

RESEARCH ARTICLE

Managing juvenile idiopathic arthritis within the context of their life: What we learnt from children and youth living with juvenile idiopathic arthritis and their parents

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Abstract

Introduction: Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in children and causes short- and long-term disability. Optimal management requires pharmacologic and non-pharmacologic interventions. Few studies have explored the youth and family experience of the management of JIA. This study's objective was to explore the management experience of youth with JIA and their parents.

Methods: This qualitative study used semi-structured interviews with youth 12–18 years of age with JIA receiving biological medication and parents of children with JIA on biological medication. Participants were recruited in clinics using convenience sampling. A thematic analysis approach was employed for data analysis.

Results: Nine youth and 14 parents participated. Four themes were identified that encompassed an overarching theme of participants managing JIA within the context of their life: aspects of life affected by JIA and its management, lived experience with JIA management, medication decision-making, and involvement in decision-making. Juvenile idiopathic arthritis management is situated within the context of their life but is normally (outside acute events) not central.

G. R. Currie and B. L. Kennedy are co-first authors.

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Conclusion: Two dimensions were added to those in the literature: parents' overall approaches to health and the sense of urgency surrounding decision-making. Our findings reinforce the importance of person- and family-centred care in paediatric rheumatology. That is, identifying what matters most to youth and their parents given their current life circumstances to provide a foundation for discussions of how they want to manage their JIA.

KEYWORDS

caregivers, children, juvenile idiopathic arthritis, qualitative, symptom management, thematic analysis, therapies

1 | INTRODUCTION

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in children, and is often associated with significant short- and long-term disability (Giancane et al., 2016). Treatment principles include: prompt initiation, annual reviews for patients in communities without access to ongoing care, tailored treatment based on patient characteristics, and frequent assessment of treatment response with a goal of inactive disease (Cellucci et al., 2016). Management requires a multidisciplinary team and uses both non-pharmacological and pharmacological interventions (Cellucci et al., 2016; Giancane et al., 2016; Gowdie & Tse, 2012). Occupational and physical therapies are core non-pharmacological interventions (Cellucci et al., 2016; Gowdie & Tse, 2012). Primary pharmacological interventions include nonsteroidal anti-inflammatory drugs (NSAIDs), intra-articular corticosteroids, conventional disease-modifying antirheumatic drugs (DMARDs), and biologic DMARDs (Cellucci et al., 2016; Giancane et al., 2016). Given all this, families face complex JIA treatment decisions (Burnett et al., 2012; Gowdie & Tse, 2012; Halyabar et al., 2019).

A 2008 study found that 92% of parents of children with JIA ($n = 52$) had also used complementary therapies (Rouster-Stevens et al., 2008). A 2014 study of adolescents with JIA ($n = 50$) found that 38% had regularly used a complementary therapy over the past year (Nousiainen et al., 2014). Complementary therapies included, but were not limited to, dietary modifications and supplements, homoeopathy, osteopathy, massage, and copper bracelets (Nousiainen et al., 2014; Rouster-Stevens et al., 2008). Provider uncertainty and national differences regarding what constitutes a complementary therapy adds complexity (Nousiainen et al., 2014).

Person-centred care is a high priority for healthcare services delivery in part because it is a foundation for patient safety and healthcare quality (Santana et al., 2018). Family-centred care includes family in care decisions and care provision (Uniacke et al., 2018).

Looking at the literature on JIA treatment decisions for patients and families, Burnett et al. used a discrete choice experiment to examine parent preferences for drug treatments and health outcomes among parents of children with JIA. Participation in daily activities, arthritis pain, and out of pocket cost were the most important decision-making factors (Burnett et al., 2012). Lipstein and colleagues

published several studies in the United States focused on parents and patients decision-making in JIA and inflammatory bowel disease (Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Lovell, et al., 2013; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013). Two specifically explored biologic DMARD decisions (Lipstein, Lovell, et al., 2013; Lipstein, Lovell, et al., 2016), Lipstein, Lovell, et al., 2016 and three explored treatment decisions more broadly (Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Muething, et al., 2013). Of those studies, two included patient perspectives and found that the adolescents took a short-term view, compared to their parents, emphasising quality of life (QoL) and the immediate effects of treatment (Lipstein, Dodds, et al., 2016; Lipstein, Muething, et al., 2013). This highlights a gap in the understanding of JIA management from the patient perspective.

The objective of this study was to explore the management experience of youth with JIA and their parents. The parents of youth with JIA were included, as well as patients, to capture a more complete view of the JIA experience consistent with the person- and family-centred approach.

2 | METHODS

A qualitative research design was selected to describe parent and youth perspectives on managing JIA, which is a component of a larger study embedded within the Canada Netherlands Personalized Medicine Network in Childhood Arthritis and Rheumatic Diseases (UCAN CANDU) project. The approach was a qualitative description, chosen because it remains close to the participants' literal description of their experience and generates a rich description (aligned with the larger research study (Bradshaw et al., 2017)). We employed a naturalistic paradigm, an epistemological position of subjectivism, and an ontological position of relativism (Bradshaw et al., 2017). A combination of inductive and deductive thematic analyses were conducted at the semantic level, aligning with the goal to stay close to the participant's description of their experience.

Ethics approval was obtained from The Conjoint Health Research Ethics Board at the University of Calgary (REB19-0360) in April of 2019. Informed verbal consent was obtained prior to data collection.

2.1 | Study participants and recruitment

This is a single-centre study, executed in Alberta, Canada. Inclusion criteria were youth 12–18 years of age with a JIA diagnosis who were currently on biological medication or parents of a child of any age with a JIA diagnosis currently on a biological medication (aligned with the larger research study). Convenience sampling was employed to recruit participants. During virtual consultations with their rheumatologist at an academic children's hospital in Alberta, Canada, eligible parents were asked for verbal consent to contact about study participation. Twenty parents who fit the eligibility criteria were invited to participate. Verbal assent was obtained from youth 12–13 years of age, and verbal consent from youth 14 years and older. In addition, verbal consent was obtained from the parent or legal guardian. Participants did not receive reimbursement for participation.

2.2 | Semi-structured interviews

Semi-structured interviews were conducted via telephone and audio-recorded. Participants were not familiar with the interviewer, and they were informed of the reasons for the research before commencing their interview. Interviews occurred with only the interviewer and participant present. The interview guides focused on three broad areas: experience managing and living with JIA; making decisions about arthritis treatment, including how children were involved; and key considerations when reducing or stopping biological treatments (Appendix). This manuscript reports on the first two areas. The study objective and input from the research team informed interview guide development.

2.3 | Researcher characteristics and reflexivity

GM, an experienced qualitative researcher, conducted all interviews and along with BK analysed the interview data. GM is the daughter of a mother who had JIA, and a mother of a child living with complex, chronic health issues. She is a health service researcher with considerable qualitative research experience and a PhD in Community Health Sciences. She has been involved in many research projects with the objective to explore and describe people's experiences living with and managing their chronic health conditions, including navigating the healthcare system. BK assisted in the analysis of the interview data. She has a master's degree in Community Health Sciences and experience conducting and analysing interviews on the topic of osteoarthritis. She had no prior experience conducting JIA research.

2.4 | Analysis methods

Interview recordings were transcribed verbatim, and participant demographic information was extracted from the transcripts. NVivo

12™ was used to support the management and analysis of interview data (QSR-International, 1999). Thematic data analysis was carried out (Braun & Clarke, 2006) to understand the complexity of the meanings of lived experiences.

GM and BK created an analytical template derived from the areas explored in the interviews, and independently coded the first four transcripts using a combination of inductive and deductive coding strategies. The analysts employed peer debriefing, and the analytic template evolved as the coding progressed. New codes were added as needed, so data were not forced to fit into the analytic template. The analysts continued meeting to ensure consensus was maintained during the coding process and to evaluate saturation. Saturation was operationalised as code saturation defined by Hennik et al. as “the point when no additional issues are identified and the codebook begins to stabilise” which is sufficient for outlining broad thematic issues, aligned with the objective to explore JIA management experiences of youth and their parents (Hennink et al., 2017). The goal was saturation in core codes pertaining to experiences with, and making decisions about, arthritis treatment (Hennink et al., 2017). Recruitment was ceased when analysts agreed that saturation in core codes was reached. After the initial coding, analysts met to discuss relationships among codes, with the goal of identifying themes and the connections between them. The analysts created a mind map during this process. Reporting followed the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

3 | RESULTS

The mean duration of the parent interviews was 40 min (range 33–61). The mean duration of the youth interviews was 32 min (range 19–46 min). One youth did not consent to be audio recorded, and notes were taken instead. The parent interviews were longer than youth interviews, in part because parents were invited to describe their journey with their child's JIA to date, while youth were not asked to repeat this information.

3.1 | Sample characteristics

Fourteen parents and nine youth participated in interviews conducted between January and December 2020 (Appendix Table A1). The youth participants were between 13 to 17 years. The children of the parents who participated were between 7 and 16 years old. Of those invited who were eligible, two youth and one parent did not consent to participate.

We qualitatively categorised the complexity of journey as low, medium, and high categorised based on diagnostic experience (time to diagnosis and how many places they sought help), whether hospitalisation was required, treatment experiences (including number of different biologics), challenges associated with treatment protocol (including how the youth coped), and the treatment impact (including flares, and time to remission (if achieved)). The complexity of journey

was low for three families, medium for five, and high for seven. Age at diagnosis ranged from 18 months to 14 years of age, with most children diagnosed between ages four to nine. Families commonly sought help when symptoms initially presented from a doctor (type not specified), family doctor, paediatrician, hospital emergency room, or a naturopath. A few participants sought help through walk-in clinics and orthopaedic specialists, and one from an optometrist. Most participants had the knee and/or ankle joints affected. Some also had the temporomandibular joint, the thumb or fingers, the wrist, or the toes. One participant each mentioned the hip, foot, or sacroiliac joint. Four children had uveitis. In addition to using biologics (per inclusion criteria), almost all patients had used methotrexate and joint injections and most had used non-steroidal anti-inflammatory drugs. Some families had tried physio and/or occupational therapy, prednisone, diet modifications and/or other complementary therapies.

3.2 | Managing Juvenile idiopathic arthritis within the context of life

The overarching theme identified was managing JIA within the context of life. Juvenile idiopathic arthritis management was situated within the context of their life but was normally (outside acute events) not central. Managing JIA within the context of life

encompassed four main themes, which included aspects of life affected by JIA and its management, lived experience with JIA management, medication decision-making, and involvement in decision-making (Figure 1). The themes and related sub-themes are described in detail below.

3.2.1 | Aspects of life affected by Juvenile idiopathic arthritis and its management

Participants emphasised that the child and family's life were affected both by the symptoms of and functional limitations from JIA as well as by the treatment itself (Table 1).

The following sub-themes were identified: symptoms and functional limitations, child and family activities, emotional health, and the families' overall approach to managing health.

Regarding symptoms and functional limitations, most parents discussed decreased range of motion or mobility issues, pain, and swelling or inflammation, while most youth discussed decreased range of motion or mobility issues, pain, and stiffness. The severity of symptoms, including the amount of pain, swelling and stiffness, affected every day functioning, including walking, sitting with their legs crossed, and rising in the morning.

Juvenile idiopathic arthritis (including appointments and treatment) impacted child and family activities. These included functional

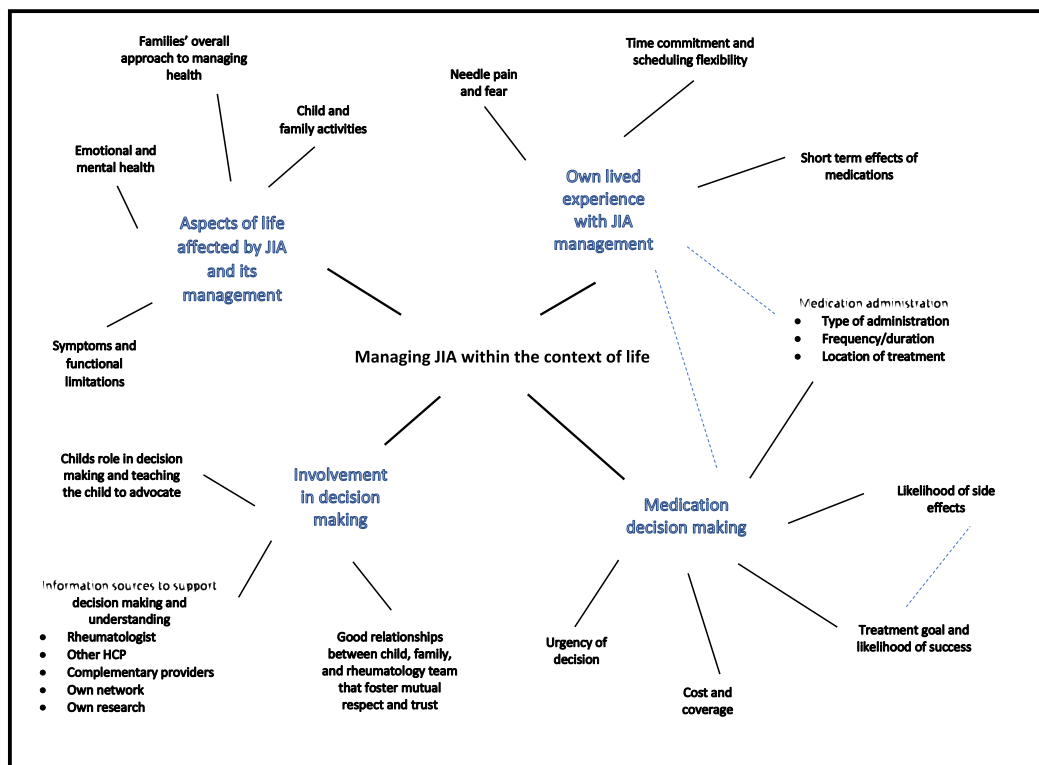


FIGURE 1 Mind map of managing Juvenile idiopathic arthritis (JIA) within the context of life. Circles correspond to themes, while squares correspond to sub-themes. Solid lines illustrate relationships within a theme, and dashed lines illustrate relationships across themes/sub-themes.

limitations impacting leisure sports, medication regimes impacting travel, and overall impacts on parental employment. All youth described the impact of their JIA on various activities (most often dance or various sports). In some cases, youth were unable to participate in an activity, while others were able to participate, but JIA did have an impact. Storage of medication and ensuring adequate supply if complications arise added a layer of complexity to travel for parents. Parents miss work to take care of their child with JIA, to take their child to appointments, and for their child's JIA treatment, and for some this created financial strain.

Parents and a few youth discussed the emotional and mental health aspects of the JIA. Some youth mentioned difficulty talking about the things they have given up because of their JIA, while for others it was the treatment of JIA that caused emotional difficulty including fear and pain related to needles and dreading treatment. This is further described in the medication administration sub-theme. Parents identified the emotional and mental health aspects of JIA, including expressing difficulty watching their child suffer.

Families had overall approaches to health management that informed their JIA treatment decisions. This was observed mostly in parents, with many describing a desire to try more natural

approaches before resorting to medications, while most youth did not discuss this.

3.2.2 | Lived experience with Juvenile idiopathic arthritis management

Lived experience managing JIA was an important sub-theme that informed medication decision-making (Table 2). Previous treatment decisions provided experience from which both parents and youth drew when making current decisions, and in thinking about the future. This included the type of medication and any side effects experienced, aspects of medication administration that worked or did not work well, and the amount of time the treatment required and how disruptive the scheduling was to their life. The experience that participants had with JIA treatment included the following sub-themes: short-term medication side effects, needle pain and fear, and time commitment and scheduling flexibility.

Short term side effects mentioned by participants included the characteristic burn of some biologics (especially by youth) as well as nausea associated with other medications. Some parents described

TABLE 1 Supportive quotes for aspects of life affected by Juvenile idiopathic arthritis (JIA) and its management theme.

Sub-themes	Quotes
Symptoms and functional limitations	<ul style="list-style-type: none"> “She had to, to learn how to walk again when she was the age of four” (#1, parent) “Like if I bend [the knee] too far, like it starts hurting a little bit. Like there's a limit to it” (#2, youth)
Child and family activities	<ul style="list-style-type: none"> “We all ski and so one thing that he always wanted to be was, was a snowboarder instead of a skier but it's just way too hard on his body.” (#20, parent) “You can't snowboard when both your knees and ankles are sore and whatever. So when that happens, I think he gets a little bit down” (#19, parent)
Emotional and mental health	<ul style="list-style-type: none"> “When it comes to, like, things I've had to give up, because of it, and things I've had to, like, let go of doing, and, like, things I had to kinda just, like, let go of, I don't really like talking about that.” (#23, youth) “I think his, his understanding of pain and his tolerance of it is so high because he's had so much since he was so little, that you know, it was—it was awful as a mother to watch him suffer and not be able to do anything.” (#19, parent)
Families' overall approach to managing health	<ul style="list-style-type: none"> “I think there's people that wouldn't do the meds because they think it's so bad. Like we're not those people, for sure. But we definitely would prefer that we can find a more um natural solution for him” (#9, parent) “I was just wanting to look for alternatives. Is there something we can do to help her, that doesn't require uh medication or, or strong medication?” (#10, parent)

TABLE 2 Supportive quotes for lived experience with Juvenile idiopathic arthritis (JIA) management theme.

Sub-themes	Quotes
Short term effects of medications	<ul style="list-style-type: none"> “When it goes in... it kind of just sits on my skin and like almost burns” (#21, youth) “Automatic—as soon as he saw it, he would be nauseated. He just developed such an aversion to it” (#19, parent)
Needle pain and fear	<ul style="list-style-type: none"> “You just mentioned a needle, and she started crying” (#22, parent) “I was very like frightened about needles at that time” (#2, youth)
Time commitment and scheduling flexibility	<ul style="list-style-type: none"> “For the IV, um at the hospital. And at first I was like, what do you mean, we have to come to the hospital for like 4 hours every 4 weeks? Like it seemed daunting. And they're only open Mon to Fri” (#6, parent)

anticipatory nausea, even the sight of the medication-induced nausea in their child. Parents and youth shared ways they tried to minimise the burn of injections, including mixing it with local anaesthetic.

Experiences shared also included the pain and fear associated with needles. Parents and youth alike shared fears about administering needles. For some youth, even the mention of a needle brought them to tears. Most youth described pain associated with the needles, while some also said that over time, they became used to it and were no longer bothered. Parents that talked about their child and injections most often used the word "hate", saying that their child hated needles. Participants discussed using antihistamines, ice packs, having someone other than the youth do the injection, and allowing the medication to come to room temperature before injection to mitigate the pain.

Some participants, mostly parents, described the lengthy time commitments associated with treatments. This included monthly hospital visits for 4 hour intravenous (IV) infusions, while others also had the added commute of travelling from outside the city. Parents noted that appointments could only be scheduled during regular business hours on weekdays and this meant youth missing school and other activities and parents missing work. Some participants had experience switching treatments administered in their own city or even at home and parents expressed that it was easier for them. The location, frequency, and duration of treatment is further described in the medication administration sub-theme.

3.2.3 | Medication decision-making

There were several factors that youth and parents considered when making decisions about medications, including starting, stopping, and switching medications (Table 3). These considerations included treatment goal and likelihood of success, likelihood of side effects, urgency of the decision, medication administration and cost and coverage.

Treatment goals and likelihood of success were prominent in medication decision-making, especially at the time of diagnosis, or if current treatment was ineffective. Treatment goals were predominantly discussed by parents and most often related to the youth's QoL including goals of symptom management or remission. Some parents were willing to try anything if the treatment helped the youth achieve a better QoL. The perceived likelihood of success was based on information parents collected from sources such as the rheumatologist.

The likelihood of side effects was another prominent consideration and was often weighed against the likelihood of success. Participants wanted to know the potential side effects when making a decision and for some, this was influenced by previous experience with short-term side effects such as nausea or injection-related discomfort. The majority of youth were concerned about short-term side effects, while long-term side effects were not often mentioned. Most parents wanted to be aware of potential long-term side effects, citing the risk of cancer, infertility, and multiple sclerosis as concerns.

Another consideration for some was the urgency of the decision. Some parents felt that their child's JIA was so severe that they had to

act immediately. They did not have time to process the decision or consider the long-term effects of the medication. Sometimes, they also felt that there was a single best option, so there was really no decision to be made. This feeling of urgency when deciding about a medication was mentioned only by parents of children whose complexity of journey was medium or high.

Medication administration encompassed the type of administration, the frequency and duration, and the treatment location. The type of administration (oral, subcutaneous injection by disposable syringe, injection pen, or IV infusion) was a consideration for most youth, and about half of the parents. Previous experience with any needle pain or fear informed their decisions about the type of administration. For some parents, it was their own reservations on injections, while for others, it was about their child's fear. The frequency and duration of the treatment were often considered together. For example, some youth prefer a more painful needle less frequently than a less painful needle more frequently. The duration of treatments greatly varied as some participants did their own injections at home, while others had to travel some distance to a major city to receive an IV infusion. Previous experiences with time consuming treatments informed future decision-making, with most aiming to find a less time-consuming treatment that was as effective. The duration was related to the location of the treatment. Some participants had experience moving from a treatment at a hospital or clinic to one at home and most parents expressed an overall preference for home options. Some youth preferred the IV infusions over injections, even if it meant they were unable to do the treatment at home, because of fear and/or pain associated with the needle itself or the short-term side effects.

Parents and some youth noted the costly nature of JIA treatments. Most of the costs were currently covered in one way or another, including group benefit plans, co pays, non-group benefit plans, and compassionate programs. Some parents had trouble obtaining coverage initially and had experience with compassionate coverage through a drug company. Some parents said that if costs had not been covered, they would have found the money, though not all participants had this ability. One parent left their job to care for their child with JIA, losing their benefits in the process, and had to navigate purchasing health insurance to cover medication costs. Most youth did not talk about cost and coverage, and of the ones who did, it was usually a situation where the youth was aware of challenges in obtaining coverage.

3.2.4 | Involvement in decision-making

Parents and youth described their involvement in treatment decision-making and what they found helpful (Table 4). These included the child's role in decision-making and teaching the child to advocate, relationships that foster mutual respect and trust, and information sources to support decision-making and understanding.

The child's role in decision-making within the family was explicitly described by parents and youth, with some parents also

TABLE 3 Supportive quotes for medication decision-making theme.

Sub-themes	Quotes						
Treatment goal and likelihood of success	<ul style="list-style-type: none"> • "I was willing to try anything and make him feel that the pain would go away. So everything they suggested, I would be like, well, if it'll make the pain go away, then we'll try it." (#6, parent) • "I just figured, you know what, this is um, what the experts know, and, and it's still new... but you know what, they were getting success... lots of people were um, getting results from it" (#12, parent) 						
Likelihood of side effects	<ul style="list-style-type: none"> • "It was uh, a brand new medication and uh, we didn't know what to expect, what the side effects would be." (#1, parent) • "When I begin a medication I want to know the side effects." (#16, youth) 						
Urgency of decision	<ul style="list-style-type: none"> • "Dr. ____ said to me... if you don't want her to be walking with a cane when she's older, due to like a wrecked joint, then you're going to have to do something about it... And I remember that was very impactful for me." (#11, parent) • "I didn't really feel like we had any other options... my main concern was getting her well, and, you know, and doing whatever we needed to do" (#22, parent) 						
Medication administration	<table border="0"> <tr> <td>Type of administration</td> <td> <ul style="list-style-type: none"> • "It was a big decision for me, because obviously the mental aspects with him getting injections... I just thought administering that would be hell... I was really nervous about the whole injection thing" (#5, parent) • "Giving him a needle once a week seemed very intimidating. Um, he was very intimidated by it." (#9, parent) </td> </tr> <tr> <td>Frequency/duration</td> <td> <ul style="list-style-type: none"> • "It was like between one that wouldn't hurt as much every 1 week, like every week, and between one that would sting a little bit more every 2 weeks. And I think I just didn't want to get a needle every week" (#4, youth) • "We kind of like, do you want to take, get a needle like once a week or twice a—once every 2 weeks, right? And he did, actually choose like every 2 weeks." (#7, parent) </td> </tr> <tr> <td>Location of treatment</td> <td> <ul style="list-style-type: none"> • "I think we stopped that because... it was a concept of, you know, coming every week. We live pretty far. It's 30--30 min away. So I think that also had something to do. Like coming every week. You know, it was a little time consuming." (#16, youth) • "At the beginning it was, we had to go to the children's hospital because they wanted to monitor. But once we got clearance to do it at um, the [local] hospital, it was so much better because you didn't have to drive that 2 hours there and back, and it's just the same thing, just a different hospital." (#18, youth) </td> </tr> </table>	Type of administration	<ul style="list-style-type: none"> • "It was a big decision for me, because obviously the mental aspects with him getting injections... I just thought administering that would be hell... I was really nervous about the whole injection thing" (#5, parent) • "Giving him a needle once a week seemed very intimidating. Um, he was very intimidated by it." (#9, parent) 	Frequency/duration	<ul style="list-style-type: none"> • "It was like between one that wouldn't hurt as much every 1 week, like every week, and between one that would sting a little bit more every 2 weeks. And I think I just didn't want to get a needle every week" (#4, youth) • "We kind of like, do you want to take, get a needle like once a week or twice a—once every 2 weeks, right? And he did, actually choose like every 2 weeks." (#7, parent) 	Location of treatment	<ul style="list-style-type: none"> • "I think we stopped that because... it was a concept of, you know, coming every week. We live pretty far. It's 30--30 min away. So I think that also had something to do. Like coming every week. You know, it was a little time consuming." (#16, youth) • "At the beginning it was, we had to go to the children's hospital because they wanted to monitor. But once we got clearance to do it at um, the [local] hospital, it was so much better because you didn't have to drive that 2 hours there and back, and it's just the same thing, just a different hospital." (#18, youth)
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Cost and coverage	<ul style="list-style-type: none"> • "My husband's um, benefits pay for most of it. And then we would have a 20 percent co-pay... and so actually [the company] does do the co-pay for us. So we don't pay anything for it" (#7, parent) • "I'm sure my mom's told you, it was really difficult to get, even the [drug] sorted out with the, um, benefits company... trying to figure out how to get it, in the first place... I've always been pretty conscious of that sort of thing... so it was, like, not being able to control any of it, but also knowing exactly what's happening, was kind of difficult" (#23, youth) 						

describing teaching their child self-advocacy. Youth involvement depended on the child's age and development at the time of the decision and evolved over time. Some youth described changes in how their rheumatologist included them in discussions and decisions over time. Decisions made when children were preschool or elementary age were primarily made by parents. Some parents discussed how they teach their child how to advocate for themselves in a medical setting as they get older, to prepare them for their ultimate transition to adult care.

Good relationships between the child, family, and rheumatology team, characterised by mutual respect and trust, emerged as important. Most parents and youth trusted their rheumatology team and by extension trusted their recommendations. Some did not feel the need to conduct their own research or look to other sources of information when the rheumatologist recommended something because they explicitly trusted the rheumatologist's professional opinion. Some parents had experiences that had eroded some of that

trust and mutual respect, specifically when it came to exploring complementary treatments. Some parents found they were met with resistance, and the lines of communication about complementary options closed. These parents expressed that they wished they could have an open dialogue with their rheumatologist and the clinic team about complementary options.

Participants' decision-making and understanding was supported by several information sources including rheumatologists, other healthcare providers, complementary providers, their own network, and their own research. For both parents and youth, the rheumatologist was a primary source of information, and this was connected to their relationship with the rheumatologist. Conducting their own online research was another primary source for some parents, while others tried to avoid this. Another source of information for some were other healthcare providers, including family doctors, pediatricians, and pharmacists. Some parents also consulted complementary providers, such as naturopaths, for information. Both parents and

TABLE 4 Supportive quotes for involvement in decision-making theme.

Sub-themes	Quotes	
Good relationships between child, family, and rheumatology team that foster mutual respect and trust	<ul style="list-style-type: none"> • “I really trust our rheumatologist. So if she says something, I don't need to go research it to try and find something for or against what she says.” (#3, parent) • “Like having conversations around auto-immune and specific diets and alternative treatments and then there was—there, I was very sternly told by one of the rheumatologists that there is no room for any of that... They're not taught, I get that. Um, but to have it shut down so abruptly, uh wasn't helpful.” (#17, parent) 	
Information sources to support decision-making and understanding	Rheumatologist	<ul style="list-style-type: none"> • When asked where they go for information: “We would usually talk to our rheumatologist” (#4, youth)
	Own research	<ul style="list-style-type: none"> • “When I did all of that research, then I was able to understand the mechanisms they were shifting within his immune system” (#17, parent)
	Other HCP	<ul style="list-style-type: none"> • “We got all the information with her paediatrician at the time” (#1, parent)
	Complementary providers	<ul style="list-style-type: none"> • “We do uh have a naturopath that we go to. Um, so we did talk to her more for you know, her input, and kind of to understand uh what [the medications are]” (#10, parent)
	Own network	<ul style="list-style-type: none"> • “Injections wise, my older sister, she's a—she's a registered nurse. So I ask her sometimes for stuff like that.” (#15, youth)

youth consulted their own networks for information and support. For youth, their parents (and sometimes other family members) were a primary source of information in addition to their rheumatologist. The parents' network included friends, family, and sometimes social media groups. The network included those with experience of JIA or its treatment, had medical or complementary expertise, or were a trusted advisor for making decisions.

4 | DISCUSSION

This study explored the JIA management experience of youth and their parents. The findings indicate that the management of JIA (outside of the initial diagnosis, or in the context of a flare) is not central to the lives of participants; rather, they manage JIA within the context of their life. Living life and ensuring the child can live as full and 'normal' a life as possible is central. Four main themes encompassed managing JIA within the context of their life. These are aspects of life affected by JIA and its management, lived experience with JIA management, medication decision-making, and involvement in decision-making.

The findings add two decision-making dimensions to those reported in the literature: first families' overall approaches to managing their health that they bring to JIA management decisions, and second the sense of urgency surrounding decisions that those with complex journeys often reported.

4.1 | Aspects of life affected by Juvenile idiopathic arthritis and its management

Eyckmans et al. interviewed patients with JIA aged 18–30 years and similarly identified functional limitations and their impact on

activities and the emotional and mental health aspects of growing up with JIA (Eyckmans et al., 2011).

Parents' often described the desire to try more natural approaches and this was not described in the aforementioned studies on JIA treatment decisions for parents and youth (Burnett et al., 2012; Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Lovell, et al., 2013; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013). However, Rouster-Stevens et al. describe the experience of use of complementary and alternative medical therapies in JIA (Rouster-Stevens et al., 2008).

Participants had lived experience with the JIA they drew on when making decisions. Drawing on prior experience was not explicitly discussed in the studies on JIA treatment decisions (Burnett et al., 2012; Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Lovell, et al., 2013; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013), however a study that focused on decisions about stopping medications similarly described past experiences informing future decision-making (Horton et al., 2021).

4.2 | Medication decision-making

Treatment goals related to QoL was consistent with some of the studies on JIA treatment decisions where the impact a medication could have on QoL was a prominent consideration (Burnett et al., 2012; Lipstein, Dodds, et al., 2016; Lipstein, Muething, et al., 2013). Likelihood of success was based on information collected on potential effectiveness was consistent with studies on JIA treatment decisions which also found expected effectiveness was an important consideration (Burnett et al., 2012; Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013). Likelihood of side effects was another prominent consideration consistent with studies

on JIA treatment decisions (Burnett et al., 2012; Lipstein & Britto, 2015; Lipstein, Dodds, et al., 2016; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013). It was often weighed against likelihood of success which was also consistent with the literature (Lipstein & Britto, 2015; Lipstein, Lovell, et al., 2016).

Another consideration identified in this study but not in previous literature was the sense of urgency where they felt like their child's JIA was so severe that they had to act now.

Participants considered factors related to medication administration if there were two or more treatment options that were equally likely to be effective. The type of administration was also found to be a consideration by other studies on JIA treatment decisions (Burnett et al., 2012; Lipstein, Dodds, et al., 2016; Lipstein, Muething, et al., 2013). Frequency and duration were previously identified (Lipstein, Dodds, et al., 2016), and so was the location of treatment (Lipstein, Lovell, et al., 2016). The cost of medications, emphasising potential future costs in the context of their child transitioning into adulthood, was also consistent with another study (Burnett et al., 2012). Currently, cost was not a major consideration for these parents because they had been able to obtain sufficient coverage.

4.3 | Involvement in decision-making

Trust has long been identified as a key component of effective therapeutic relationships within chronic disease and it is recognized that those relationships evolve over time (Robinson, 2016; Thorne & Robinson, 1989). Participants' desire to explore complementary treatments were often met with resistance from the rheumatology team, which eroded trust in some cases. Consistent with other studies on decision-making in JIA, we found that the rheumatologist was a primary source of information for all participants, with youth also often looking to their parents for information (Lipstein, Lovell, et al., 2013; Lipstein, Lovell, et al., 2016; Lipstein, Muething, et al., 2013). Many parents also described consulting the Internet and their network which was consistent with the literature (Lipstein, Lovell, et al., 2013).

All the decisions about JIA and its management made by parents have an impact on the child and their life at the centre. Initially potential effectiveness is weighed against potential side effects as well as administration features of the medication and as the family gains experience living with JIA and with the treatments their experience influences the features that become important when making medication decisions. Managing the illness is usually not central to the family's life; rather, the youth's overall health and wellbeing and the ability to live a good life with JIA is central. This finding provides an opportunity to focus on supporting families in how they want to manage JIA within the context of their life. For some families, this may mean supporting them with complementary treatments in addition to what the rheumatology team recommends to foster trusting relationships. For others, this may discontinue an effective treatment which has a negative impact on their child's mental health and QoL. These shifts would be a meaningful step towards enhancing person- and family-centred care in JIA (Santana et al., 2018; Uniacke et al., 2018).

4.4 | Strengths and limitations

This study had several strengths including centring youth and their parents as experts in living with JIA. Interviews facilitated an in-depth understanding of participants' experience living with JIA, which may not have been achieved through other methods such as focus groups. The interviewer was not part of the youth's JIA care team and as such parents and youth were able to provide honest and raw thoughts. Youth and parents were separately interviewed, allowing both parties to share their experience without the other present. Two analysts coded and analysed the interview data independently before meeting to ensure consistency to enhance the trustworthiness of the data. The study also had potential limitations. Parents and youth did not have input on interview guide development; however, the guide was open ended and thus participants shaped the direction of the interviews and ultimately the findings. In most cases, a parent and child were interviewed from the same household; however, their interview data were separately analysed, and thus it is possible that their viewpoints were represented more than those where only one member (parent or child) was interviewed from a household. At the same time, parent and child opinions and experiences may differ despite living in the same household. Participants were recruited from a single children's hospital in Canada and demographic characteristics were limited and as such, it could be difficult to assess whether all the findings are transferable to other settings. We only interviewed one father and it was not an ethnographically diverse sample.

5 | CONCLUSION

This research contributes to the limited understanding of JIA management from the perspective of those living with the disease. The findings reinforce the need to incorporate what matters most to children and their families in their life context when determining how to manage JIA. This epitomises the shift required to fully practice person- and family-centred care.

AUTHOR CONTRIBUTION

All authors contributed to the study conception and design. Data collection was conducted by GM, and analyses were performed by BK and GM. The first draft of the manuscript was written by BK, GRC, GM and DAM. All authors commented on the manuscript, and all authors read and approved the final manuscript.

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CONFLICT OF INTEREST STATEMENT

DAM reports non-financial support from consultancy (Illumina) and ISPOR, and personal fees from Analytica outside the submitted work; RSMY reports consulting fees from Novartis and Lilly outside the submitted work. SJV reports grants and personal fees from SOBI and Novartis during the conduct of the study; JFS reports consulting fee from Amgen outside the submitted work; all others (GRC, BLK, SMB, NMW, MMAK, GM) have nothing to disclose.

DATA AVAILABILITY STATEMENT

The raw data from this study can not be shared as the ethics approval and participant consent did not allow for this.

ETHICS STATEMENT

Ethics approval was obtained from The Conjoint Health Research Ethics Board at the University of Calgary (REB19-0360) in April 2019. Informed verbal consent was obtained prior to data collection.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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APPENDIX 1

Interview Guides

Parent Interview Guide

Introduction

Interviewer(s) to identify themselves.

We are working with XXX at the XXX on a research project to understand how children with arthritis and their parents make decisions about starting and reducing biological medications.

As you know, biologics are a relatively new treatment for children with arthritis. Once a child has been in remission for a while, there is the possibility of tapering and stopping the medication. There is little known yet about the best way of doing this. Understanding how children with arthritis and their parents make medication decisions then is really important, so your decision-making can be better supported?

Review the consent form and ask if there are any questions. We will be audio-taping the conversation and deleting the files once transcribed and verified.

Do you agree to participate?

Questions

To begin with, could you please tell me a little bit about your experience with your child's arthritis, beginning when you and/or your child knew that something was wrong but you did not know what it was? What has this journey been like?

< I thought it might be good to start with something like this, as it seems from the articles that issues like how severe the arthritis has been (e.g., # of jt.'s involved; jt. Erosion; how long it took to achieve remission; how long the child was in remission).>

Possible prompts:

- Where you sought help
- How long it took for your child to get a diagnosis
- The kinds of treatments tried, and how long it took to find one that worked
- How long has your child been in remission
- Etc.

Now I'd like to talk about your experience starting a biological medication

1. What were your initial thoughts about biologics as a treatment for arthritis?
2. What kinds of things did you think about or consider when starting your child on a biological?

Possible prompts:

- Treatment effectiveness (e.g., increase child's ability to participate in daily activities including play & school; reduce child's pain)?

- Medication costs?
- Possible side effects?
- How is medication given/administered and by whom (injection, IV)?
- Do you have to travel to have the medication administered?
- How frequently is the medication given?
- Other?

3. Where did you turn for information and/or advice when making a decision about trying a biological?

Possible prompts:

- your child's arthritis doctor/rheumatologist; your child's paediatrician or family doctor; other health professionals; family; friends; online sites; other parents/kids with arthritis; online sources; social media?

4. How did you involve your child in these decisions?

5. Anything else you want to say about starting your child on a biological?

Now, I'd like to talk about reducing or stopping biological treatments.

As we noted previously, once a child has been in remission for a while, there is often the possibility of reducing and stopping biological medication. There is little known yet about how best to do this, and children's and parents' preferences.

1. Have you had any experience reducing or stopping biological treatments? If yes, please describe.
2. If no, what are your thoughts about reducing or stopping biological treatments?
3. What are the things/factors you would/did consider when making a decision about reducing or stopping biologics?

Possible prompts:

- Potential benefits/good things?
- Potential concerns/bad things?
- Weighing these potential benefits and concerns (i.e., the child's arthritis might flare, but there are also risks to staying on the biologics for a long time)?
- Past experiences with achieving remission; amount of joint damage???
- Any preferences around the tapering and stopping protocol (e.g., reduce dose, decrease frequency of/space out doses, stop all at once)?
- 4. What kinds of support would you and your child need to be willing to give this a try?
- 5. How did/would you involve your child in this decision-making process?
- 6. Anything else you want to say about reducing or stopping biological treatments?

Possible prompts:

- Regular monitoring, and by whom?

Closing

Is there anything else you want to talk about your child's arthritis and/or treatment? Anything that I didn't ask you directly about? Anything that has come to mind?

Thank you!

Youth Interview Guide

Introduction

Interviewer(s) to identify themselves.

We are working with a team of researchers at the XXX on a research project to understand how children with arthritis and their parents make decisions about starting and reducing biological medications.

As you know, biologics are a relatively new treatment for children with arthritis. Once you've been in remission/been well for a while, there is the possibility of reducing and then stopping the medication/treatment. We do not know a lot yet about the best way of doing this. This makes it really important to understand what matters to children with arthritis, and their parents.

Review the consent form and ask if there are any questions. We will be audio-taping the conversation and deleting the files once transcribed and verified.

Do you agree to participate?

Questions

1. Could you tell me a little about yourself. What school do you go to? What kinds of things do you like to do?

Possible Prompts:

- read, play video games, listen to music, draw
- play sports, dance, play an instrument
- hang out with your friends
- play with your pets

2. How does having arthritis affect your life, and the things you like to do [refer back to things talked about in response to the first question]?

Now I would like to talk with you about your arthritis treatment. I understand that you <briefly describe treatment, based on interview with parent>

3. Can you tell me a little bit about making the decision to start that treatment. What kinds of things did you think about? What was important to you?

Possible prompts:

- Treatment effectiveness (e.g., less pain; less tiredness; able to do more things that I like; able to do more with my friends; able to go to school more easily)?
- Possible side effects?

- How is medication given/administered and by whom (injection, IV)?
- Do you have to travel to have the medication administered?
- How frequently is the medication given?
- Other?

4. Who helped most in answering any questions you had about starting this treatment? Where did you get the information you needed?

Possible prompts:

- Your family doctor or paediatrician
- Your arthritis doctor
- Other health professionals (e.g., nurse, physiotherapist)
- Your parents or others in your family
- Your friends
- Social media
- The Internet

5. What have been the best things about this treatment? The worst things?

Now, I would like to talk with you about reducing or stopping biological treatments.

We are beginning to learn that once you have been well/in remission for a while, you can sometimes reduce and stop biological medication/treatment. We do not know a lot yet about the best way of doing this. This makes it really important to understand what matters to children with arthritis, and their parents.

7. Have you had any experience reducing or stopping your biological treatments? If so, could you tell me a little about how that worked for you?

Possible prompts:

- What went well
- What didn't go well

8. If no, what are your thoughts about reducing or stopping your biological treatments?

9. What are the kinds of things you wanted/would want to know when making a decision about reducing or stopping biologics?

Possible prompts:

- Possible good things about trying this
- Possible bad things about trying this
- How long it took to find a treatment that worked well for you
- The best way to reduce or stop the treatment (e.g., reduce dose, decrease frequency of/space out treatments, stop it all at once)

10. Anything else you want to say about reducing or stopping biological treatments?

Closing

Is there anything else you want to tell me that I haven't asked you about yet?

Thank you!

APPENDIX 2 Participant Demographics.

Respondent observation	Parent interviewed	Parent #	Youth interviewed	Youth #	Youth age	Complexity of journey
1	√	1	√	2	16	Medium
2	√	3	√	4	13	High
3	√	5	X	NA	7	Medium
4	√	6	X	NA	11	High
5	√	7	√	8	15	Low
6	√	9	X	NA	13	Medium
7	√	10	X	NA	7	Low
8	√	11	√	13	14	Medium
9	√	12	X	NA	12	Low
10	√	14	√	15	15	Medium
11	X	NA	√	16	17	High
12	√	17	√	18	15	High
13	√	19	X	NA	9	High
14	√	20	√	21	14	High
15	√	22	√	23	16	High