Empowering young people living with juvenile idiopathic arthritis (JIA) to have more purposeful communication with families and care teams: A content analysis of semi-structured interviews

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**Background** Young people living with Juvenile Idiopathic Arthritis (JIA) face a number of communication barriers for achieving optimal health as they transition from pediatric care into adult care. Despite growing interest in mHealth technology it is uncertain how these engagement tools might support young people, their families, and care teams to optimize preference-based treatment strategies.

**Objective** This study aims to examine how a novel mHealth patient support system fosters partnership between young people living with JIA, their families, and care teams.

**Method** Semi-structured interviews with young people (ages 5-15), their families, and JIA care teams were conducted using researcher-developed interviews guides. Transcribed data were qualitatively analyzed using conventional content analysis.

**Results** We conducted semi-structured interviews with 15 young people, their parents, and 4 care team members. Content analysis brought to light the potential of an mHealth Patient Support System (mPSS) to support elucidative dialogue between families and care teams. We identified four main themes: 1) *Isolation due to JIA challenges communication*; 2) *Normalizing illness through shared experience may improve adherence*; 3) *Partnership opens window into illness experiences*; 4) *Readiness to engage appears critical for clinic implementation*.

**Conclusions** A human-centered PSS design that offers JIA patients the ability to track personally relevant illness concerns and needs shows potential to enhance communication, generate consensus-based treatment decisions, improve efficiency and personalization of care.

**Practice Implications** Technology that supports continuous learning and promotes better understanding of disease management may reduce practice burden while increasing patient engagement and autonomy in fostering lasting treatment decisions and ultimately supporting personalized care and improving outcomes.
Introduction

Young people living with Juvenile Idiopathic Arthritis (JIA) face a number of communication barriers for achieving optimal health. JIA is one of the most common acquired chronic diseases during childhood and affects both short-term and long-term disability. JIA may develop at any age during childhood, and girls are more often affected than boys. Nomenclature as well as classification has been controversial. There have been discrepancies between the American College of Rheumatology (ACR) criteria for the classification of juvenile rheumatoid arthritis (JRA) and those of the European League Against Rheumatism (EULAR) for the classification of juvenile chronic arthritis (JCA). In an attempt to develop globally accepted terminology and criteria the International League against Rheumatism (ILAR) has introduced the term JIA [1]. Using these ILAR criteria, a Nordic population-based epidemiological study reported a JIA incidence of 14 per 100,000 [2]. JIA is not a single disease but rather a heterogeneous group of diseases, divided into seven different subgroups. Among these three major onset subtypes can be identified: 1) systemic JIA, a systemic form with rash, fever, and commonly perimyocarditis; 2) polyarthritis with 5 or more joints involved; and 3) oligoarthritis (or pauciarticular JIA) with 4 or fewer joints involved. Most patients belong to this latter group. JIA may develop at any age during childhood, and girls are more often affected than boys. However, sex ratios differ in various subgroups of JIA.

Among young people it can be quite painful and limiting well into adulthood with most experiencing resolution of their disease and for some it is a lifelong challenge [3]. Although the disease is self-limiting in some children, it is not possible at the onset of disease to predict which child will recover and which will have a lifelong challenge. Early diagnosis and active therapeutic interventions are essential to minimize residual deformity and disability due to irreversible consequences of the disease such as joint contractures and asymmetric bone growth, as well as vision impairment. The treatment for JIA is multifaceted and requires a combination of monitoring, physical therapy, joint injections,
medications, and sometimes surgery [4]. Although optimal treatment of JIA varies extensively by individual patient, making it highly preference-sensitive, research on preferences among young people living with JIA is minimal. A review of 27 studies found that children with JIA fear being seen as different from their peers and are interested in seeking health information to manage their own illness [3]. In other words, the perspective of the young people in these studies, whose preferences for developing autonomy around care management, has been shown in other work as well [5]. These young people are optimistic about their future, and like to have the tools to help them make informed decisions about their care and social needs.

As widely recommended, the best way to determine the most appropriate treatment options, where uncertainty is high, are through assessing patient values, priorities, and experiences as part of preference elicitation [6–8]. Research suggests that children who are actively engaged in treatment consultations with parents may improve their confidence in managing JIA into adulthood [9,10]. By continuing to support children, youth, and adolescents with information, social support, and active involvement in the management of their illness, their confidence and long-term health may improve [3]. Over the last 20 years researchers have been working on building tools to help patients with chronic conditions better communicate preferences with clinicians. Patient engagement tools like decision aids have shown that adult patients are more knowledgeable, better informed, understand their values, and may be more engaged in decision making than previously thought [11], but there is little comparable evidence for young people.

Approaches to minimize the effects of JIA on young people vary widely and their success is often very personalized to the individual. One study evaluating a decision aid for children with JIA found that the tool had high acceptability but lower efficacy, leading authors to call for more innovative approaches to using decision aids and assessing outcomes among children [12]. A review of mobile phone and tablet apps that support personal management of illness in young people found that apps for diabetes, asthma,
and chemotherapy recovery show some impact on monitoring and adherence, but the strength of
evidence is weak [13]. Others examined an online decision aid for patients with rheumatoid arthritis and
found that decision comfort and knowledge improved [14]. While these types of online tools provide a
report with patient preference feedback to share with clinicians, we were unable to find an intervention
or app designed to promote communication, partnership, or collaboration between young people,
families, and clinicians.

The benefits of using the internet to search for information related to illness and JIA are well-
known, yet the documented benefits for online peer-support for young people is less robust [15]. Recent
evidence of other applications for engaging young people in mobile applications for self-management
demonstrate high acceptability and usability [16]. There is also evidence in other fields that peer-support
has emerged naturally in online environments, where the benefits appear based on personal preferences
for use, ease of access, and interaction with others who face similar illness challenges [17]. This suggests
that online tools or applications should be meaningful to those who use them and will benefit those who
take time to engage with them online [13]. The question remains how these newer technologies may
best support young people to develop skills in self-management and treatment decision making that will
serve them into adulthood.

In addition, developing tools to support adolescent transition to long-term self-management in
JIA are needed [18]. Some point to the need to shift habits of clinician-centered problem solving to an
expanded understanding of patient experience [19,20], arguably demonstrating a shift to co-produced
care plans [21]. This mode of patient-centered care involves clinicians supporting a standardized
assessment of patients, applying guidelines to inform care, and offering non-narcotic medication
management protocols [22–24]. Other patient-centered approaches include pre-visit planning by giving
evidence-based information and advocacy tools to guide preference development, with decision making
at the point of care [25]. When it comes to developing communication skills for young people as they
transition from parent/clinician-supported decision-making models to more autonomous decision-making ones, the best approaches are less understood.

While the challenges of communicating with young people with JIA have been well described [26], a major contributing factor to reduced quality of care outcomes for young people with JIA is poor adherence to treatment [27,28]. Adolescence is a critical time for developing long-term healthy habits as adults, and while online and mHealth skill development for self-management is suggested, there is little evidence on how best to build and evaluate these skills [26].

The purpose of this study was to examine how a PSS could help improve health communication between young people, their parents, and their providers. Admittedly, while the larger goal of this research was to investigate the implementation of a mobile PSS with young people living with JIA, we determined a more immediate need to examine how this tool might ready children with chronic illness for their inevitable transition to adult care. Specifically, we explored how the PSS influenced the engagement in self-management of JIA and communication between young people, their families, and their clinical care providers.

Method

Genia (http://www.genia.se) is a mobile iOS PSS designed to establish patient, family, and care team partnerships, with an emphasis on placing the young person at the center of the decision-making process. The mPSS captures the patient experience using a series of daily observation "trackers" which allow the patient to record daily observations of living. For example, one tracker allows a patient to record how they are feeling that day. Another tracker allows a patient to record their level of physical activity. Other trackers include the patient's social interests and his or her assessment of life with family and with friends. Patient-reported daily observations enable young people to document their disease activity and preferences in real-time in-between clinical visits. Each of these daily data points is collected
into a dashboard that can be shared electronically with a patient-determined list of observers such as family or friends they can invite to their network. They can also include these dashboards in pre-visit reports to clinical care providers. For older children and adolescents, the patient is the locus-of-control, determining who has access, the level of interaction with the application, and the amount of data being shared. For younger pediatric patients, parents can serve as proxies by entering daily observations about their child into the app.

We approached the research aim from the perspective that subjective experiences in the scope of JIA are influenced by place, persons, and institutions. For this study the place was Sweden, the persons were children between the ages of 5 and 15 living with JIA and their parents, and the place of care was the largest pediatric rheumatology clinic in Sweden, at Astrid Lindgren Children’s Hospital, within Karolinska University located in Stockholm, Sweden. We conducted semi-structured interviews with Swedish young people, their parents, and JIA care teams about their use of and reactions to the potential benefits of the mPSS. Two researcher-designed interview guides were developed (one for families and another for clinical team members) with clinical and project partners to include the following domains: current use of technology, health communication between clinicians and patients, personal health tracking and symptom monitoring, preparation for clinic visits, and current illness management. Data collection and analysis were supported by a multidisciplinary team, which included a medical sociologist, a healthcare policy expert, and a developmental psychologist. This research team worked closely with Upstream Dream, the PSS development team in Sweden who created Genia, to gain access to clinical care partners, understand clinic organizational dynamics, and examine product development history. The study was determined to be exempt from ethics review based on common rule 2 by the Committee [blinded for review] for the Protection of Human Subjects at Dartmouth during a blinded review. This study was approved by the

**Study Participants**

Potential study participants were identified by clinical partners who already use the mPSS with some of their patients and families. Clinicians then sent recruitment letters to participants with a Genia brochure inviting them to participate. The JIA clinical care team invited patients to participate in the study. Consent involved reading an informational script including the study purpose, design, and goals. Families who agreed to participate were subsequently interviewed in-person by Swedish researchers at a location and time that were convenient. Interviews were conducted with parents and children together. Some of the participants had not used the mPSS prior to being interviewed, while others had already started using the mPSS. All interviews were conducted in Swedish and later transcribed into English. The clinical care team interviews were led by the US research team and conducted face-to-face in English at the JIA clinics in Stockholm. The clinical care team included a physiotherapist, occupational therapist, and the physician leader of the JIA clinic. Research team members provided the interview guide to the care team members prior to the interview to give adequate time to prepare responses in English.

**Data Analysis**

We conducted a conventional content analysis as described by Hsieh and Shannon [29]. Initial codes were developed independently by two researchers (ML & SG) using ATLAS.ti version 8.1.2. These first set of codes reflected interactions and observations by the research team from 2016-2017 as recruitment, design, and data collection were occurring. This initial code set was later updated through a second coding process based on the interview transcripts for both young people and families as well as care providers. Secondary codes were substantively related to the interview guide, in part because of the how the guide was organized by domains, as well as due to the nature of the conversations that focused
on specific JIA related experiences. Following the second round of coding, the research team discussed emergent codes, which were labeled new language and concepts. Team members (SG + ML) developed memos (a process of writing short descriptive narratives summarizing meaningful aspects of the data) during the coding and discussion process to draw attention to notable relationships in the codes. Team members (SG + ML + GK) met several times over the course of 2017 to build consensus around grouping codes based on emergent and context-based themes. During the coding and subsequent consensus process, the Genia development team was asked to react to initial codes and offer alternative explanations and suggestions. This iterative coding, memo writing, and theme building process mimics a type of data triangulation [30]. Final themes were developed by grouping codes around larger meaning units, whose content sufficiently reflected all data under consideration.
Results

Study Participants

Table 1. Description of participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age (years)</th>
<th>Sex (M, F)</th>
<th>JIA Subtype\textsuperscript{a}</th>
<th>Duration of disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
<td>11</td>
<td>female</td>
<td>oligo JIA</td>
<td>1 year</td>
</tr>
<tr>
<td>Patient 2</td>
<td>10</td>
<td>male</td>
<td>PsA</td>
<td>4 years</td>
</tr>
<tr>
<td>Patient 3</td>
<td>13</td>
<td>female</td>
<td>ERA</td>
<td>2 years</td>
</tr>
<tr>
<td>Patient 4</td>
<td>12</td>
<td>male</td>
<td>oligo JIA</td>
<td>3 years</td>
</tr>
<tr>
<td>Patient 5</td>
<td>11</td>
<td>female</td>
<td>poly JIA</td>
<td>1 year</td>
</tr>
<tr>
<td>Patient 6</td>
<td>5</td>
<td>male</td>
<td>oligo JIA</td>
<td>2 years</td>
</tr>
<tr>
<td>Patient 7</td>
<td>15</td>
<td>female</td>
<td>PsA</td>
<td>14 years</td>
</tr>
<tr>
<td>Patient 8</td>
<td>12</td>
<td>male</td>
<td>poly JIA</td>
<td>4 years</td>
</tr>
<tr>
<td>Patient 9</td>
<td>15</td>
<td>male</td>
<td>undifferentiated</td>
<td>1 year</td>
</tr>
<tr>
<td>Patient 10</td>
<td>15</td>
<td>male</td>
<td>PsA</td>
<td>2 years</td>
</tr>
<tr>
<td>Patient 11</td>
<td>11</td>
<td>male</td>
<td>oligo JIA</td>
<td>4 years</td>
</tr>
<tr>
<td>Patient 12</td>
<td>14</td>
<td>female</td>
<td>JIA</td>
<td>5 years</td>
</tr>
<tr>
<td>Patient 13</td>
<td>13</td>
<td>female</td>
<td>oligo JIA</td>
<td>1 year</td>
</tr>
<tr>
<td>Patient 14</td>
<td>14</td>
<td>female</td>
<td>poly JIA</td>
<td>9 years</td>
</tr>
<tr>
<td>Patient 15</td>
<td>14</td>
<td>male</td>
<td>JAS</td>
<td>4 years</td>
</tr>
</tbody>
</table>

\textsuperscript{a}Subtype for Juvenile Idiopathic Arthritis (JIA): Oligo JIA is Oligoarticular JIA, Poly JIA is Polyarticular JIA, PsA is Psoriatic JIA, ERA is Enthesitis-related arthritis, JAS is Juvenile ankylosing spondylitis, and Overalap is multisayment JIA.

The young people interviewed for this study ranged in age from 5 – 15 years old. There were 7 females in the group and 13 of the 15 had used Genia prior to the interview. The time since diagnosis ranged from 1 year to 14 years. We also interviewed four clinicians who used Genia as part of their routine practice: 2 MDs, 1 Physiotherapist and 1 Occupational Therapist. Interviews were conducted with both the young person and at least one parent present. The clinician interviews were conducted individually, except two, which included both the physiotherapist and occupational therapist together.

A content analysis of transcripts generated four themes that characterize attitudes and beliefs as well as fears and expectations on how a PSS may foster a strategy for improving communication and achieving shared decision making in JIA treatment. Experiences of young people dealing with JIA everyday reflected feelings of frustration and confusion, which we termed: Isolation due to JIA
challenges communication. While the data suggest there is a developmental difference between younger and older patients’ feelings about sharing their diagnosis status with friends, there was affirming content that supported a second idea we portrayed as: Normalizing illness through shared experience may improve adherence. When asked about the potential of technologies or current care processes, families spoke about the value of routine check-ins between visits and symptom updates. The habit of checking-in and preparing for visits appeared to lead to deeper engagement between young people and their parents. We described this concept as: Partnership opens window into illness experiences. Interview data was further informed by clinician points of view, which included support for more informed patients and families as well as for recognizing the challenge of communicating with young people. More to the point of implementation and use of a novel technology in clinical practice, we observed wide support for a PSS and called this idea: Readiness to engage appears critical for clinic implementation. We present supporting illustrative quotes drawn from transcripts to characterize the categories below.

Isolation due to JIA challenges communication

Young JIA patients described feeling frustrated because when they experienced pain, often people (classmates) do not believe them, or the classmate/s believed they were lying to get out of an activity. This appeared to separate the young person from others, both physically and socially.

Patient 14 (14-year-old): Everyone in my family is aware so it’s okay. It’s hardest with classmates

Interviewer: What do they say then?

Patient 14: One time there was one who said that I always blame everything on my foot.

We observed a tendency in these interviews, where parents would describe interrupting the doctor visit to elaborate on details that either the child did not think was important or did not remember. These interruptions were viewed by young people as acceptable and often confirmatory.
Patient 7 (15-year-old): I usually do it [the clinical visit] but sometimes Mom helps me to make it fair. Sometimes I say it doesn’t hurt at all, though it actually has been hurting also, then Mom jumps in [giggles].

We noticed that parents also have their own ways of dealing with their children’s’ pain and social struggles. Some have begun to reach out to other parents using social media platforms like Facebook, while others have talked with other parents in person. This reaching out for help reflects both the complexity and challenges of supporting children with JIA. Parents showed a desire to be helpful by wanting effective tools for their children, but often lack the resources. The act of reaching out to other parents through Facebook groups underscored the importance and value of a PSS designed to support parents to better understand their children’s’ illness and acquire the skills to better assist their children.

We observed young children talking about the benefits of working with their parents to help them communicate about pain and patterns in their eating and behavior. Some reflected how parents were motivated to help them develop techniques to manage their JIA independently. In one case this approach appeared to work.

Patient 10 (15 years old): Ehh ... I often do not have so many own views. He [the clinician] usually asks me things. Sometimes I have my own questions, for example last year I had trouble with my knees, then my questions could be about that.

Mother: It’s most about how you’ve had it lately.

Interviewer: Do you usually go with him (asking the mother)?

Mother: yes, I usually do. But we try to hand over it more and more to [my son] because he’s getting older. It is important now that he is moving over to adult care.

Interviewer: How do you feel about moving over to adult care?

Patient 10: Hmm... well it feels good.

We further noted that most young people and adolescents in the interviews were reticent to complain about pain or discomfort. Many felt they were a burden on their parents. Reluctance to talk may also be linked to an inability to communicate feelings effectively or how they experienced pain. As one young
person showed reluctance may be a show of strength. For example, one young person expressed his feelings and attitudes on sharing symptoms, which may have signaled strength or fear. Certainly, the interjection by the parent in the following dialogue called our attention to the challenge of communication for both parents and their children.

Patient 9 (15 years old): It feels good.

Interviewer: Do you feel that you are telling him [the clinician] exactly how you feel?

Patient 9: Yes, I think so.

Mother: ...but he always says he's better than he is.

Patient 9: No.

Mother: Yes.

Normalizing illness through shared experience may improve treatment plan adherence

There were some comments on connecting others with JIA through social media as a means of overcoming feelings of isolation and inability to offer help. The act of reaching out for connection may be a means of feeling normal or at least confirming that one is not alone. As we observed, younger children seemed uninterested in reaching out through social media. Yet, the fact that a 14-year old was attempting connection suggested that as the young people age they become more aware of their friends and social networks as sources of support.

Interviewer: Do you know how to get in touch and talk to peers?

Patient 12 (14-year-old): Yes, those I've met I have on Snapchat and Instagram.

Interviewer: Do you have Facebook?

Patient 12: No, I don’t. But I have their numbers so I can call them.

Interviewer: The old way (ha-ha) Mother: ha-ha

Mother: (She) is in touch with some from her last rehab trip. Then also from her physical therapy, not just people with rheumatism, even people who need training.
Interviewer: How do you think it's having friends who also have rheumatism?

Patient 12: Nice. The other day we sat up and talked and it was very nice.

We saw that young people seemed reliant on communicating with their parents, particularly when it came to navigating their relationship with their doctor or care provider. We noticed how this type of communication was not only about symptoms but about being empowered to communicate comfortably and build trust. Further, parents reflected on the power of sharing in a way their children felt confident when hearing.

Father of 11-year-old patient: Yes, absolutely. Since it is so reoccurring... and to be able to share how (she) feels, and how bad it is. If this could be possible through an app it would be great, both for us and for the doctors.

In one example, we saw parents being challenged to think about ways the PSS may help support behaviors like monitoring pain or symptoms over time. This was seen widely as a way to improve their child's awareness and self-management skills.

Interviewer: Do you have diary about how you feel?

Mother: No, we do not actually. But I have very much in my head all the time, but it's the same all the time. But on the other hand, I think the app [Genia] can help because we do not remember the days that actually are good. It's the most misery all the time. I think it would be great for [my daughter] to see her situation over time. So, she can see that she has better days.

Partnership opens window into illness experiences

We heard from young people and their families that using a patient support tool to keep daily observations and reminders for routine updates was very helpful for developing strategies to communicate with providers.

Interviewer: In Genia you can send a report before a healthcare meeting, do you think that could be something for you?

Patient 12 (14 years): Yes, for me at least.
Interviewer. In what way?

Patient 12: I have difficulties remembering. I mix things. I cannot tell when something was, it could have been two weeks ago or two months ago.

Mother: Although we try to be a bit prepared, it is incredibly difficult.

At the same time, clinicians also believed there was real, meaningful value in young people and their parents being better prepared for their visit.

The data is helpful, and the registry really helps me see the patient condition over time – but it only shows data at a point in time (at the time of visits). It doesn’t help me understand what is going on in the patient’s life between visits. And if they aren’t communicative during the visit, or their feelings contradict those of their parents, then it is hard for me to truly understand the patient needs; it is hard for me to understand why the patients’ perceptions of their pain and quality of life is different than my perception. (Physician 1)

While having informed young people and families might improve visit efficiency by targeting interests and generating focused questions, additional behavior changes appeared to guide strategies for improved clinical conversations. The clinicians we interviewed argued that the PSS presented a connection into the lives of patients that was meaningfully different from routine practice.

For the first time, I feel part of her [patient’s] team" (Physician 1)

Readiness to engage appears critical for clinic implementation

Patient monitoring following a care visit was expressed as a gap in care by clinicians. This has particular significance given that patients contend with a majority of their care challenges outside the clinic. The clinicians we interviewed shared an interest in being able to track and/or follow patient progress over time, which permits new and advantageous support systems.

With Genia, if we can get patients to send us status reports in between scheduled visits then we can confirm what is working, and try new ideas much more frequently. (Physician 2)

Besides the importance of tracking, clinicians reflected that engaging patients outside the clinic in meaningful and proactive ways was essential for improving communication during the clinic visit. In this
way, clinicians recognized the pre-visit data sharing feature of the PSS app enabled more targeted and thoughtful interactions.

To improve pre-visit planning, to provide more time for dialogue with the patient during the visit, to help patients better understand what causes flare-ups and what therapy seems to work, and to provide a mechanism to track patients between visits. (Physician 1)

Other reactions highlighted the potential of the PSS to modify routine practice. This was seen as a major improvement compared to standard care. One clinician pointed to gaps in current communication where patients are unable to speak to their symptoms, pain, or status.

When I asked how are you today- everyone says ‘fine’ but I don’t really have a clear picture. To know if there is something more I can do. (Physician 1)

Another clinician also emphasized the need for more robust efforts to guide patients prior to coming to their clinical visit. When asked if she understood the needs of her patients, one clinician suggested there was a need for improvement.

No-not really. Patients complete a long questionnaire when they get to the office, which captures responses based on industry standard instruments, but they don’t tell me [their] goals or key concerns. (Physiotherapist)

We noticed that the PSS clarified the role of the patient, which fostered guided support and strengthened self-management skills. In fact, we saw that use of the PSS in practice, with patients over time, appeared to change their behavior. In the case of one young person, a clinician commented that they would normally rely on the parent to share symptoms. After using the PSS, this parent felt their child was able to do much more with the doctor.

The mother used to bring in a clipboard and do all of the talking, now the patient herself leads the conversation, leaving the mother a more bystander role. (Physician 1)

Discussion

Principal Results
A co-designed patient support system (PSS) that meaningfully engaged users beyond the clinic visit expanded opportunities for improving treatment strategies between young people, their families, and care teams. Through the promotion of consensus-building design features we observed improved communication in young people and their parents about symptom recognition and pain characterization. As a mHealth application, Genia, appeared to hone communication skills that parents and clinicians believe ensure a healthy transition from pediatric to adult care – a space with clear unmet need. The insights for young people, families, and clinicians to enable more substantive, targeted, and authentic communication, where young people learn to reflect on symptoms without being prompted by their parents, was a novel finding. As a smartphone application, the routine monitoring of symptoms and pain over time normalizes a type of sharing process that appears to ease disclosure and improve efficacy in young people and parents. This was particularly relevant for young people who felt isolated by this illness and struggled to disclose their experiences. While evidence has shown how integration of novel interventions into clinical practice can be difficult, clinicians who were ready and prepared for using a novel approach appeared to mitigate barriers to Genia implementation.

Comparison with Prior Work

With the explosive growth of and interest in mHealth initiatives there seem to be endless opportunities for patients to engage the health system in new ways. This is one of the first studies to identify a mHealth application designed to modify communication strategies between patients, families, and care teams. Most mHealth interventions reviewed focus on self-management skill development rather than improving or optimizing patient-provider communication strategies [31]. For mHealth technology to advance behavior change strategies in young people living with JIA, more should be done to build skills that enhance consensus-building frames between patients, families, and care providers. Such an
approach is consistent with the literature on the benefits of building a shared-mind as a treatment strategy [32].

This study, we believe, is a step towards being able to identify how a mHealth app, co-designed with patients, families, and care teams helps identify what matters most and ways of translating patient goals into actionable solutions. Focusing on principles of continuous learning and consensus building the patient support system prioritizes processes of monitoring, reporting, and pre-visit planning to inform clinical communication. Despite the wide growth and interest in these novel technologies for improving access, there is mixed evidence on the long-term impact on patient health outcomes or behaviors [33]. Though not entirely new, this form of co-development has been well supported by health services research, which has pointed to the benefits of co-designed tools for behavior modification strategies [34–36].

A recent paper detailed the development and evaluation of an app called "JIApp," which applied this same person-centered development framework and strongly supports our findings [37]. What we see as unique to Genia when compared to JIApp is the co-design strategy focused on improving consensus for optimizing treatment decision making. While the authors suggest that JIApp supports self-management, our findings point to the utility of Genia as a PSS that enhances patient-provider communication and subsequent behaviors that characterize better communication skill development for long-term management of treatment. While this is still a nascent area of investigation, more research is needed on understanding the co-design and implementation process of mHealth apps. When compared against apps developed in isolation and often not in partnership with care providers, there is a clear benefit of co-designed apps that foster evidence-based approaches and direct input from end-users like patients...
and care providers [38]. Apps that support self-management and symptom management have higher potential for success, which supports the design and implementation of Genia as a PSS [39].

What appears unique about the Genia approach in comparison to other published apps, is the intentional strategy used to guide both patient and family engagement. The use of qualitative data to inform evidence on platforms that are most effective for patients has been suggested elsewhere [40]. Much of the current literature points to the strengths of mHealth to enhance self-management [33,41], tracking and monitoring [42], as well as routine behavior modification [43], and medicine adherence [33,44]. We were unable to find any evidence of mHealth apps developed to improve communication strategies or consensus based strategies to enhance patient, family, and care team integration [33]. Failures or limitations of other mHealth applications and strategies appear driven by a one-dimensional approach, which prioritizes biomarkers and tracking and fails to incorporate consensus building and communication skills. There is no question that mHealth initiatives are the way of the future; they are cheap, easy to build, and potentially highly accessible to large populations. The benefits of mHealth technology are that its personal, adaptive, and sustainably designed. Yet, these benefits are mitigated by lack of clear standards of evaluation and measurement [45].

Limitations
Although the study had 15 participants and involved both families and young people, the data analysis included triangulated data sources to help clarify and validate responses. While this data and our findings provide a rich and context-specific perspective of how a PSS was adopted, integrated, and utilized by a small sample of patients and clinicians in Sweden, we were limited in our ability to generalize these findings to different patient populations or clinical settings. Although we are less concerned with generalizability in the current study, this will be an important methodological feature in
any future project that strives to determine the overall efficacy of a PSS in improving patients' clinical and psychosocial outcomes.

Conclusions
A technology-enabled PSS that meaningfully engages care providers to partner with patients, families, and their support networks, permits novel care planning through the formation of a consensus-building strategy. We believe that offering patients the opportunity to engage friends, family, and their care team in developing treatment solutions may provide the emotional and clinical support they need to meet their personal health goals and sense of well-being.

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Conflicts of Interest
A. Hager, M. Montan, and R. Bergquist are employees of Upstream Dream, a private company that developed the Genia app. Authors affiliated with The Geisel School of Medicine at Dartmouth (M. Longacre, S. Grande, G. Kotzbauer) have no financial conflicts of interest to report.

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