not diagnosed
Charlize	50s	Female	Arthritis Newsletter	4 months	Less than 1 week	3 months	Diagnosed
Cynthia	60s (estimated)	Female	Arthritis Newsletter	1 year	5 months	2 months	Diagnosed
Danielle	40s (estimated)	Female	Rheumatologist Office	8 years	3 years	2-3 months	Uncertain but treated for RA
Debbie	50s	Female	Rheumatologist Office	2 years 4 months	2 years 4 months	3 months	Diagnosed
Dodi	50s (estimated)	Female	Rheumatologist office	5-6 months	2-3 weeks	10 months	Diagnosed
Dorothy	30s	Female	Rheumatologist office	1 year 10 months	2 months	2 months	Diagnosed
Flossie	50s	Female	Arthritis Newsletter	24 years	unknown	6 weeks	Diagnosed
Jackie	40s	Female	Arthritis Newsletter	8 months	3 months	9 months	Uncertain but treated for RA
Jane	60s	Female	Arthritis Newsletter	8-9 months	5 months	1 month	Diagnosed
Jane 2	50s	Female	Arthritis Newsletter	4 months	1 month	6-8 weeks	Diagnosed
Jean	50s	Female	Arthritis Newsletter	19 years	8 years	2 months	Diagnosed
Jessie	50s	Female	Rheumatologist office	3-4 months	3-4 weeks	6 weeks	Diagnosed
Julie	50s	Female	Physiotherapist office	3 months	3-4 weeks	1 month	Diagnosed
June	50s	Female	Arthritis Newsletter	3 months	unknown	6 weeks	Diagnosed
Kerry	30s	Female	Arthritis Newsletter	3 months	No delay	10 days	Diagnosed

Lee	40s	Female	Family doctor office	14 years	Unknown	Unknown	No diagnosis (has complex multi-morbidities tests ongoing)
Laurie	60s	Female	Arthritis Newsletter	1-2 years	1-2 years	At regular rheumatologist regular appointment	Diagnosed
Maple	40s	Female	Arthritis Newsletter	2 months	6 -7 weeks	1 day	Diagnosed
Marie	60s	Female	Rheumatologist office	3 weeks	2 weeks	1 week	Diagnosed
Marlain	50s	Female	Rheumatologist office	4-5 years	2-3 years	< 6 months	Diagnosed
Martha	70s	Female	Unknown	9 years	6-8 years	1 year	Diagnosed
Nicole	30s	Female	Arthritis Newsletter	1 month	2 weeks	2 weeks	Diagnosed
Nicolette	50s	Female	Rheumatologist office	12 months	11 months	1 month	Diagnosed
Nora	50s	Female	Rheumatologist office	11 months	1 month	3 months	Diagnosed
Rain	50s	Mail	Arthritis Website	4 years	11 months	10 months	Diagnosed
Rosie	60s	Female	Arthritis Newsletter	26 years	26 years	1 month	Diagnosed
Sally	50s	Female	Arthritis Newsletter	1 year	2 months	1 month	Diagnosed
Sarah	50s	Female	Arthritis Newsletter	3 years	16 months	1 month	Diagnosed
Shari	60s	Female	Unknown	6 months	unknown	No referral family doctor diagnosis	Diagnosed
Sharon	60s	Female	Family doctor office	7 years	unknown	2 months	Diagnosed
Sherry	40s	Female	Rheumatologist office	9-10 years	5 years	6 months	Diagnosed
Smokie Jean	60s	Female	Rheumatologist	40 years	4 years	3 weeks	Diagnosed
Teresa	50s	Female	Unknown	11 months	9 months	5 months	Diagnosed
Yoda	50s	Female	Rheumatologist office	3 years 6 months	1-2 weeks	6 months	Diagnosed

\* Age estimated by interviewer when not given by participant.

Patient accounts of medication use in early rheumatoid arthritis from symptom onset to early post diagnosis

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Abstract

Objective: To examine accounts of medication use in participants with early rheumatoid arthritis (RA) from symptom onset to early post diagnosis.  
Design: Qualitative study with in-depth, personal interviews.  
Participants: 37 women and one man, aged 30s-70s, with a diagnosis of RA <12 months.  
Main outcome measure: Participants' experiences and feelings of medication use in early RA.  
Setting: British Columbia, Canada.  
Results: Medications were central to how people managed symptoms and disease. Two main themes were identified, showing that optimum medication use was hampered, and how this related to delayed diagnosis and effective care. The first theme, 'paradox of pre-diagnosis reliance on over the counter (OTC) medications', describes how people's self-management with OTC medications was 'effective.' Participants relied extensively on OTC medications for pain relief and to maintain 'normal life.' However, as this contributed to delayed medical consultation, diagnosis and effective treatment, OTC medication was also potentially detrimental to disease outcome. The second theme, 'ambivalence around prescription medications post diagnosis,' describes how adherence was hindered by patient beliefs, priorities and ambivalence towards medications.  
Conclusions: This study highlights how people use medications in early RA and contributes to a better understanding of medication use that may transfer to other conditions. Given the drive toward active self-management in health care and patients' ambivalence about using strong medications, in-depth understanding of how these combined factors impact patient experiences will help health care providers to support effective medication practices. The reported extensive reliance on OTC medications may speak to a care gap needing further investigation in the context of health behaviours and outcomes of patient self-management

ARTICLE SUMMARY

Article Focus

To understand the experiences of medication use in people with early RA from symptom onset to early post diagnosis.

Key Messages

Our study suggests an over-reliance and extensive use of OTC medications detrimental to health. People continued to self-medicate in place of a [general practitioner \(GP\)](#) consultation when symptoms were severe and debilitating but masked by high and regular doses of OTC medications.

Ambivalence about medication use suggests that we need to understand patient priorities and experiences better in order to support adherence.

Strengths and Limitations

This is an in-depth analysis of a relatively large qualitative dataset, offering insight into our participants' experiences of medication use. However, given the nature of qualitative research, we do not claim generalization to other populations. Experiences may be transferable to other settings with individuals who have similar characteristics.

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Researchers are independent from funders.

## Introduction

Medications paradoxically promise both relief and burden for people with chronic illness. In rheumatoid arthritis (RA), medications ease symptoms and can limit disease progression, but often complex regimens can exacerbate adverse reactions and side effects.<sup>1</sup> These combined factors can promote tensions and ambivalence around medication use and foster non-adherence detrimental to individuals and healthcare systems: “Non-adherence is important because many therapeutic interventions are effective only if used correctly, which requires continuous personal investment of time and effort from patients. The epidemiological transition from acute diseases, where the emphasis was on cure, to chronic illnesses that instead require management also means that patients take on a lifetime burden. Poor adherence can lead to complications in professional-patient relationships, additional ill health and expenditure for patients and their families, and the waste or misallocation of healthcare resources”<sup>2</sup> (p1) Given it is the patient who decides whether and how to take medications, we need to better understand over the counter (OTC)<sup>3</sup> and prescription use in chronic illness.<sup>4-5</sup> Qualitative research is designed to explore, interpret and gain a deeper understanding of social phenomena, and is well-suited to examine participants' experiences and use of medications. The shift in chronic illness care from passive

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patient to active partner coupled with policy support for shared decision-making and self-managing<sup>6-8</sup> makes this topic particularly important. Our objective in this analysis was to understand medication use from the patient perspective and identify barriers to optimum care from onset of symptoms to early post diagnosis. This information will be useful to health care providers who work with patients to improve adherence and who support shared decision-making. Our findings also highlight the potential pitfalls of unsupported self-management through a reliance on OTC medications, which may delay diagnosis and negatively impact outcome.

We used a qualitative approach<sup>9</sup> to investigate people's early RA medication use in the context of their daily lives. In this paper, we focus on two predominant themes, which emerged from interviews: 1) The paradox of self-managing 'effectively' with OTC medication; 2) Ambivalence and tensions around taking prescribed medication. We then discuss how medication use was a core self-management strategy for our participants, and how it influenced help-seeking, a timely diagnosis and effective treatment interventions. The accounts of people with early RA provided a rich source of qualitative data. The interviews offered insights into medication use, which may be transferable to others with similar illness experiences characterized by pain, unpredictable symptoms and concerns about the course of the illness and what to do about it. Other qualitative research shows that, like RA, various long-term conditions impact *functional* ability and daily life, and reveals how patient attempts to minimize incapacity provoke various decisions around medication use.<sup>5</sup>

As the goals of RA treatment are to ease pain, reduce inflammation and prevent joint damage,

combinations of medications are required. Disease modifying anti-rheumatic drugs (DMARDs), biologics, non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics are treatments that include both OTC and prescribed medications.<sup>10</sup> As well as combinations of medications, current evidence shows that DMARD therapy controls disease progression and improves long-term outcomes when initiated within the first three months of symptoms appearing.<sup>11</sup> Delays in DMARD use are associated with poorer disease control and have been reported across communities and at several stages of disease from onset to securing specialist visits. A delay in DMARD use ranging from 6.5 months to 11.5 months was reported in a Canadian study, which assumed that patients started the drug immediately upon prescription.<sup>12</sup> A UK study concluded that for their participants “the majority of the delay in assessing patients with RA in secondary care lay at the level of the patient seeking medical advice.” (p3)<sup>13</sup> Other qualitative research in the UK identified how multiple factors, e.g. the nature of symptoms, knowledge of RA and attitudes towards health care providers, influenced when to consult in early RA patients.<sup>14</sup> A study examining women’s use of prescribed RA medications identified the decision-making process as complex and multi-faceted.<sup>15</sup> Further research investigating the experience of medication use in women and men with long-term multi-morbidity (including RA) identified the central role of medication and patient ambivalence around taking different types of medicines.<sup>5</sup>

We know little about the factors impacting decision-making and medication use in early RA from onset to diagnosis. Our study extends this knowledge by comparing OTC and prescribed medications use.

## Participants and methods



This analysis formed part of a wider study on the experience of help-seeking in early RA from onset of symptoms to early post diagnosis.<sup>16</sup> The overarching aim was to better understand the patient experience of early illness in the context of their daily lives and to identify delays along the care pathway. The original aim then was not to investigate medication use, but to understand the priorities and the experiences of the participants. Perhaps unsurprisingly, medication use emerged as an important theme. Other results have been published elsewhere.<sup>16, 17</sup>

**Recruitment**

A purposive sample was recruited through patient organization websites, newsletters and information leaflets at local arthritis centres, as well as clinician offices. To be eligible, volunteers had to be adults with a self-reported RA diagnosis within the previous 12 months, and be able to converse in English (see Table 1). Potential participants contacted the research coordinator either by phone or e-mail, the study was described and volunteers were sent an informed consent document to be discussed and signed at interview. All eligible participants who made contact agreed to participate and gave written consent. One person who agreed to participate died prior to interview. Participants lived in a range of households in British Columbia (BC) and comprised individuals who were in paid employment, those receiving disability benefits, homemakers, and retirees. The participants lived in communities ranging from Vancouver, a large city on the West coast, to small, mountain and rural communities in the North and East of BC. Participants were Caucasian, which does not reflect the diversity of parts of the Vancouver metropolitan area. All names are pseudonyms chosen by the participants. The University of British Columbia’s Behavioral Research Ethics Board granted ethical approval for the study and all participants gave written informed consent.

## Interviews

A topic guide was used to elicit in-depth accounts of participant experiences<sup>18</sup> conducted at a time and place convenient to the participants (30 in their home and eight in a research centre). The topic guide was organized around three separate but overlapping sections: 1) Symptoms/onset/impact including illness actions; 2) Consulting the general practitioner (GP) and gaining a diagnosis/healthcare system and professionals; 3) Post diagnosis experiences. Open questions were asked, and probes and prompts used for elaboration. The guide was formulated after discussion with the multi-disciplinary team including consumers (individuals with inflammatory arthritis) and rheumatologists. The topic guide was tested in a pilot study (eight participants) and the main format was unchanged.<sup>19</sup> A follow-up telephone interview allowed for further elaboration and clarification, and to check main results of the initial interview (18 phone and one e-mail follow-up were conducted). Interviews were conducted by AT research associate (n=19), PA outreach coordinator at an arthritis clinic (n=5) and LL (n=1). The remaining interviews were conducted by a research coordinator (n=8) and three students supervised by PA (n=5). AT and PA are both experienced qualitative researchers. Prior to data collection, AT conducted a field-work/interviewing training session. Field notes were taken to aid interpretation and validity of the data driven claims. Most interviews lasted between 60 and 90 minutes. One participant was interviewed with spouse present.

## Data analysis

The audio-recorded interviews were transcribed verbatim. Transcripts were checked for accuracy against the recordings and identifying information removed. Analysis was iterative and thematic, guided by a constant comparative approach.<sup>20</sup> We used paper-based methods in the initial stages

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and nVivo 7 was then used for storage and handling the extensive dataset. No pre-selected codes were identified prior to data analysis. AT and PA annotated a selection of transcripts independently and devised preliminary codes for all data. All authors read a selection of transcripts and, after discussion and negotiation, preliminary codes were revised, agreed upon and major themes identified. AT and PA then applied the codes to further transcripts and constantly compared themes. Early broad themes related to medication use were clear, e.g., taking OTC medicines as a major self-management strategy. Other themes emerged as analysis progressed such as OTC medicine use as paradox (the more ‘effectively’ people self-managed with OTC medication, the less likely they were to seek medical help, gain a diagnosis and be prescribed RA treatments). All transcripts were re-read as higher themes emerged. Deviant cases were sought and analyses and interpretations were discussed with a medical sociologist experienced in qualitative research as a form of peer-checking. The multi-disciplinary author team also offered differing perspectives to aid validity of the data driven claims. Statements made by participants are indicated by italics.

**Results**

Both OTC and prescribed medication was core to illness management from onset to post diagnosis. All participants experienced trial and error with a combination of drug regimens over time to gain efficacious treatment with minimum negative effects. All took a mix of medications, most reported side effects and adverse reactions to varying degrees, and depended on medicines for symptom relief and to maintain function in daily life. Most conveyed medication as highly effective in easing severe and debilitating symptoms, and limiting the impact of the disease. Only a few reported medication use as unproblematic. The majority described concerns and anxieties

about *aggressive treatments* and the risk of complications, which required monitoring and repeated medical appointments. Perhaps unsurprisingly, participants relayed ambivalence around medications use, grateful for the significant benefits whilst voicing concerns about actual or potential harms such as side effects (e.g., mood changing, extreme fatigue, diarrhea) or adverse effects that required long-term monitoring (e.g., for liver or eye damage). Paradoxically, the more 'effectively' participants used OTC medications the more likely was a delayed diagnosis and prescribed treatment, key to optimum disease outcome. Below we discuss two predominant themes from the interviews.

### **Paradox: Pre-diagnosis use of over the counter (OTC) medicines**

OTC medicines were conveyed as core to daily life and central to managing symptoms at onset of RA, for time periods that ranged from a few days to several years. Typically participants described using OTC medicines for several weeks alongside other strategies, e.g., pacing activities and turning to alternative therapists and treatments. Several participants expressed adapting to or *pushing through the pain*. Their priority to *keep going* swamped any general aversion to medication, or concerns about consuming large quantities of OTC analgesics, both routinely and for long periods.

Prior to diagnosis, participants relied on OTC medications for extended periods of time (see Box 1 Alicia), using OTC analgesics to alleviate symptoms of pain, maintain function and facilitate *normal life*. For example, OTC medications enabled people to fulfill social roles and obligations, e.g., in the family (see Box 1 Flossie) and paid work (see Box 1 Julie). Although participants were recruited within 12 months of diagnosis, many described taking OTC

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medicines for months/years prior to their reported diagnosis of RA. One participant described negotiating symptoms and multiple roles (as a mother, student and employee) noting that over a period of a few years she was *relying on Ibuprofen* (see Box 1 Danielle). OTC analgesics were an integral component of daily life, allowing participants to keep busy and *push through* symptoms. Consequently, negotiating symptoms around daily life by relying on OTC medications meant delaying a GP consultation while they continued to self-manage. Significantly, in the context of busy lives, consulting the GP did not occur to some if they could *carry on*. For many, it was only when the OTC medicines failed to control pain and people could no longer function in core roles that they consulted their family doctor (see Box 1 Nicole).

**INSERT HERE Box1: Paradox: Pre-diagnosis use of OTC medications to function**

**Self-assessing symptoms and regulating OTC medication intake**

Participants continued to self-regulate with OTC medicines after seeing their family doctors and prior to a diagnosis. This could mean changing medications or varying the dose, balancing symptom relief against side effects, or doing a self-assessment check to gauge how many OTC medications would be required (see Box 2 Bonnie). Danielle favoured OTC analgesics to those her GP had prescribed, to which she attributed significant side effects (see Box 2 Danielle). Another participant took OTC medications together with anti-inflammatory medications prescribed for another condition (see Box 2 Charlize). Martha relied on both OTC and prescription painkillers over a period of years when she made several visits to her doctor with escalating symptoms of pain (see Box 2 Martha). The quotes in this second section illustrate how people self-managed their symptoms in daily life by self-regulating OTC medications: doing a self-assessment check to gauge how many OTC meds would be required (Bonnie), increasing

OTC medications when required (Charlize), choosing to take OTC medications to avoid side effects (drowsiness) from prescription drugs (Danielle). Although the majority relied on OTC medicines to control symptoms and function in daily life, a small minority of participants explicitly noted a clear aversion to OTC medicines (see Box 2 Marlain, Nora). Self-regulating OTC medications was a core self-management strategy, which for many meant avoiding a GP consultation. This 'effective' self-management hampered a speedy diagnosis and prescribed treatments that could reduce disease damage.

**INSERT HERE Box 2: Self-assessing symptoms and regulating OTC medicine intake**

**Ambivalence: Post-diagnosis prescribed medication use**

In the face of debilitating, severe and unpredictable symptoms and uncertainties about disease prognosis, participants were relieved to see a specialist and to be prescribed medications designed to control disease activity and improve symptoms. An RA diagnosis, however, was treated with ambivalence. First, participants described relief at being diagnosed but concern about having to live with a long-term condition. Second, participants came to rely on multiple prescription medications, but voiced a desire to come off/reduce them due to experiencing side-effects and concerns about potential toxicity and adverse effects.

Most participants were familiar with analgesics and anti-inflammatory drugs (both OTC and GP prescribed) and had been taking them to relieve symptoms and function in daily life, prior to RA diagnosis (see Boxes 1, 2). Prescribed medications were perceived differently. Participants reported they were faced with *aggressive treatment* (Ruth) and *drug cocktails* (Jane-2), for which they were grateful but also had misgivings about. Ambivalence was expressed most clearly

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around taking DMARDs. For example, although desiring treatment, some participants delayed initiating or filling prescriptions. A few delayed taking DMARDs because they anticipated disruption at work or on holidays (see Box 3 Cynthia). One participant described a combination of reasons, which put her off methotrexate: a lack of information from her rheumatologist; having to inject it, and recognizing that it was a cancer treatment all meant that Bianca delayed taking methotrexate until she could discuss it with her family doctor (see Box 3 Bianca). Another participant was reluctant to take prescribed DMARDs because she initially wanted to manage the RA herself along with her other chronic conditions and limit her multiple medication intake (see Box 3 Nicole).

**INSERT HERE Box 3: Ambivalence: a need for and an aversion to prescribed medications**

Nearly all of the participants described side effects. Most participants sought optimum symptom relief, disease control and minimum side effects, which meant finding a combination of prescription medications which suited them. For many, this was a process of trial and error, as the side effects were sometimes extreme and outweighed the benefits (see Box 4 Flossie). Several noted they continued to take, but were keen to reduce the level/frequency of their medications because of their aversion to them (see Box 4 Debbie). Yet only one person noted that she had stopped taking all prescription medications and this was reportedly with the knowledge of her family doctor and rheumatologist (see Box 4 Sharon).

**INSERT HERE Box 4: Ambivalence: weighing up the benefits and potential harms of prescribed medications**



A few did not report side effects and they were prepared to endure potential adverse effects to their system, if it meant that they could function ([see](#) Box 4 Sherry). [Nora](#) noted how she tolerated an aversion to DMARDs but [had](#) a need for it ([see](#) Box 4 Nora). In this example, an anti-[medication](#) attitude combined with knowledge of the potential toxicity of [DMARDs](#) is outweighed by the benefits (of symptom relief and functional ability) gained.

The tensions underpinning *aggressive* treatment [as care](#) (as described by participants) [were](#) clear in the accounts. [Participants balanced the risks \(of toxicity and adverse effects\) and benefits \(effective treatment of disease\) of prescribed RA medications](#) ([see](#) Box 4 Charlize). Another contradiction voiced by many was the use of prednisone, a drug [that](#) offered relief but also side effects and could only be taken for limited periods of time ([see](#) Box 4 Jessie). Overall, ambivalence around taking effective and intensive treatments [was](#) amplified by information [gathered](#) from multiple sources (e.g., the Internet, family members' experiences) combined with a reported lack of opportunity to meaningfully discuss risks, benefits and options in the specialist consultation.

## Discussion

Paradox and ambivalence arose around medicine use in the accounts of study participants, recently diagnosed with RA. Participants commonly reported OTC medication use as an [‘effective’](#) self-management strategy prior to seeking medical attention, which for many [participants](#) ultimately delayed diagnosis and effective treatment. Paradoxically, the more ‘successful’ self-managers risked longer delays and more harmful outcomes. Post-diagnosis, although most participants conveyed a [strong](#) desire for prescription medicines, they also

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described an aversion to them and concerns with complications of both side effects and adverse effects. Understanding patient perceptions and priorities can inform several elements of practice and care, fostering effective patient-provider communication and shared decision-making. Ultimately, this may lead to more prompt diagnosis and higher levels of adherence.

Our study has limitations. Given the nature of qualitative research, we do not claim to make generalizations from this sample, although it is an in-depth analysis of a relatively large data set. The participants recruited could have been more inclined than others to be active self-managers or help-seekers.<sup>21</sup> They could also have been more prone to have problems, complex trajectories and experience tensions around help-seeking and medicine use than others with RA. Despite purposive approaches, we recruited just one man and all participants were Caucasian, so the sample is limited. Trainee/multiple interviewers may have affected the quality in a minority of the interviews, though this was taken into account in the analysis. Nevertheless, the in-depth analysis gave insight into how medication ation use was experienced over time, taking account of the changing context in which people manage chronic illness from symptom onset to diagnosis. It is possible that people with similar chronic conditions may have similar experiences. For example, there are similarities between RA and multiple sclerosis (MS). Both are chronic, systemic, autoimmune conditions with fluctuating pain and fatigue disrupting life roles.<sup>16</sup> Given that symptoms and activity disruption drove some of the pre-diagnosis medication decisions in the present study, there may be questions to explore in MS and other similar conditions.

Consistent with literature spanning 50 years,<sup>22,23</sup> participants commonly reported delaying a GP consultation. A significant finding was that it simply did not occur to people to consult their GP

or other health professional, as long as OTC medicines masked symptoms for prolonged periods. The delays some participants reported in obtaining prescribed medication reflected experiences of patients with chronic illness in a study 40 years ago.<sup>24</sup> More recent research has revealed how people's use of OTC medications to manage early RA symptoms contributes to delays in seeking a medical appointment.<sup>12</sup> This may point to a need to increase public awareness about the symptoms of inflammatory types of arthritis and importance of early intervention for optimal outcomes. The attitude towards managing symptoms oneself and prolonged use of OTC medicines could be unintentionally encouraged by policy messages about inappropriate use of overburdened health systems and the need for self-management.<sup>3,8</sup> The accounts revealed reluctance to go on prescribed medicines, and a desire to reduce or come off them to avoid side effects. Another significant finding was that although participants were concerned about the risks of prescription medicines, consistent with other populations,<sup>25</sup> they largely reported little concern about using OTC medications because they perceived them as less harmful compared to recommended prescription medicines. This mirrors what others have identified in terms of encouraging a more active and empowered patient, which may increase OTC medicine use and underplay the harms involved.<sup>3,8</sup> Findings also show patients assess risk when making decisions about medication use in ways that may not be consistent with advice from health professionals.

Consequently, these findings have implications for policy and practice. First, the ambivalence that was conveyed by so many of the participants supports the need for concordance, which involves clinician and patient discussion around patient concerns, experiences, perspectives,<sup>5,19</sup> risks and benefits associated with both prescribed medications<sup>26</sup> and OTC medicines. In this way, interventions are needed that incorporate patient perspectives<sup>26</sup> and priorities in meaningful

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ways. Second, medications occupy a central place in people’s lives as they self-manage *prior to* seeking formal help. The long established concept of the ‘iceberg of illness’<sup>27</sup> bears witness to this extensive activity long before policy extolled the version of an expert patient who is to be encouraged to self-manage.<sup>7</sup> People do not take OTC medications in a cultural vacuum. Established cultural attitudes of stoicism, more recent notions of overburdened health systems and taking responsibility for one’s health combine to encourage OTC medicine use and avoidance of GP consultations. As such, it is perhaps unsurprising that people self-medicated for long periods of time and used maximum dosage drugs to help contain symptoms, even when symptoms were persistent and severe. Third, a mix of potent drugs *that* work well but also have negative effects build on the cultural ambivalence and aversion to medications, which people often already have.<sup>5</sup> The *cocktail of drugs* offered as *aggressive treatment* is complicated further by the existence of multi-morbidity, associated poly-pharmacy and drug interactions, or fears of such. These factors need to be considered as part of the patient experience of medication use, which informs decision-making.

**Conclusions**

Our research re-emphasizes the role of and tensions around medication use in a changing health care environment. It suggests that one key challenge facing interventions to improve a timely RA diagnosis is to redress the public health message of appropriate help-seeking and individuals’ responsibility to self-manage. Unless mixed messages are clarified, people may well continue to use OTC medicines extensively and inappropriately to mask severe symptoms and maintain function in their daily lives. Interventions also need to acknowledge how the patient and clinician roles are changing, as well as recognize the complications of multi-morbidity and how these

separate but often interlinking factors impact adherence. Interventions need to better communicate the need to gain treatment and the ramifications of having a chronic, systemic disease. RA is more than just joint pain, which many people feel comfortable in self-treating rather than gaining a diagnosis. Finally, the risks and benefits of OTC medications compared to prescription medications need to be clarified in ways that support more informed decision-making in RA.

### Acknowledgements

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### Statements

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All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) (available on request from the corresponding author) and declare that (1) AT, PA, CB, LL have support from University of British Columbia, and Vancouver Coastal Health for the submitted work; (2) AT, PA, CB, LL have no relationships with companies that might have an interest in the submitted work in the previous 3 years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the submitted work; and (4) AT, PA, CB, LL have no non-financial interests that may be relevant to the submitted work.

Anne Townsend PhD– contributed to the conception and design of the study, conducted interviews, analysis and interpretation, led writing of all drafts, guarantor of the study.

Paul Adam – contributed to the conception and design of the study, conducted interviews, co-led analysis and interpretation, commented on all drafts.

Catherine Backman PhD- contributed to the conception and design of the study, analysis and interpretation, commented on all drafts.

Linda Li PhD- led study design and conception, conducted interview, analysis and interpretation, commented on all drafts.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Further data are available relating to quotes around OTC medication use and ambivalence of prescribed medications.

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**Boxed Quotes**

**Box1: Paradox: Pre-diagnosis use of OTC medicines to function**

*I was just taking regular Tylenol and I mean I was sucking those back because I mean the pain was excruciating (Alicia)*

*When you have two little kids you just keep going... I kept going to skating lessons... the pain of tying up those laces... undoing them... getting them in and out of car seats...I didn't pay a lot of attention to it because I just thought... that's life...you just keep going and you take Tylenol or Advil and that's the way it is... I was almost full-time work and I really loved my work... I was so stimulated... really enjoyed my kids... I just kept taking pain medication to function (Flossie).*

*My husband had to help me to get a T-shirt on because everything was so stiff. I couldn't move and it was very painful... all these Tylenol / I would take up to 4 tablets of 650 mgs... by 11:00 the pain would go down to the point where I felt like I was happy to be at work. I could function fairly good. But the morning was a really tough time... At that point I had only taken occasionally more than six tablets a day to keep on going to work... it would go up to over 4,000 mgs. a day (Julie).*

*Just took Tylenol and Ibuprofen and tried to keep it at bay... to try... to see a doctor... wasn't worth it with the hassle of... baby and work. It wasn't that urgent... I spent... up to 14 hours a day on my laptop... eating Ibuprofen like a box of Smarties to try to keep the pain under control (Danielle).*

*I could hardly do anything... and when I started missing work I knew that that wasn't right... I tried the normal you know Tylenol or Aspirin or whatever to try and help as far as the pain went and nothing really worked. Nothing helped. So that's – again I decided – OK I can't go on like this on my own obviously. So again I decided – I made it clear that I had to go to the doctor and see what was wrong (Nicole).*

**Box 2: Self-assessing symptoms and regulating OTC medicine intake**

*Every morning, I take Tylenol for arthritis. Some days, I take two every morning. Some times I take a lot more.... I also take two at dinnertime. So a minimum of 4 a day. Sometimes more ... Each day I ask myself: Now do I need them today? (Bonnie).*

*I didn't like the effects of the other stronger stuff that was prescribed at the doctor's because... I didn't have time for drowsiness in the program and then raising a child, drowsiness was just not in the equation so I just went back to the Ibuprofen.... Being drowsy does not help you fight the fatigue (Danielle).*

*Interviewer: Where there any other things that you were doing besides the ice to manage it at that early point?*

*There were things I probably shouldn't have been doing but because... I already was on some inflammatory medications... I sort of upped the dose, not the dosage of the prescription medication but I would use 'over-the-counter' anti-inflammatories as well and by that I mean I would take extra doses of Aspirin... with codeine and caffeine, which would get me through some of the times (Charlize).*

*[I kept going to the doctor] because they (pains) were getting worse and because I was taking Tylenol and you know Tylenol 3 and everything and it wasn't helping (Martha)*

*I am not one to take pills. I hate even taking Tylenol for a headache (Marlain)*

*I am just afraid to take medication. I don't even have Tylenol in the house. I take maybe, I don't know, through my whole life I might have taken three Tylenols or something (Nora).*

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**Box 3: Ambivalence: a need for and an aversion to prescribed medications**

*The truth is... that right after my (specialist) appointment (Husband) and I were planning to go to Edmonton and I didn't want to be starting on a new medication (DMARD) when I was on a trip...I waited to see my GP (Cynthia).*

*Since he didn't give me a lot of information, the specialist, about Methotrexate I had to do a lot of reading on my own about it and I was very reluctant, to use it... So it was probably a month after I was prescribed it to when I actually started taking it... It was... injectible... it's a little bit more of a hassle to take... when the drugs are so strong you'd like to know a little bit more information than if it was... take an antibiotic and you're going to feel better. It's... take this drug and maybe in six months you'll feel better... Well Methotrexate was also used to treat cancer so it's a very, very strong drug. ... (Bianca).*

*We talked a little bit about... treatment and things that might help and he (rheumatologist) asked me how I felt about medications... because I struggle with other health issues and I take so many different medications already I asked if we might be able just to try managing things on our own (GP and me) before we got into a big treatment sort of plan and he said that was fine. He did prescribe a pain killer that was a little bit more than what my family physician had given me and he said: ... "See how you do and if you need to come back before, call me but otherwise we'll see you in two months." ... but things didn't get a lot better and I still missed the odd day of work... So when I went back to the (rheumatologist) I said... I need help.... So then we started talking about treatment options... He put me on a treatment program (DMARDS).... the medication has been a good thing because I tried to go without it and I couldn't (Nicole).*

**Box 4 Ambivalence: weighing up the benefits and potential harms of prescribed medications**

*The Methotrexate cleared all the symptoms of rheumatoid... right away. Like eventually, it was just the side effects I couldn't tolerate... It created a whole host of other symptoms that were not weighing up the benefits... it... alters your psyche... it's harder to dig your happy self out of that (Flossie).*

*After my first shot (a biologic) I was able to get off the chair without any help... by the third shot I think I was almost back to normal....I am going to ask Dr. X. if I can take my [biologic] If I can not do it once a week maybe every 10 days. Just slowly and see how my body reacts to that. Because when I get my shot the first two days now I don't feel that well. I'm feeling a little bit agitated (Debbie).*

*The Methotrexate and Sulfasalazine so changed my personality. I was miserable. When I think back on the nine months it's like a blur. It's like something I don't really want to remember. I just quit the medication and then I went back to see [the rheumatologist] and he said: "Well you had a reaction". And he kept pooh, poohing me off... He's very dedicated. But he just needs to crawl into his patients' shoes sometimes (Sharon).*

*I have been on Methotrexate for just over a month. And it seems to be working ... But it terrifies me (Sherry).*

*I just have to take it. I don't think my attitude has changed. If I have to I have to... It will still be hard to do because I know I am destroying other parts of my body with the medications. ...I wouldn't take it if I didn't have to (Nora).*

*So either way you're treated there is a negative side effect... you try not to kill yourself with the treatment and still manage your daily life (Charlize).*

*I would like to get off the Prednisone as soon as possible... it's almost weird... Prednisone is a magic drug until you find out the side effects... It's almost cruel to give it to people because it works so well (Jessie).*

Table 1 Participant characteristics (self-reported at time of initial interview) \*

	Age range	Sex (M/F)	Recruited via	Symptom onset to seeing Rx	Seeking medical help for symptoms leading to a diagnosis/ RA test	Referral wait time to see a rheumatologist	Diagnosis
Alicia	60s	Female	Unknown	1 year	3 months	6-8 weeks	Uncertain but treated for RA
Barbara Anne	40s	Female	Family doctor's office	10 years	1 year	6 months	Diagnosed
Bianca	30s	Female	Rheumatologist office	2 years 3 months	7 months	2 months	Diagnosed
Bonnie	60s	Female	Arthritis Newsletter	40 years	20 years	No referral	Not diagnosed
Charlize	50s	Female	Arthritis Newsletter	4 months	Less than 1 week	3 months	Diagnosed
Cynthia	60s_ (estimated)	Female	Arthritis Newsletter	1 year	5 months	2 months	Diagnosed
Danielle	40s (estimated)	Female	Rheumatologist Office	8 years	3 years	2-3 months	Uncertain but treated for RA
Debbie	50s	Female	Rheumatologist Office	2 years 4 months	2years 4 months	3 months	Diagnosed
Dodi	50s_ (estimated)	Female	Rheumatologist office	5-6 months	2-3 weeks	10 months	Diagnosed
Dorothy	30s	Female	Rheumatologist office	1 year 10 months	2 months	2 months	Diagnosed
Flossie	50s	Female	Arthritis Newsletter	24 years	unknown	6 weeks	Diagnosed
Jackie	40s	Female	Arthritis Newsletter	8 months	3 months	9 months	Uncertain but treated for RA
Jane	60s	Female	Arthritis Newsletter	8-9 months	5 months	1 month	Diagnosed
Jane 2	50s	Female	Arthritis Newsletter	4 months	1 month	6-8 weeks	Diagnosed
Jean	50s	Female	Arthritis Newsletter	19 years	8 years	2 months	Diagnosed
Jessie	50s	Female	Rheumatologist office	3-4 months	3-4 weeks	6 weeks	Diagnosed
Julie	50s	Female	Physiotherapist office	3 months	3-4 weeks	1 month	Diagnosed
June	50s	Female	Arthritis Newsletter	3 months	unknown	6 weeks	Diagnosed
Kerry	30s	Female	Arthritis Newsletter	3 months	No delay	10 days	Diagnosed

Lee	40s	Female	Family doctor office	14 years	Unknown	Unknown	No diagnosis (has complex multi-morbidities tests ongoing)
Laurie	60s	Female	Arthritis Newsletter	1-2 years	1-2 years	At regular rheumatologist regular appointment	Diagnosed
Maple	40s	Female	Arthritis Newsletter	2 months	6 -7 weeks	1 day	Diagnosed
Marie	60s	Female	Rheumatologist office	3 weeks	2 weeks	1 week	Diagnosed
Marlain	50s	Female	Rheumatologist office	4-5 years	2-3 years	< 6 months	Diagnosed
Martha	70s	Female	Unknown	9 years	6-8 years	1 year	Diagnosed
Nicole	30s	Female	Arthritis Newsletter	1 month	2 weeks	2 weeks	Diagnosed
Nicolette	50s	Female	Rheumatologist office	12 months	11 months	1 month	Diagnosed
Nora	50s	Female	Rheumatologist office	11 months	1 month	3 months	Diagnosed
Rain	50s	Mail	Arthritis Website	4 years	11 months	10 months	Diagnosed
Rosie	60s	Female	Arthritis Newsletter	26 years	26 years	1 month	Diagnosed
Sally	50s	Female	Arthritis Newsletter	1 year	2 months	1 month	Diagnosed
Sarah	50s	Female	Arthritis Newsletter	3 years	16 months	1 month	Diagnosed
Shari	60s	Female	Unknown	6 months	unknown	No referral family doctor diagnosis	Diagnosed
Sharon	60s	Female	Family doctor office	7 years	unknown	2 months	Diagnosed
Sherry	40s	Female	Rheumatologist office	9-10 years	5 years	6 months	Diagnosed
Smokie Jean	60s	Female	Rheumatologist	40 years	4 years	3 weeks	Diagnosed
Teresa	50s	Female	Unknown	11 months	9 months	5 months	Diagnosed
Yoda	50s	Female	Rheumatologist office	3 years 6 months	1-2 weeks	6 months	Diagnosed

\* Age estimated by interviewer when not given by participant.

# Participant Interview Guide

**Preamble:**

Thanks so much for agreeing to take part in this study. What I really want to hear from you today is your experience of RA, in your own words, from when you first noticed any signs of illness, right up to now; e.g. how it has affected you, and what you have been able to do about it, and what happened around the time of diagnosis.

**Ice-breaker: To start with, can you tell me what a typical week is like for you?**

**1. Can you tell me about your arthritis, starting from when you first noticed anything?**

*Probes: (only if appropriate)*

- What about when you first noticed any aches/pain/stiffness in joints or general tiredness?
- How did your symptoms affect your day-to-day life? (Work / leisure / family)
- What helped? Medication / treatments / equipment.
- Health professionals/alternative practitioners?
- What sorts of information did you have / find?
- What about people you know, like friends and family (with arthritis or others).
- Anything else you can think of?

**2. Can you tell me what happened leading up to, and around the time of diagnosis?**

*Probes: (only if appropriate)*

- From when you first noticed anything was wrong, about how long was it before you saw your doctor, or another health worker?
- Can you remember the last thing that happened before making the appointment to see the doctor?
- About how long was it from when you saw your doctor (or other) to when the RA was diagnosed?
- Was anybody particularly helpful or unhelpful at that time?
- How did receiving the diagnosis make you feel?
- Did you see anybody else or do anything else during that time which helped your symptoms?
- Can you remember how your symptoms were affecting your day-to-day life at around that time?
- Anything else you can think of?



### 3. What about since the diagnosis?

*Probes: (Only if appropriate)*

- How are things now? Symptoms / impact / anything else
- Many people say there are times when they feel they have no control over their RA, what's been your experience? What helps at times like this?
- What helps best now? Can you say a little more about that?
- Can you tell me about your experience with medications?
- Could you tell me about a time when your current GP / rheumatologist was most helpful to you? What about a time when he or she was least helpful?
- Can you think of any time when you expressed dissatisfaction to your health professional, or perhaps that you wish you had?
- Can you give an example of when things might have been done better or gone smoother?
- What health professionals have you seen/do you see in relation to your RA?
- What about alternative practitioners?
- Anything else?

**If required/time – summing up:**

**4. Overall:** (section getting at most salient points before interview close)

#### a) What/Who has been the most helpful to you in managing your arthritis?

*Probes: (If appropriate)*

- Information / health professionals / friends and family / yourself / medication / alternative treatments/practitioners
- How important is your attitude? Can you tell me a bit more about that?
- How important is past experience, e.g. previous/other illness or past use of health services?
- How satisfied are you/have you been with the information you have received / found?
- Can you suggest anything else that would be, or would have been helpful to you in managing your arthritis?

#### b). Bottom line / in a nutshell; What would you say was the main reason you went to see your family doctor?

#### c). And briefly, what would you say was the main thing that stopped you from making that appointment till then?

- Have you any advice or tips you could give others about RA?
- Is there anything else that you would like to talk about?
- Just before we finish, can you tell me about why you chose to take part in this interview?

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Thanks very much for your time, and telling me about your experiences.

For peer review only

# Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
<b>Domain 1: Research team and reflexivity</b>		
Personal Characteristics		
1. included in text	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2. identified	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>
3. identified AT and PA	Occupation	What was their occupation at the time of the study?
4. identified	Gender	Was the researcher male or female?
5. included in text	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>
8. reference to validity and reliability and independent checks in text	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>
<b>Domain 2: study design</b>		
Theoretical framework		
9. identified	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>
Participant selection		
10. identified	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>
11. identified	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>
12. identified	Sample size	How many participants were in the

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4			study?
5	13. identified	Non-participation	How many people refused to participate
6			or dropped out? Reasons?
7	Setting		
8			
9	14. identified	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>
10			
11	15. identified	Presence of non-participants	Was anyone else present besides the participants and researchers?
12			
13	16. identified	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>
14			
15	Data collection		
16			
17			Were questions, prompts, guides
18	17. identified	Interview guide	provided by the authors? Was it pilot tested?
19			
20			Were repeat interviews carried out? If
21	18. identified	Repeat interviews	yes, how many?
22			
23	19. identified	Audio/visual recording	Did the research use audio or visual recording to collect the data?
24			
25	20. identified	Field notes	Were field notes made during and/or after the interview or focus group?
26			
27			What was the duration of the interviews or focus group?
28	21. identified	Duration	
29			
30	22. identified	Data saturation	Was data saturation discussed?
31			
32	23. identified	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
33			
34	<b>Domain 3: analysis and findings</b>		
35			
36	Data analysis		
37	24. identified	Number of data coders	How many data coders coded the data?
38			
39	25. identified	Description of the coding tree	Did authors provide a description of the coding tree?
40			
41	26. identified	Derivation of themes	Were themes identified in advance or derived from the data?
42			
43	27. identified	Software	What software, if applicable, was used to manage the data?
44			
45	28. identified	Participant checking	Did participants provide feedback on the findings?
46			
47	Reporting		
48			
49			Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>
50	29. identified	Quotations presented	
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53			
54	30. checked	Data and findings consistent	Was there consistency between the data presented and the findings?
55			
56	31. checked	Clarity of major themes	Were major themes clearly presented in the findings?
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32. identified e.g. only  
a few described  
medication use as  
unproblematic.

Clarity of minor themes

Is there a description of diverse cases or  
discussion of minor themes?

For peer review only