RESEARCH ARTICLE

The Involvement of Adolescents With Chronic Health Conditions in Medical Education: An Exploratory Qualitative Study

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ABSTRACT

OBJECTIVES: In this study, we explored the involvement of adolescents with chronic health conditions in medical education. We focused specifically on adolescents' desired level of involvement in the education of medical students and residents, strategies for involving them in it, and topics on which they would feel comfortable educating these learners.

METHODS: We used a community-based participatory research approach and qualitative one-on-one semistructured interviews. Adolescents (ages 13–18) with chronic health conditions lasting >3 months who were admitted on inpatient wards and were well enough to participate in an interview were eligible. Two investigators analyzed the interview transcripts to identify common categories across the interview data.

RESULTS: A total of 17 adolescents participated. Data analysis revealed that adolescents want to be regularly involved in medical education, compensated in some way for their time and effort, and receive support and oversight in their activities. Adolescents discussed the following 5 strategies for involving them in the education of medical students and residents: face-to-face presentations, shadowing and mentoring, videos, handouts and books, and assessment feedback. Adolescents want to educate learners on their experiences and coping strategies as well as on how to interact and develop rapport with adolescents.

CONCLUSIONS: The adolescents with chronic health conditions who participated in this study want to be actively involved in medical education and can provide innovative insights and strategies for doing so. However, future researchers need to explore the benefits and limitations of such involvement.

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Although patients have traditionally played passive roles in medical education,[1–3] patient-centered movements encourage active patient involvement. Adult patients describe how educating learners empowers them and enhances physician relationships.[4,5] Medical students and residents articulate that these experiences educate them on patients' psychosocial needs and improve patient interactions.[6,7] Yet, active involvement in medical education is not mainstream,[5] especially among adolescent patients.

Several researchers have focused on adult patients' involvement in medical education, but few have explored adolescents' involvement in this area.[8] Authors of a bibliography on patient involvement noted only 2 studies in which researchers focused on adolescents.[8] In 1 study, researchers involved children and youth in the development of resources for practitioners,[9] whereas in the other, researchers included children and youth in physician assessment.[10] Researchers have also investigated adolescents' perspectives on factors that influence communication with physicians as well as their general health care preferences.[11–13] Although these studies have implications for medical education, there is limited research on adolescent involvement in the education of medical students and residents. This is unfortunate because adolescents, particularly those with chronic health conditions, may want to be involved, and can contribute unique perspectives to medical education.

Our purpose with this study was to explore the involvement of adolescents with chronic health conditions in medical education. We focused specifically on adolescents' desired level of involvement in the education of medical students and residents, strategies for involving them in it, and topics on which they would feel comfortable educating these learners.

METHODS

Study Design

Because we focused on adolescent involvement in medical education, it was important for us to select a research approach that also focused on, valued, and encouraged adolescent involvement in research. As such, we used a community-based participatory research approach[14,15] by actively involving 12 adolescents from 2 hospital-affiliated youth advisory groups in the study design, implementation, and validation of findings. We met with the adolescents 4 times to collaboratively discuss the study rationale, develop the interview guide, establish recruitment processes, and review the findings. Overall, we used this research approach to incorporate the adolescents' suggestions into the study, stimulate their research interests, and ensure that the recruitment strategies, interview questions, and findings were adolescent-friendly. Our center's ethics board approved all procedures.

Setting

We conducted the study at a Canadian pediatric academic hospital. It has 4 general inpatient wards with a total of 52 beds. At all times, 3 medical teams cover the 4 wards and use patient- and family-centered rounds.[16] Each team includes 3 to 4 medical students, 2 to 3 junior residents, and 1 to 2 senior residents. The medical student and resident training blocks are 3 and 4 weeks, respectively. Although each patient may interact with many medical students and residents during hospitalization, the hospital tries to assign patients to specific medical students and residents for care continuity.

Participants

English- or French-speaking adolescents (ages 13–18) with chronic health conditions lasting $>$3 months[17] who were admitted on general inpatient wards and were well enough to participate in a 45-minute interview (as determined by a member of the patient's care team and confirmed by the patient) were eligible. We continued data collection until we had a breadth of information-rich data to fulfill our study purpose.[18,19]

Procedures

Data collection occurred from April to June 2016. In consultation with a member of the patient's care team and by using electronic medical records, a bilingual research associate (RA) screened for eligible patients. When the member and RA identified an eligible patient, the member asked the patient if he or she would be interested and felt well enough to participate in a 45-minute interview. If the patient was interested and felt well enough, the member then informed the RA that she could approach the patient. The RA provided the patient with an information letter and consent form. If the patient consented, the RA scheduled a one-on-one interview. The semistructured interview guide included a general description of medical students' and residents' roles as well as major and probing questions (see Table 1).The RA conducted each interview in the patient's room and performed in vivo member checking to verify her understanding of the participant's perspective(s). Participants completed a demographic survey and received a $10 participation gift card. Interviews lasted 30 to 45 minutes and were audio recorded and transcribed verbatim. A professional translator translated any French transcripts to English for reporting purposes. Another professional translator then back-translated all newly created English transcripts and compared them with the French originals to ensure translation accuracy and quality.

Data Analysis

Our data analysis goal was to explicate common categories across the interview data. Two bilingual investigators used NVivo 11 to manage the data. By using Miles, Huberman, and Saldaña's cyclical process,[20,21] they condensed the data, displayed the data, and drew and verified conclusions. After each interview, they collectively listened to the audio recording. By using NVivo memos, they summarized the interview, flagged emerging categories, and identified probes for subsequent interviewees. After data collection, they independently reviewed the memos, read each transcript, and inductively coded the data by using non-hierarchical nodes. They then met to discuss, compare, and refine their coding as well as create an agreed-on non-hierarchical coding scheme. By using this scheme, they independently reviewed the nodes for linkages and created node hierarchies (ie, categories and

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Table 1 Interview Questions

1. Tell me a little bit about yourself.
2. During your experiences and interactions with medical students and residents, what do you think they learn from you?
3. Would you like to be involved in educating medical students and residents? Tell me what you think.

   Example probes:

   a. Why would you want to be involved?

   b. Why would you not want to be involved?
4. How do you think you could be involved in educating medical students and residents?

   Example probes:

   c. How do you think you could be involved in teaching medical students and residents?

   d. How do you think you could be involved in assessing medical students and residents?
5. What topics do you think you could educate medical students and residents on?

   Example probes:

   a. How to communicate with teenagers?

   b. Your social experiences?
6. In what specific ways would you want to be involved in the education of medical students and residents?

   Example probes:

   a. Can you think of examples of activities you would want to be involved in?

   b. Why is this an activity you would want to be involved in?

   c. Why do you think this is a good way to educate medical students and residents?
7. What could we do to help you become involved in educating medical students and residents?

   Example probes:

   a. Pay you?

   b. Provide you with training?
8. Is there anything else on this topic that you would like to talk about?

Probes used for each question varied depending on the flow of and information provided in each interview.

subcategories) to reflect these associations. Again, they met to debate, compare, and revise their node hierarchies as well as develop a common hierarchical coding scheme. With the revised scheme, they independently reviewed the transcripts and memos as well as their previous coding and revised it accordingly. Throughout the analysis, they used NVivo visualizations (eg, coding stripes, charts, comparison diagrams) to identify common categories across the interview data. Once satisfied with the analysis, they exported the content coded at each node to a table in Microsoft Word. Together, they reviewed the findings to generate conclusions and extract exemplar quotations for reporting. The inclusion of exemplar quotations and the use of 2 coders contributed to the trustworthiness of the analysis. Throughout the study, the investigators also created memos on their coding decisions, which provided an audit trail. Finally, the investigators met with the above-mentioned adolescents from the hospital-affiliated youth advisory groups to examine and discuss the findings. This debriefing process helped the investigators confirm appropriate wording for the founded categories and subcategories and further enhanced the trustworthiness of the analysis.

RESULTS

A total of 17 adolescents participated in the study. Table 2 provides the participants' demographic characteristics. We conducted 16 interviews in English and 1 interview in French. As presented below, the findings include major categories related to adolescents' desired level of involvement in the education of medical students and residents along with their preferences for compensation, as well as training and guidance to facilitate such involvement. The findings also comprise the major categories of involvement strategies and educational topics, each containing multiple subcategories.

Desired Level of Involvement

All the participants want to contribute regularly to medical education by sharing their perspectives and stories. For example, participants stated, "It doesn't have to be too crazy formal…we just want to tell our story" and "It could be open, where you can just talk about your experiences." When asked why they would want to be involved, the adolescents simply and straightforwardly echoed the following statements: "I want to tell my story," "I want them [doctors] to know what teens like me go through," or "I want to improve care for teenagers." They also overwhelmingly recognized the notion that "teens are experts on teens" and thus, "It's best to have teens teach doctors about teens…because teens know teens."

Compensation

The majority of the participants thought that "incentives" or "rewards" would encourage adolescents to become involved in medical education. For example, when probed if they would like to receive financial payment for their involvement, they stated, "If you fill out surveys on doctors and then you get put in a draw for gift cards or a money thing. Need some sort of reason for people to be like, 'This is important.'" None of the participants prescribed a specific payment amount.

The participants also described how the Ministry of Education mandates that students complete 40 volunteer hours in high school. They suggested that they could accumulate these hours through medical education involvement: "We need to get documented volunteer hours for that kinda thing, for high school credits." They reflected on how adolescents could include these activities on their resumes or university applications: "If they are trying to get into university and with resumes and stuff like it would look good to add to a portfolio that I spoke to doctors at an academic thing."

Training and Guidance

Most participants indicated that they do not want formal training on how to educate learners. They prefer that organizers simply invite them to participate and, in the case of face-to-face sessions, provide a facilitator who can ensure discussions are relevant and include necessary components. For instance, participants stated, "We need someone to make sure we stay on topic, make sure everything was appropriate" and "You gotta make sure they [adolescents] tell and have both the mental and physical side of it so that doctors know both sides, you need someone to make sure they do that."

Involvement Strategies

The participants in this study discussed the following 5 strategies for involving them in medical education: face-to-face presentations, shadowing and mentoring,

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TABLE 2 Interviewees' Demographic Characteristics ($N = 17$)

Characteristic	n (%)
Patient age	
13	4 (24)
14	1 (6)
15	3 (18)
15	6 (35)
17	3 (18)
Gender identity	
Female	8 (47)
Male	9 (53)
Approximate no. of doctor's appointments per year	
2–4	6 (35)
5–7	5 (29)
14 or more	6 (35)
Approximate no. of overnight stays in hospital per year	
1–3	13 (77)
4–6	2 (12)
7–9	1 (6)
13 or more	1 (6)
Specialties or programs used at the pediatric center[a]	
Adolescent health	2 (12)
Audiology	2 (12)
Cardiology	2 (12)
Cystic fibrosis	2 (12)
Dentistry	2 (12)
Dermatology	2 (12)
Diagnostic imaging	7 (41)
Endocrinology	2 (12)
Gastroenterology and hepatology	5 (29)
Hematology	2 (12)
Infectious diseases	2 (12)
Mental health	6 (35)
Nephrology	1 (6)
Neurology	1 (6)
Nutrition	1 (6)
Occupational therapy	2 (12)
Oncology	1 (6)
Ophthalmology	1 (6)
Pediatrics	1 (6)
Physiotherapy	3 (18)
Pulmonary function laboratory	1 (6)
Respirology	3 (18)
Speech-language pathology	1 (6)

[a] Interviewees checked all that apply.

videos, handouts and books, and assessment feedback.

Face-to-face Presentations

Several participants wanted to provide face-to-face presentations. Through presentations, they thought that adolescents and learners could interact and learners could understand the adolescents' perspectives: "The only way you are going to make an impact is if you talk to them directly in the classroom…you can actually have a conversation with them and ask them what's their understanding." Contrasting face-to-face with paper-based and noninteractive strategies, most adolescents described how face-to-face presentations would create experiences that are more engaging and memorable for themselves and the learners. This strategy would ensure that the learners see the person behind the illness. As 1 participant stated, "In a presentation you're in contact with them, not just behind a screen or a piece of paper. I want to see, instead, I get to see what's going on and remember it." Another also elaborated: "I think the in-person is even better than videos or papers because the doctors would be able to ask questions and maybe because it's a real person, they would say, "'Wow this is a real person, this isn't an actor or anything,' and yeah, that would be better because doctors remember us. I think the presentation thing would force them, the doctor, to take it serious."

Shadowing and Mentoring

The adolescents in this study wanted to be involved in mentorship or shadowing. They believed these initiatives would provide themselves and learners with opportunities to get to know each other's perspectives and improve clinical interactions. Quotes reflecting this belief included, "Getting to know them and just talking, understanding each other's lives, what each of us does" and "Meet like every 2 days and chat about our days, be in more contact with the teenagers, this would help us better with them in the hospital."

The adolescents explained how they could provide information to learners on interacting with teenagers. For example, they noted, "I would like to shadow the doctor to see how they interact with kids and like then give feedback to them…you know, be the teenage eyes and ears for the doctor" and "If [the] doctor tells us what another adolescent is anonymously experiencing, we could help out by telling them some strategies to try…advice from a teen who has been through it."

Videos

Although several adolescents preferred face-to-face initiatives, others wanted to create videos for learners. They stated how it is important to "Film the presentation that teens give [to learners], so all the doctors get the 'memo' [about interacting with adolescents], not just those who attend the presentation and they could also review it after." Meanwhile, others thought that video diaries would be educationally beneficial: "A camera beside them [the adolescent] and then every time they felt like it they could just videotape and say how everything is impacting them…you could go put them all together with editing, kinda like a video blog, what's happening with all their social life, what's it like being in hospital, or how they are actually feeling…[they] want doctors to see what they look like at the time while experiencing it."

To increase the authenticity of the content, the adolescents thought that it is important for them to star in their videos: "Cause I don't know what they did before, if they had actors or something [laughter], but I think it's a good idea to have real patients, the real deal, and then before they get into the field, doctors know exactly what they will be handling…because teenagers are difficult people."

Handouts and Books

Most participants suggested adolescents could develop educational handouts: "Before, it's probably like adults making these handouts for how to communicate with teens and nobody knows better than teens, we should create them." However, in regards to written material, they worried that "They [learners] might read it once and throw it away or put it in a cabinet" or that "They have so much documents and paperwork, they could throw it out like it

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was nothing." To ensure use, the participants thought that the material should be unique: "It could be a comic book–like thing…it's got like comic strips and it deals with what they are going through at the time and it kinda just explains how to explain things."

Others recommended the creation of edited books that include several patients' contributions. Illustratively, 1 participant said, "If we were like 25 people, we could do a book. Each could do like our tips for interacting with teens for 2 or 3 pages." Likewise, another articulated: "Get a bunch of people and do like a group book with a bunch of people with the same condition and ask them, 'What do you want doctors to know about your experience?' You will get a lot of views and then it's just not 1 person representing that condition."

Assessment Feedback

Most adolescents in this study wanted to provide anonymous feedback on learners' abilities through electronic or hardcopy assessments. As 1 participant said, "Oh, there could be like a website or something where like teens could make comments about their experiences and the doctors' skills and doctors could take the time to read those comments, especially at discharge." Another recommended: "You could have like at Timmies [a Canadian coffee shop], when you have a box with a bunch of papers on top with a pencil and kinda write how your experience and interaction was, what the doctor did well and not good, and then you put it in the box…and then when doctors met they could pick out a few of the comments from the box and read them and discuss them."

Educational Topics

The adolescents in this study suggested they could educate medical students and residents on their experiences and coping strategies as well as on how to interact and develop rapport with adolescents.

Physical Experiences

Many participants noted that they would like to teach learners about their pain, symptoms, and limitations. For instance, when asked what they would like to teach, they stated, "I would like to teach [them] how it feels and how it actually hurts physically," "things I have tried at home to manage my symptoms," and "teach about physical limitations and like small things I can't do because of cancer."

School Experiences

Numerous adolescents discussed how they would like to teach learners about challenges encountered at school: "I would like to teach them what it's like to go to school with a catheter…it's kinda really awkward when you need to go to school with a bag on your leg and you have to wear baggy pants and your friends ask you 'Oh, why are you walking funny?' and you say, 'Oh, no reason.' Others indicated that they would like to explain to learners "how what they have interferes with their school and maybe how they have to continue school work even from the hospital."

Coping Strategies

The majority of participants described their coping strategies and that learners do not always understand their rationales for using them. Therefore, they wanted to educate learners on these strategies: "They could learn more about teenagers and how they cope with things…why a person might isolate themselves, smoke, or go for a walk." Another coping strategy that some participants discussed was the use of inspirational quotes. They thought adolescents could explain to learners why these quotes are important, especially when in the hospital, and teach learners how to write them: "Teach them how to write 'positives' on the white boards [in hospital rooms]…how to tell me they are proud of me and that I am awesome, how to make me feel better about myself…write a message about how well they [the patients] are doing and draw them a picture, it kinda just brightens their day."

Interacting With Adolescent Patients

Treating adolescents appropriately emerged as another educational topic. Several participants echoed that they could teach learners how "not to treat us like children" and to "remember that they are young adults and they should be spoken to like they are an adult." Others also mentioned that they could "teach them how to involve us; I really like it when they actually involve me, they ask my opinions on rounds, and really involve me" or teach learners to "talk to and involve teens the same way they would talk to the parents…just being honest about what is happening."

Involving Parents

All the adolescents in this study also wanted to teach learners "how to communicate when parents are in the room." They would like to teach medical students and residents that adolescents value confidentiality and engagement in medical encounters. The following quotations reflect these sentiments: "The biggest thing is just maintaining confidentiality, teaching them like when to ask if we want the parents in the room is a big thing, confidentiality is a big thing" and "Sometimes they just look at the parents and you are just sitting there, they may be talking to you but they are looking at your parents, teaching them that's not okay."

Establishing Rapport With Adolescent Patients

Several participants thought that they could coach learners on how to develop relationships with adolescent patients "so that the patients could be more confident and have more trust in the physician." The participants thought that the key to relationship building is to have adolescents teach medical students and residents: "How doctors can allow teens to get to know them, you know the person behind the doctor…I want to know about them [learner] as people…they are handling my body and what's going on and they are a complete stranger." Through shadowing and mentorship, they want to teach learners to "talk to teens about them [the learner] a little bit so that the teens can get to know them [the learner]."

DISCUSSION

With this study, we are the first to explore adolescents' perspectives on involving them in the education of medical students and residents. We showed that the adolescents with chronic health conditions in this study wanted to be actively involved in medical education. Their desired level of involvement reflects the middle rung, Level 3 (ie,

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Growing Involvement), on a 5-level ladder, ranging from No Involvement (Level 1) to Partnership (Level 5), that Tew et al[22] created to categorize patient involvement in health training. Specifically, the adolescents in this study wanted to contribute regularly to educational processes (eg, teaching and assessment), receive a form of payment (eg, gift cards, volunteer hours) for their contributions, and obtain some support and oversight (eg, facilitators). This information provides insight on how and what these adolescents wanted to contribute to medical education as well as where to effectively focus efforts and resources to facilitate such contributions. It also illuminates that they did not expect full partnerships (Level 5) in medical education, in which, for example, institutions employ them as patient-educators on long-term contracts and involve them in all key medical education decisions.[22]

The way in which the adolescents desire to share their stories and perspectives is not overly formal, but it can potentially add knowledge and experiences that extend beyond typical medical education.[23] Although the participants favored face-to-face educational opportunities (eg, presentations, shadowing, mentoring), they highlighted that they would also like to create videos and written material. These suggestions are consistent with previous research on adult patient involvement in health professions education.[24–27] The adolescents' willingness to be involved in learner assessment is also encouraging because researchers have demonstrated that patients have first-hand experience of how physicians perform and can add unique insights to assessments.[28,29]

For educational topics, the adolescents stated that they could teach learners about their health experiences and coping strategies. Stacy and Spencer[1] noted similar topics after their inquiry on adult patients' teaching roles. However, the participants in their study also taught students about health care team composition as well technical aspects of conditions.[1] Nonetheless, the participants in our study discussed educating learners on interacting and developing rapport with adolescents. Jha et al[30] and Towle et al[4] noted comparable topics in their literature reviews of patient involvement in health professions education. Woodgate[31] also found that adolescents want health professionals to treat them as persons, spend time getting to know them beyond their diseases, and be honest and empathic when communicating with them. Moreover, Beresford and Sloper[13] and van Staa et al[12] noted physicians' challenges in communicating with adolescents when parents are present as well as developing trust and relationships with adolescents, respectively.

Although we actively involved a diverse group of adolescents in this study (we conducted the research with, rather than on, them),[32] our findings in this exploratory study are not generalizable to all adolescents. It is probable that those who participated are more outgoing and, thus, more likely to participate in medical education. It is also possible that their opinions and ideas differ from those of the patients who were too unwell to participate as well as from those from outpatient clinics or other centers. In addition, as reported in the results, when we probed the adolescents on why they would want to be involved in medical education, they all provided simple and straightforward answers. They were more interested in detailing how they could be involved rather than why they would want to be involved. As such, researchers conducting future studies should explore other adolescents' perspectives and attempt to better elucidate why adolescents want to be involved in medical education. Moreover, to maintain participant confidentiality, because some had rare chronic conditions, we did not collect information on the adolescents' specific health conditions or their length of hospitalization at the time of the interview. We also did not collect information on their previous involvement in medical education. Acknowledging that this information may have influenced the adolescents' perspectives, we believe that it would be valuable to conduct future studies to see if adolescents' desired level of involvement in medical education varies by previous experience as well as demographic or health characteristics. Lastly, although we conducted this study at an academic hospital that uses patient and family-centered rounds, we did not specifically investigate adolescent involvement in bedside teaching, which is an important part of these rounds.[16] Thus, researchers conducting forthcoming studies could investigate adolescents' views on their involvement in bedside teaching.

CONCLUSIONS

The adolescents with chronic health conditions who participated in this study want to be actively involved in medical education and can provide insights and strategies for doing so. These study findings can inform the creation of innovative educational activities for medical students and residents that are inclusive of adolescents' experiential knowledge. For example, educators can include adolescent-led presentations or adolescent-created videos in academic half days or classroom teaching. They can also facilitate patient shadowing and mentorship opportunities for learners, the distribution of adolescent-developed handouts and books on interacting with teens, or strategies for including adolescents in the assessment of learners' skills and abilities. When implementing such activities, it will be important to investigate the benefits and limitations associated with them. Specifically, researchers could investigate if these educational activities improve learners' interactions with adolescents as well as their understanding of what it is like to live with a chronic health condition. They could also explore if adolescents' involvement in medical education influences adolescents' sense of empowerment, satisfaction with care, or understandings of their health conditions.

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