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Developing a patient-educator program for adolescents with juvenile arthritis: exploring motivation sources, barriers, and facilitators

Marie-Paule Morin,[1] Aimun Qadeer Shah,[2] Maria Mylopoulos,[3] Marie-Pascale Pomey,[4] François Bowen,[5] Lawrence Grierson,[2] Claude Julie Bourque[6]

[1]CHU Sainte-Justine, Université de Montréal, Québec, Canada; [2]Department of Family Medicine, McMaster University, Ontario, Canada; [3]The Wilson Centre for Research in Education, University of Toronto, Ontario, Canada; [4]Department of Management, Evaluation and Health Policy, Université de Montréal, Québec, Canada; [5]Département de Psychopédagogie et D'andragogie, Université de Montréal, Québec, Canada; [6]Dép. de Médecine de Famille et Médecine D'urgence, Université de Montréal, Québec, Canada

Correspondence to: Marie-Paule Morin, MD; Immunoallergy and Rheumatology, Department of Pediatrics, CHU Sainte-Justine, 3175 Chemin de la Côte Sainte-Catherine, Montréal, Québec, H3T 1C5; email: marie-paule.morin@umontreal.ca

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Abstract

Background: Patients can be valuable contributors to medical education, offering nuanced perspective and guidance, based on lived experience. While numerous training programs have integrated adult patients in this manner, very few have engaged adolescent patients. Recognizing adolescent educators may be particularly helpful in teaching pediatric conditions, this study appraises the potential for including those with juvenile arthritis in pediatric rheumatology training.

Methods: Using an exploratory qualitative approach, we conducted semi-structured interviews with adolescents with juvenile arthritis receiving treatment at two tertiary-care pediatric centres in Canada about the motivations, perceptions, facilitators, and barriers that influence their engagement as patient educators. The interview transcripts were analyzed using an iterative qualitative descriptive method.

Results: Participants (n = 19, aged 13-18) identified intrinsic factors, such as learning about their condition and socializing with peers, and extrinsic factors, such as helping students learn and promoting greater disease awareness, as relevant drivers for participating as patient educators. They pointed to balancing school and medical appointments, transportation, and discomfort with sharing personal experiences in large groups as barriers. Parental support, accruing volunteer hours, and engaging health professionals in the teaching sessions were seen as facilitators that could meaningfully enhance the relevance and impact of adolescents' contributions to medical education.

Conclusion: Adolescents with juvenile arthritis are motivated to participate as patient educators. Understanding the factors that promote their involvement supports the development of training initiatives involving adolescents that are likely to be successful and sustainable.

Résumé

Résumé français à venir.

Introduction

The field of rheumatology has had a long tradition of active patient involvement in medical training, which precedes its wider uptake in health professions education.[1,2] Referred to as patient-educators, these individuals use their illness experiences to foster health science student learning in the areas of physical examination, communication, and patient-centred care.[3] In rheumatology, they are engaged to help students master the musculoskeletal physical examination and understand the impacts of chronic rheumatism.[3-7] These sessions allow students to palpate joints and receive feedback on the level of discomfort or pain experienced by patients.[3] Discussions with patient-educators about the impact of the disease on their lives also helps place the patient perspective at the heart of practice.[8-10] Medical students report several factors that make these teaching sessions valuable, especially their realism and authenticity. Patient-educators also benefit, as their participation fosters improved self-esteem, a better understanding of their medical condition, a deeper understanding of the doctor-patient relationship, and a greater sense of participation in their own care process.[10-13]

Until recently, patient-educator programs have primarily engaged adults. However, adolescents with rheumatological conditions have also signaled an interest in contributing to these initiatives.[14,15] This is relevant as physicians report discomfort in performing pediatric musculoskeletal physical examinations[16] and this skill often gets inadequate attention in the musculoskeletal curricula.[15,17,18] Accordingly, we have embarked on a project to develop a training program that involves adolescents with juvenile arthritis as patient-educators. As a foundational step in this process, the present study seeks to explore adolescent patients' motivations for participating in a patient-educator program, as well as the barriers and facilitators that may influence their engagement.[8] While many adolescents are likely to have the capacity to participate as patient-educators, we also anticipate that that factors related to their relative lack of professional experience, rigid school schedule, and overall reliance on parental involvement will coalesce to influence their willingness and constrain or promote their involvement. Determining such factors early in the development process will serve to optimize the integration and sustainability of adolescent patients into the program,[10,19] while also extending perspectives on patient-educators to better include adolescents.

Methods

Theoretical orientation

We initiated our investigation with deep consideration for Ryan and Deci's (2000) *Self-Determination Theory*,[20,21] which contemplates two main forms of motivation: *intrinsic* and *extrinsic* motivation. *Intrinsic motivation* is defined as the engagement in an activity for the pleasure and satisfaction of participating. *Extrinsic motivation*, on the other hand, is characterized in terms of goal-oriented activities. Notably, this theory spotlights the relevance of autonomy, competence, and feeling connected in influencing one's interests and behaviours. Given the exploratory nature of this study, Self-Determination Theory provided a useful framework for reflecting on the reasons why an adolescent may or may not be motivated to participating in a patient-educator program. It promoted a qualitative methodological approach; ensured that our data collection probed adolescents' perspectives on control, effectiveness, and relatedness to others; and it offered a conceptual grounding for organizing the meaning participants attributed to their experiences within our analysis.

Study design

We utilized a qualitative descriptive approach rooted in the constructivist paradigm.[22-25] This methodology is particularly well-suited for studies aiming to understand participant experiences in a manner that remains close to their own language and perspectives.[24] Qualitative description allows for both flexibility and rigor in data collection and analysis.[26,27] It is especially appropriate when the goal is to provide a rich, straightforward account of a phenomenon.[23,25] In our study, this approach enabled us to generate descriptive insights into how adolescents perceive their potential involvement in a patient-educator program, situated within the context of their lived experiences.

Recruitment

Participants were recruited from two large pediatric tertiary-care centres (CHU Sainte-Justine; Toronto SickKids Hospital) in two Canadian provinces; Quebec and Ontario respectively. These centres were chosen because of the high throughput of patients with juvenile arthritis. We used purposive sampling methods, which is the process of selecting a small number of important cases that are likely to yield the most information and have the greatest impact on the development of knowledge.[28] We asked practicing rheumatologists to identify, from within their clinic, adolescents with a diagnosis of juvenile arthritis who they believed might be interested in contributing to a patient-educator program. The diagnosis of juvenile arthritis was defined according to the International League of Associations for Rheumatology (ILAR) classification criteria.[29]

Data collection

The primary data were derived from short semi-structured interviews with individual participants.[30] We chose interviews because they are particularly useful for collecting nuanced data about personal experiences, perspectives, and motivations, which were key targets of the research study. The interviews were conducted by a practicing pediatric rheumatologist and doctoral trainee in medical education research (MPM), in-person, in a hospital room, except for three adolescents who lived more than a 30-minute drive away from the hospital. In these exceptional cases, the interviews were conducted in public spaces (e.g., a café) near their residence. The interviewer had no prior relationship, professional or otherwise, with any of the participants. Only one of the interviews was conducted with a parent present. The interview guide was divided into three sections. The first served to describe the general role and activities of a patient-educator. The second posed questions that explored their motivations for becoming patient-educators and perceptions on the role and function of the physical examination. The third focused on the potential structure of the patient-educator program, including possible barriers and facilitators to their engagement. All interviews were digitally recorded in audio format and transcribed in full, removing identifying participant data.

Data analysis

We analyzed the transcripts via an unconstrained deductive approach,[31] which was sensitized, but not bound, to the core features of Social Determination Theory. The analysis was conducted via an interactive and iterative process, whereby stages of analysis inform subsequent data collection. Once we completed the first three interviews, three members of the research team (MPM, CJB, MM) conducted in-depth individual readings of the transcripts to develop a descriptive coding framework. At this point, we modified the interview guide to include new probing questions that reflected key ideas from the early analysis.[30] For example, since some adolescents mentioned their motivation to participate in the program was to socialize, new questions were added to elicit data pertaining to this particular source of motivation in subsequent interviews. As additional data were collected, the study team met regularly to refine this framework, ensuring analytic rigor through collaborative discussion and consensus-building. To enhance consistency, we cross-referenced codes and consulted with the senior author who is experienced in qualitative methods (CJB). This process led to the development of overarching themes that captured the descriptive content of the data. We also remained attentive to contextual factors, such as the voluntary nature of participation, the in-person location of interviews, and the presence or absence of parents during interviews. These were considered during team discussions to support consistency in our data descriptions and reflect on potential biases or limitations of our analysis. Once a stable coding grid was established, one researcher (MPM) coded all remaining data using the qualitative research software NVivo 12.[32]

Ethics

The project was approved by the Research Ethics Boards (REBs) associated with CHU Sainte-Justine (Montreal, Quebec, Canada; REB 3328) and the Toronto SickKids Hospital (Toronto, Ontario, Canada; REB 1000028282). Written consent was obtained from all minor participants and their parents or legal guardians. Participants received compensation in exchange for their participation in the form of a gift certificate.

Results

Participants

We recruited 19 adolescents (14 girls, 5 boys) aged 13 to 18 years who had been living with juvenile arthritis for 2 to 11 years. Their conditions represented oligoarticular, polyarticular, and systemic forms of the disease.[29] The predominance of girls in our sample is reflective of the known epidemiology of juvenile arthritis.[33,34] Nine interviews were conducted in French and 10 in English.

Summary

Through analysis, we were able to develop two categories of participant motivation for engaging in a patient-educator program. These were intrinsic motivations and extrinsic motivations. The category of intrinsic motivations centred on the way notions of *helping themselves* and *socializing* were described by participants as encouraging their involvement as an educator. In the extrinsic motivation category, the analytic descriptions pointed to how *helping students learn* and the act of *disease advocacy* held value in encouraging involvement. Notably, the analysis revealed no purely extrinsic motivations—i.e., motivations based on submission or fear – rather this category was reflective of extrinsic motivation that involved integrated regulation.[20,21] With the motivations distilled, our analysis was also able to produce a considerable list of perceived facilitators and barriers to participants' prospective engagement as a patient-educator. These are presented in aggregate form at the conclusion of the results section.

Intrinsic motivations

Helping themselves. Our participants expressed interest in patient-education because they saw it as a way to *help themselves*. In this regard, some participants told us their motivation stems from the opportunity to learn more about their disease:

> *It would help me understand and help me go further with my disease…It would be more than what I know now.* [Translated from French] (P6, female, 13 YO)

When discussing prospective involvement as an educator, they described how they felt the experience would assist them in "know[ing] first-hand" about the tests that they undergo (P2, female, 13 YO). They described this proposition as reassuring, appreciating that involvement in an educator program may build their ability to better explain their disease and how it affects their lives to their friends and family:

> *It would be better for me to… I can actually explain it, because sometimes my friends will be like 'Well, what do you have?' I'll be like 'Oh, arthritis, I'm not really sure why. I know it's like inflammation of the joints and stuff, but I don't know what specifically.'* (P3, female, 14 YO)

They described that participation as a patient educator would also enrich their own education, with a small number reporting that they would consider such a program their first step towards a career in healthcare:

> *I think it's interesting because I also want to be a doctor when I grow up so I think it would be nice to know first-hand what they do and what I'm teaching them, I guess. (P2, female, 13 YO)*

Socializing. Motivations associated with *socializing* emphasized the appeal of connecting with peers in something new. Participants repeatedly expressed that it would be "fun" and "cool" to be "like, a mini doctor," and "part of an experience like that" [Translated from French] (P6, female, 13 YO).

They also perceived a patient-educator program as a good way to connect with other adolescents with juvenile arthritis that they "don't get to meet…very often" (P2, female, 13 YO):

> *You don't really have a way of connecting with other people who have the same disease as you, and sometimes it's hard to live with all the limitations of arthritis.* [Translated from French] (P9, female, 17 YO)

Extrinsic Motivations

Helping students improve. Several of the participants reported a prevailing need for improved pediatric musculoskeletal examinations, identifying a marked difference between the quality of exams performed by medical learners and experienced rheumatologists:

> *But I feel like [the residents] are more… I don't know, I feel like they're less… I wouldn't say 'rough'… they're less intense, they try to be more careful, but sometimes by being more careful, it's like they don't execute the movements as well.* [Translated from French] (P10, female, 17 YO)

Given this recognition that residents are still learning the skills, participants expressed that their involvement, "coming from someone who actually has arthritis, that isn't actually a doctor," would be beneficial to help their improvement (P16, male, 16YO). In this, they wished to "spare other people from [the pain]" (P15, female, 15 YO) they themselves have experienced and to make the examination process faster and "more efficient" [Translated from French] (P9, female, 17 YO).

Disease advocacy. Motivations tied to disease advocacy were raised by a small number of participants who felt that there was a general lack of knowledge about juvenile arthritis across society and that "it would be good if there was a program that made people more aware" (P1, female, 15 YO). They believed that engagement as a patient educator had the potential to draw attention to their condition.

Facilitators

Prospective facilitators included positive parental support, with several participants noting that their parents "liked the idea" (P2, female, 13 YO) and viewed it as a potentially valuable learning experience "that [would] help me and the students" (P14, female, 16 YO). The program's potential alignment with school requirements, such as meeting the requirement for mandatory high school volunteer hours, was also seen as a likely benefit, particularly for those "going to high school next year" (P2, female, 13 YO) or interested in going above and beyond "the 40 hours" (P17, male, 17 YO). Participants emphasized that adequate training on how to teach, including guidance on how to communicate effectively and a structure that was "not too complicated… (that's when teens lose interest)" (P17, male, 17 YO) would be a facilitator. A familiar location, such as the hospital they already attended, was also seen as a likely facilitator: “I’ve been here. I know my way around” (P2, female, 13 YO). Additional prospective facilitators included appropriate supervision (e.g., the presence of a healthcare professional during sessions) and a consistent group composition, which would help foster peer connection and continuity.

Barriers

Prospective barriers included the challenge of balancing participation with school and other responsibilities, especially avoiding additional absences beyond those already required for medical appointments. As one participant noted, “We already miss enough… physiotherapy and everything, it’s quite a lot” (P9, female, 17 YO). Transportation difficulties were also cited as a likely barrier, particularly for those reliant on parents or unfamiliar with public transit: “Because my parents work late and I don’t know how to bus there by myself” (P18, male, 14 YO). Finally, several participants expressed that their discomfort with teaching, including feelings of incompetence or shyness about instructing older students, and reluctance to share personal experiences, especially in group settings was a likely barrier. Some described themselves as “not very good at public speaking” (P18, male, 14 YO) or preferring to “keep things to [themselves]” (P12, male, 15 YO).

Discussion

The results of our study contribute to the literature on the development of educational programs that involve adolescent patient-educators, building on previous studies that have distilled motivations, facilitators, and barriers to adults with chronic diseases to engage in such programs.[35] The opportunity to help students and, in turn, other young patients with arthritis was identified as an important motivating factor for our adolescent participants. This motivational factor was largely based on their own illness experiences and their desire to increase awareness of juvenile arthritis, reminding us that the general public and health professionals know little about the disease.[36] Similar drivers have also been reported in adolescent patients who wish to become actively involved in research.[14,37]

While adult patients taking part in similar programs have been shown to have similar motivations,[11,38,39] many of the adolescent motivations we distilled are different from adult patients. For instance, adolescents saw the opportunity as relevant to a potential future healthcare career. This source of motivation echoes the concept of occupational identity formation, a central aspect of the process of identity development in adolescence.[40] The consistent and realistic development of occupational identity is said to have an impact on adolescents’ future well-being.[41] Further, it may reflect a desire for competence or autonomy, which are two of the basic psychological needs identified in Self-Determination Theory,[42] as participants sought to contribute meaningfully and develop skills aligned with their aspirations. Given this, it would be interesting to explore how this desire might be integrated into patient-educator programs; to promote uptake but also to provide a way for these adolescents to explore and validate their career preferences.

Moreover, the adolescent focus on socializing also differentiates them from potential adult patient-educators. Engagement in recreational activities, regardless of physical condition, allows adolescents to be part of a group that shares common goals and experiences.[43-45] This sense of belonging speaks to the importance of relatedness, another core tenet of Self-Determination Theory,[42] and suggests that fostering peer connection may be key to sustaining engagement.[46,47] When developing the program, participant socializing could be optimized through the creation of groups and the promotion of continuity in their composition.

Of course, adequate motivation is, in and of itself, insufficient to ensure engagement. While we have identified potential facilitators and barriers to participation, these should not be seen as fixed categories. Rather, they offer a practical foundation for early program design, with the understanding that such factors are likely to shift as the program evolves. Their value lies in guiding initial implementation while remaining open to adaptation through ongoing feedback and reflection. Our study highlights that parental support, in terms of approval and transportation, is likely very important. This is consistent with other studies that show patient proximity and available support with logistics are key factors for young people with juvenile arthritis to participate in leisure activities.[48,49] Accordingly, future research for the development of adolescent patient-educator programs should explore parents’ perspectives on their children’s participation. Our findings also highlight constraints associated with feelings of discomfort. We know that adult patient-educators who have participated in education programs have also experienced challenging emotions or vulnerability in sharing their experiences.[50-52] Medical education programs should therefore pay special attention to the impact that participation might have on adolescents and create mechanisms to support participants and ensure their well-being. For example, programs could consider offering structured training, small group formats, and opportunities for peer collaboration.[53,54] These strategies may help reduce anxiety, foster confidence, and ensure that participation is both meaningful and emotionally safe.[54]

Limitations

The participants in our study were from two major Canadian urban hospitals. It is possible that some perspectives may not adequately represent the opinions and experiences of adolescents from rural areas or from other provinces wherein living conditions, including the distance from hospitals, may have a different impact. Complementary studies could enrich our results through diversification of the study environments. Furthermore, our decision to recruit adolescents potentially interested in the program allowed us to obtain rich data on their sources of motivation; however, this methodological choice could also limit the list of constraints to participation identified as we did not hear from those who were considered unlikely to be interested. Additionally, knowing that adolescents' motivations for engaging in an activity (training or otherwise) can fluctuate considerably between the time of the initial decision and the actual engagement,[55] it will be important to investigate sources of motivation throughout the duration of a patient-educators program. Further, our study captures motivation as a snapshot in time; future work should consider how motivation evolves through ongoing interactions with the program and its actors, and how these dynamics might inform program adaptation and sustainability.

Conclusion

Gaining a deeper understanding of the intrinsic and extrinsic motivations, as well as perceived barriers and facilitators to engagement in a future patient-educators program, marks an innovative first step in developing educational initiatives that involve adolescents with chronic conditions. This approach allows for the integration of these factors in a program's design to stimulate sustained patient engagement and true co-development of educational activities alongside adolescent patients with a chronic disease. The imperative of patient engagement in medical education is growing and as such, understanding how to develop programs that promote patient engagement and fairly integrate their perspective is essential.

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