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"I'm the One Taking It": Adolescent Participation in Chronic Disease Treatment Decisions

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ABSTRACT

Purpose: To understand adolescents' roles and preferences in chronic disease treatment decisions, using biologic therapy decisions as an example.
Methods: We conducted semistructured interviews with adolescents who have Crohn's disease (n = 7) or juvenile idiopathic arthritis (n = 8). Questions focused on biologic therapy decisions, including who participated, preferred roles, and factors considered in the decision. We used pie charts to help teens describe the division of decisional responsibility. We open-coded the initial interviews to develop a coding structure. Interviews then were coded by two people, with disagreements resolved through discussion. Interviews were analyzed using content analysis.
Results: Nearly all adolescents participated in the decision about biologic therapy. Roles varied from telling parents about specific symptoms to having the final say in the decision. In addition to discussing their own roles, adolescents identified specific decision-making roles for both parents and physicians. Most factors that influenced adolescents' decision-making related to their quality of life, such as the desire to feel better, concerns about painful injections, and the time needed for treatment. Some adolescents did consider potential side effects and the expected treatment efficacy. Most adolescents were satisfied with how the decision was made, but given a choice would have preferred a different role in the decision.
Conclusion: Adolescents with chronic disease wish to be involved in treatment decision making, but also seek the involvement of parents and physicians. Parents and providers can assist by providing adolescents with relevant information and by helping teens develop the skills necessary for future medical decision-making.

IMPLICATIONS AND CONTRIBUTION

Adolescents with chronic disease wish to be involved in treatment decision-making and may have specific information needs. They perceive themselves to have a role that is distinct from that of their parents or physicians. Although satisfied with how decisions occurred, given another opportunity many would prefer a different role.

New therapies offer adolescents with chronic disease renewed hope for improved disease control and better quality of life. Unfortunately, such therapies may involve tradeoffs between the risks associated with poor disease control and the risks of treatment. For parents of children with chronic conditions, medical decision-making is particularly challenging because such decisions may occur over a period of time [1–3], increasing the complexity of decision-making compared with the acute setting [4]. Adding an adolescent patient who is undergoing rapid physical and emotional changes to this mix adds further complexity to medical decision-making.

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Typically, pediatric decision research has focused on parents, but for diseases that affect adolescents and have long-term risks, it is crucial that adolescents' decision-making roles are understood. Given their growing autonomy in other areas of life, adolescents may also seek to differentiate themselves from their parents in health care settings. Moreover, participating in medical decision-making is an essential skill for adolescents to develop [5]. This is particularly true in the setting of chronic disease, where such skills may help in the transition from pediatric to adult care settings [5].

Existing literature related to medical decision-making among adolescents has focused largely on decisions related to reproductive health. Yet, the decision-making process in these settings, where adolescents are expected to be relatively independent [6], may not be consistent with how decisions are made in chronic conditions. Studies investigating hypothetical medical decisions show discrepancies between parents' decisions and decision-making style preferences and those of their adolescents [7,8]. Despite these differences, many adolescents report wanting their parent involved in medical decisions [9–13]. Existing research [14,15] has not investigated the roles and preferences of adolescents in a specific, real chronic disease treatment decision.

The decision to initiate treatment with tumor necrosis factor-α inhibitor (TNF-αi), a biologic therapy, in Crohn's disease (CD) or juvenile idiopathic arthritis (JIA), serves as a model for understanding adolescent decision-making and considering how best to include adolescents in decisions about chronic disease treatment. This particular decision is complicated by the fact that TNF-αis, such as infliximab, may limit disability and alleviate symptoms but have limited long-term effectiveness data and are associated with immune suppression, risk for opportunistic infections, and possible increased risk of late-onset lymphoma [16]. Given these tradeoffs, the decision to initiate treatment with TNF-αi is ideally suited to explore the role of adolescents in difficult chronic disease treatment decisions.

Methods

Sample

Participants were recruited from a large, academic children's hospital. We approached patients with JIA or CD, for whom TNF-αi therapy had been considered, and who were ages 11–18 when their parent participated in a related study on parent decision-making [17]. Parents had been identified through local disease registries and provider referrals. Parents were eligible if they had considered TNF-αi treatment in the past year, were English-speaking, and the patient did not have a comorbid diagnosis that could also be treated with TNF-αi. Twenty parent participants had adolescent children.

We recruited until potential participants (based on parent participation) were exhausted. Data analysis showed that this strategy also led to information saturation [18], the point at which no new concepts were discussed after three consecutive interviews.

Interview guide and process

Based on existing adult and pediatric literature about treatment decision-making [19–26] and input from clinicians, we developed an interview guide (available on request) focused on decisions related to CD or JIA. Interviews started with general questions and moved toward an in-depth discussion of adolescents' participation in disease-related decisions, with an emphasis on treatment decisions. Before discussing the decision about TNF-αi therapy, participants filled in a pie chart indicating the degree to which various parties participated in that decision, and another indicating how they wish participation had been divided [27] (Figure 1). In discussing the TNF-αi decision, we included questions about participants in the decision, factors considered in the decision and information used. After reviewing the first two interviews, minor changes were made to the guide.

Following an introductory letter, potential participants were contacted by telephone to schedule an in-person or telephone interview with one of two trained interviewers. Telephone interviews were used for families who lived more than 1 hour from Cincinnati Children's Hospital and did not have an upcoming appointment. In those cases, the pie chart worksheet was sent to the participant ahead of time and then mailed back after the interview. With one exception, parents were not present during the interviews. Interviews were audiorecorded for verbatim transcription. All transcripts were verified by study staff. The Cincinnati Children's Hospital Medical Center Institutional Review Board approved this study. Informed consent and assent was obtained for all participants. Participants received $20 remuneration.

Data coding and analysis

We used content analysis [28–30] for data coding and analysis. The research team, including an adolescent medicine specialist and an older adolescent (undergraduate summer student), annotated and open-coded two transcripts. The team used these transcripts to develop a coding structure. Thereafter only minor, clarifying changes were necessary. Two researchers independently coded the remaining transcripts, with disagreements resolved by a third. Data were analyzed by two study team members according to thematic groupings, such as decision-making role, decision process, or influencing factors, and then compared by age and disease. NVivo 8 (QSR International, Victoria, Australia) was used for coding and analysis.

Results

We interviewed 15 adolescents, 7 with CD and 8 with JIA. Of the remaining five potential participants, two declined to participate and three, for logistical reasons, were unable to be scheduled. Participants' median age at the time of the decision was 13 years (Table 1). For all participants, the initial decision was to initiate treatment with TNF-αi. However, by the time of our interviews three participants had discontinued or were considering discontinuing that treatment. There were no major differences in the data collected from adolescents with JIA or with CD. Therefore, the results were combined. Adolescents are identified by their age in years, gender, and disease.

Adolescents' roles in decision-making

All but one participant indicated that they participated in the decision regarding TNF-αi. In the outlying case, the decision was made during a time of significant family distress and, per the adolescent, based solely on a change in insurance coverage. Many adolescents described being included in decision-making at the end of the decision process, such as in this description by