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Original article

Self-Management of Health Care Among Youth: Implications for Policies on Transitions of Care

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A B S T R A C T

Purpose: Transitions from pediatric to adult health care are important milestones for youth. In surveys, providers report that youth lack the motivation or skills to manage their care independently, a prerequisite for successful transitions. To assess the validity of this belief, we surveyed youth regarding their current and desired level of involvement in their care.

Methods: In 2017–2018, we conducted a national text message survey of youth aged 14–24 years. The survey included three open-ended questions assessing participants' independence on three health care tasks (scheduling appointments, attending appointments, and picking up prescriptions) and one open-ended question assessing their desire to be more, less, or equally involved in their care as they are now. We qualitatively analyzed free-text responses to identify themes.

Results: Among 1,214 eligible participants, 805 (66.3%) completed all four questions and were included in the sample. Forty-one percent of youth reported wanting to be more involved in their care. Among young adults aged 18–24 years, 22% were not fully independent on the three health care tasks and reported wanting to be less involved or equally as involved as they are currently.

Conclusion: Many youth should be viewed as partners in health care transitions instead of as barriers, but some youth are at high risk for failed transitions. Policymakers and providers should promote routine screening of youth for their current levels of engagement in care and desire to be more involved.

IMPLICATIONS AND CONTRIBUTION

In some surveys, 80% of providers reported a belief that youth lack the skills or motivation to manage their own health care. This large-scale mixed method study reveals that a minority of youth are at high risk for failed transitions but also demonstrates that many youth desire to independently manage their care and should be viewed as allies in health care transitions instead of barriers.

Adolescence is a critical period in which youth gain the skills they need to become independently functioning adults [1,2]. One important skill young people develop during adolescence is the ability to manage their own health care, which is associated with a decreased likelihood of adverse health outcomes as well as the development of other life skills necessary to succeed in adulthood [3,4]. Self-management of health care is a prerequisite for successful transitions from pediatric to adult care. When done properly, health care transitions give youth the best chance to independently manage their care in the future [5–8]. Recognizing the importance of health care transitions, the federal

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government partnered with physician groups in 2014 to create a standardized approach to these transitions called the "Six Core Elements of Health Care Transitions," which outlines specific tasks that youth should be able to perform independently to have completed a successful health care transition [9].

National assessments of this federal initiative reveal that few providers are meeting benchmark goals [10,11]. In these assessments, providers report that the most significant obstacle is that youth do not want to be involved in their care. These reports are consistent with prior studies in which providers commonly report that youth lack the skills or motivation to successfully transition to adult care [12–18].

However, it is unclear whether these perceptions are generalizable to the overall population because prior research examining youths' desire to be engaged in health care transitions has been restricted to patients with specific chronic or complex diseases; there is little research on large groups of youth and healthy youth [19–25]. If most youth do not want to be engaged in their health care, then efforts must be made to understand the reasons and to develop solutions accordingly. On the other hand, if youth do want to be engaged in their health care, then alternative reasons for failed transitions to adult care should be explored. In this study, we conducted a mixed method analysis of a national sample of youth aged 14–24 years to gain a nuanced understanding of their current and desired level of involvement in managing their health care.

Methods

Overall approach

We conducted an explanatory sequential mixed method study in which quantitative analyses informed qualitative data analysis [26]. Specifically, we conducted a survey to characterize participants' desire to be more, less, or equally involved in their health care as they are now, as well the degree to which participants currently manage their health care independently. We then qualitatively analyzed themes among groups of youth defined by these quantitative results.

Data source

Participants came from the National MyVoice Text Message Cohort, a large-scale longitudinal mixed method study of youth that has been described in detail previously [27]. Briefly, this cohort is comprised of a rotating panel of youth aged 14–24 years who agree to receive text message surveys on a broad variety of topics relevant to the adolescents and young adults [28–31]. The primary purpose of the study is to understand youths' understanding of and perspective on important issues. Youth who agree to be part of the cohort can choose whether to answer surveys, which are administered approximately once per week.

Sample

Participants were eligible if they were aged 14–24 years and had access to a phone with texting capability. Participants were recruited between October 4, 2017, and March 24, 2018, through Facebook and Instagram advertisements. These advertisements were targeted based on demographic characteristics, with the goal of maximizing the degree to which the sample matched national demographic benchmarks for age, gender, race/ethnicity, educational level, family income, and region of the country (based on the 2016 American Community Survey). Participants were paid $1 for completing the survey and were excluded if they did not respond or responded but did not complete the entire survey.

This study was approved by the University of Michigan Institutional Review Board. Consent was obtained electronically from all participants; parental consent was waived for minor participants to enable equitable recruitment of low-income and at-risk youth.

Survey questions

Enrolled participants were asked the following four questions using an open-ended text message survey:

(1) Who schedules your doctor's appointments? Why?
(2) Who usually goes with you to your doctor's appointments? Why?
(3) Who usually picks up your prescription medicine? Why?
(4) Do you wish you were more or less involved in your health care? How?

These questions were chosen because they align with goals of the national "Six Core Elements of Health Care Transition" framework on successful pediatric-to-adult health care transitions, including the abilities to schedule and attend appointments independently; they also match questions commonly used in other studies on health care transitions [5].

Quantitative analysis

The primary outcome was whether respondents desired to be more involved in their health care, less involved in their health care, or equally as involved as they were now. This outcome was based on the response to the fourth question listed previously. The proportion of respondents with this outcome was calculated overall and by demographic characteristics, including gender, age group (adolescents aged 14–17 years vs. young adults aged 18–24 years), race/ethnicity, respondent education, parental education, parental marital status, free lunch status while in high school (an indicator of low socioeconomic status), and census region. Differences in proportions by these demographic characteristics were compared via chi-square tests.

Because the interpretation of the primary outcome depends on how independently respondents operate at baseline, we examined variation in this outcome by "independence scores," which were based on responses to the first three questions of the survey assessing responsibility for health care tasks. For each task, respondents were assigned a maximum of one point if they were responsible. We calculated the proportion of respondents who desired to be more, less, and equally involved among respondents with an independence score of less than 3 (i.e., someone helped them complete at least one task) and 3 (i.e., they did all the tasks themselves). We primarily focused on the distinction between scores of three versus less than three because each of the tasks may have varying levels of correlation with health care independence (i.e., a 1-unit increase in the score does not necessarily signal an equivalent increment of the level of independence across all possible increments). For the three questions assessing who performs health care tasks, there were no instances in which respondents provided the name of a

responsible individual without specifying the relationship of the individual to the respondent.

The secondary outcome was the proportion of young adults (aged 18–24 years) who may be at risk for failing to successfully transition to adult health care, defined as any young adult with an independence score of less than 3 (not fully independent) and who wants to be less involved or maintain their current level of involvement in their care.

Qualitative analysis

For the qualitative components of responses to each question (e.g., why a respondent did or did not schedule their appointments), two members of the study team (S.S. and O.I) conducted a thematic analysis using an inductive framework without a prespecified codebook. A codebook was created and iteratively refined through discussion. Discrepancies were resolved until consensus was reached.

Themes were analyzed among adolescents and young adults with independence scores of 3 (not reliant on others for any of the three tasks assessed) versus 0–2 (reliant on others for at least one of the tasks). In each of these two groups, themes from the qualitative analysis of the fourth question were further analyzed among adolescents and young adults who wanted to be more involved, less involved, or equally involved in their health care.

Results

Among 1,214 eligible participants to whom the text message survey was sent, 802 (66.3%) responded to all four questions and were included in the sample. The mean age of the sample was 18.9 years (SD = 3.0); the majority were female (58%), white (70%) with 11% Hispanic, and 29% qualified for free or reduced lunch in school (Table 1).

Table 1
Demographic characteristics of the study sample and independence group

Overall sample, n (%)	802 (100%)
Demographic subgroups	
Age (years)	
14–17	289 (36.0%)
18–24	513 (64.0%)
Gender	
Male	283 (35.2%)
Female	467 (58.2%)
Other	51 (6.4%)
Race	
White	563 (70.2%)
Black	67 (8.4%)
Asian	88 (11.0%)
Other (including multi-racial)	84 (10.4%)
Hispanic	88 (11.0%)
Education	
High school or less	437 (54.5%)
Some college or completed associates/tech school	245 (30.4%)
4-year college graduate	120 (15.0%)
Parent education	
High school or less	99 (12.3%)
Some college or completed associates/tech school	142 (17.6%)
Bachelor's	211 (26.3%)
Graduate degree	350 (43.6%)
Parent marital status	
Married/together	569 (71.0%)
Divorced/separated	180 (22.4%)
Other (widowed, unsure)	44 (5.5%)
Free/reduced lunch	
Yes	231 (28.9%)
No	571 (71.1%)
Region	
West	91 (11.4%)
Midwest	506 (63.1%)
South	137 (17.1%)
East	64 (8.0%)

The overall proportion of respondents desiring to be less involved, equally involved, or more involved in their health care was 6.8%, 51.3%, and 41.5%, respectively. Male respondents (12.7%) were more likely to desire to be less involved in their health care than females (3.2%; $p = .001$). Among racial and ethnic subgroups, nonwhite youth were more likely to report a desire to be more involved in their care compared with white youth ($p < .001$).

Overall, 33.9% of the sample had independence scores of three, whereas 60.1% had independence scores of less than 3. Figure 1 plots respondents' mean independence score by age. Before age 18 years, the mean independence score was less than 1, but it increased quickly to an average of 2.5 by age 22 years.

Figure 2 reports respondents' independence scores by age group and desired level of involvement. Independence scores are dichotomized into scores of 0–2 versus a score of 3. Most adolescents (aged 14–17 years) had independence scores of zero (74%); of these adolescents, 9% wanted to be less involved, 46% wanted to maintain their current involvement, and 45% wanted to be more involved. In contrast, most young adults (aged 18–24 years) had an independence score of 3 (60%); in this group, 3% wanted to be less involved, 63% wanted to maintain their current involvement, and 33% wanted to be more involved. Among young adults, 22% were at risk for a failed health care transition, as indicated by an independence score of <3 and a desire to be less or equally as involved as they are now.

Table 2 reports the themes identified in the qualitative component of each question, grouped by respondents with independence scores of 0–2 and respondents with independence scores of 3. Respondents with an independence score of three all shared a common theme of autonomously managing their care ("I do it because I'm an adult" and "I schedule appointments because I know when works best for me"). In contrast, respondents with independence scores of 0–2 cited common reasons why they were not managing their care, including logistical reasons such as schedule keeping or transportation ("My mom does because she drives me there"), financial reasons ("Parents because they pay for it"), or because respondents believed they were too young to do it themselves ("My mom because I'm not old enough to go alone").

Additional themes were identified based on if respondents wanted to be less, equally, or more involved in their care, which again varied by independence score. Among those who wanted to be more involved in their care, respondents with an independence score of 3 generally expressed a desire to understand more about health systems or financing ("I wish I knew more about what was covered in my insurance"), whereas respondents with an independence score of 0–2 expressed a desire to learn what to do when they were adults ("[I wish I were] more involved so I can do it by myself later"). Among those who wanted to maintain their current level of involvement, respondents with a score of 3 indicated that they were unable to be more involved ("Same involvement because I do it all already"), whereas respondents with a score of 0–2 who wanted to maintain their current level of involvement expressed comfort with the status quo ("I like that my parents take care of things for me").

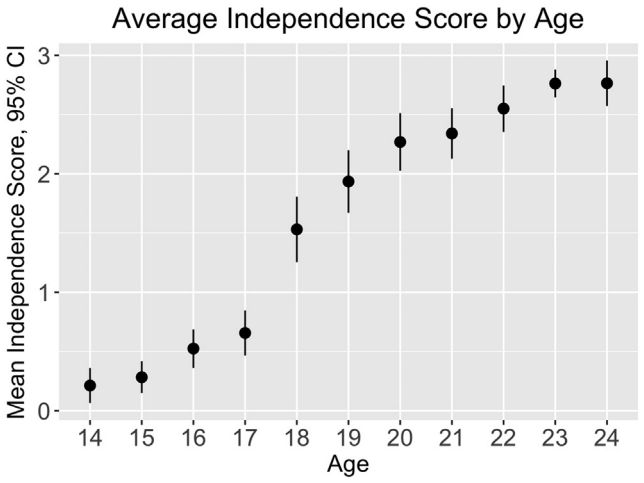

Figure 1. Average independence score by age among survey respondents. Independence scores were calculated by awarding respondents one point for each task they performed independently and approximate how independently youth are managing their health care.

Among those who wanted to be less involved, respondents reported finding their current level of involvement burdensome, regardless of their independence score ("I want to be less involved because it's a hassle").

Discussion

To our knowledge, this is the first large-scale study to elicit youths' perspectives regarding their current and desired level of involvement in their care. We found heterogeneity in the degree to which adolescents and young adults reported being involved in their health care, as well as heterogeneity in the degree to which they reported wanting to be involved. Contrary to the perceptions among some health care providers, we found that many youth are interested in becoming more involved in their health care, suggesting that youth can often be viewed as partners in health care transitions rather than barriers. However, we also found that an important minority of young adults have levels of involvement and attitudes toward involvement that may put them at risk for failing to successfully transition to adult care. These youth require special attention from policymakers and providers.

Youth desire to be involved in their health care

Providers frequently perceive adolescents themselves as an impediment to a successful transition to adult health care [12]. In an American Academy of Pediatrics survey, more than 80% of pediatricians reported that a lack of knowledge and/or self-advocacy skills was a barrier to a successful transition among children with chronic or complex health care needs (about 20% of the population) [32,33]. In a 2017 national survey about the implementation of the federally recommended health care transition protocol, providers reported that their greatest struggle was in engaging youth and their families [10].

However, in our survey, many youth (42%) wanted to be more involved in their care, whereas few (7%) wanted to be less involved. When discussing why they wanted to become more involved, most youth specifically talked about their desire to become more independent and take control of their lives. These findings would suggest that providers perceiving a lack of engagement may

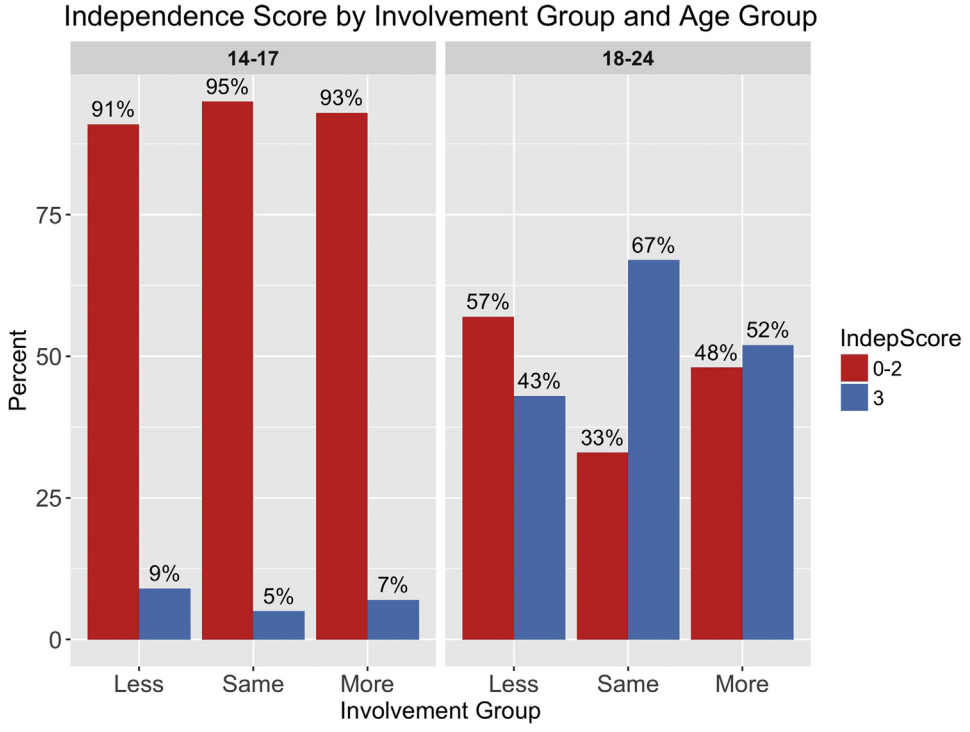

Figure 2. Respondents' desired level of involvement in their health care separated by independence score and age group.

Table 2
Questions, themes, and representative quotations

Independence score	Questions	Themes	Respondent characteristics	Quote
0–2 (completely or partially dependent on someone else for health care management)	Who schedules your doctor's appointments? Why? Who goes with you to your doctor's appointments? Why? Who picks up your prescription drugs? Why?	I need help for logistical reasons	15, white, male, some high school[a]	My mom schedules them because I do not know how to do adulty things.
			22, Asian, female, bachelor's degree[b]	My dad goes because I'm not comfortable driving. My mom sometimes goes in because I get scared/ nervous.
		I need help for financial reasons	14, black, female, some high school[b]	Mother because I do not have money for my prescription medicine.
			17, white, male, some high school	My mom goes [to my appointments] because she pays for them.
		I need help because I'm legally prevented due to age	15, white, female, some high school	My mom does that because I'm not allowed to as a minor.
			17, American Indian, male, some high school[b]	My parents [schedule and go to appointments] cause I'm underage
	Do you wish you were more or less involved in your health care? How?	I wish I were less involved	17, white, male, some high school	Less, it's kind of a hassle sometimes
		No change; I'm fine with my current level of involvement	16, Asian, female, some high school	I'm as involved as I want to be
			17, white, female, some high school	I think I'm good where I am. I'll be more when I'm older
		I wish I were more involved	14, American Indian, female, some high school[a,b]	I wish I was more involved so I know what to do when I'm older.
			14, white, transgender male, some high school[b]	More involved so I could make decisions for myself.
3 (completely independent)	Who schedules your doctor's appointments? Why? Who goes with you to your doctor's appointments? Why? Who picks up your prescription drugs? Why?	I manage these tasks on my own	16, black, male, some high school[a,b]	Just me, I do not need anyone else.
			20, black, female, some college[b]	I do because I'm an adult and it's my responsibility.
			22, white, female, Bachelor's degree	I do because I am independent enough to do that and I know my body best.
	Do you wish you were more or less involved in your health care? How?	I wish I were less involved	22, white, female, Bachelor's degree[b]	Less. I control 100% of my own healthcare but it's a really tricky system to navigate.
		No change; I already manage all my care	22, black, female, bachelor's degree	I think I'm as involved as I need to be. I really take care of the bulk of it myself.
			23, white, nonbinary, some graduate school[b]	Neither I think I'm managing everything fine.
		I wish I were more involved	20, Asian, female, some college	I wish I was since I do not understand these health insurance things.
			23, Asian, male, Bachelor's degree	Yes, understand what my healthcare provides, what I am covered for, the terms and conditions, nomenclature etc.

[a] Hispanic.
[b] Qualified for free/reduced lunch.

assume that this is because of lack of desire when in reality many youth desire to be engaged but are not for a variety of other reasons.

As states continue to implement the Six Core Elements of Health Care Transition, they should recommend that providers explicitly ask about current levels of youth engagement in their care and desire to be more involved. This knowledge could help providers identify opportunities to partner with youth who are eager to be more involved in their care, as well as youth who require greater attention based on their levels and attitudes toward involvement. This screening should be presented by pediatric and adult providers, as it is important to move youth along the continuum to transitioning to adult health care at each opportunity. For youth who infrequently receive physical examinations, primary care providers should take advantage of any other opportunities in which patients contact the health care system, including acute care visits. Importantly, responsibility for screening should not fall solely on primary care providers, as screening should also be

performed by specialists responsible for transitioning youth with chronic conditions to adult care.

For youth identified as having a low risk for poor transitions during screening, it is important for parents, educators, and providers to support youths' desire to be engaged through education and opportunities to practice independence in managing their health care. For youth identified as being at high risk for poor transitions, the same community of parents, educators, and providers must understand the perspectives of these youth to foster their desire to be engaged and provide them with the skills to eventually manage their own health care. Understanding why youth are uninterested in engaging further in their health care will help providers understand specific barriers that need to be overcome. Research is needed to identify real-life models that are most effective in maintaining engagement among youth who desire to be engaged and in increasing engagement in those who do not wish to be engaged. These models could then be highlighted and disseminated more broadly by state and federal policymakers.

Some young adults are at risk for an unsuccessful transition to adult care

Although our data suggest that most youth take over the management of their health care in early adulthood and are comfortable doing so, an important minority of young adults aged 18–24 years may be at risk for unsuccessful transitions. Specifically, more than one in five young adults were not fully independent and did not express a desire to be more involved. These youth are taking longer to successfully transition to adult care and may not successfully transition at all, increasing their risk for health care complications, especially if they have a complex or chronic disease [13]. If they do not develop these skills now, as most of their peers are, their lack of preparedness may be a risk factor for poor care in the future [34].

Although the Six Core Elements of Health Care Transition is focused on the steps necessary to integrate and transfer pediatric patients to adult care, in the future, it may be useful for this program to provide additional information on how to identify and educate young adults who are failing to demonstrate age-appropriate transition-related skills. Many of the young adults at risk for poor transitions are cared for by adult providers, meaning that they also play an important role in identifying and educating youth at risk for failing health care transitions.

Many adolescents believe their age is a legal barrier to accessing health care services independently

In our survey, 25% of adolescents reported that their age is a legal barrier preventing them from accessing health care services independently ("my dad goes [with me] because he's my legal guardian" and "I can't do that because I'm a minor"). Although it is indeed the case that children must be accompanied by adults for many types of medical care, state minor consent laws often protect the rights of youth to confidentially receive care for potentially sensitive services including sexually transmitted infections, contraceptive management, and mental health conditions [35–38]. These minor consent laws can be highlighted in policy interventions, during clinical visits, and through direct advertisements to youth [39]. Informing youth that they can access certain services privately could be one strategy to help them develop the skills they will need to manage their care later in life.

Limitations

Findings from this study need to be considered in light of some limitations. First, our sample is not nationally representative, although targeted recruitment was performed to maximize representativeness [27]. Second, although our response rate exceeds 60%, we acknowledge that respondents may differ from nonrespondents in unobserved ways [40]. For instance, it is possible that some nonrespondents had little insight or interest in the topic because they are completely dependent on others for their health care. Alternatively, some nonrespondents may have felt the questions were beneath them to answer because they are already independent. Finally, although survey questions were chosen because they are easy to understand and reflect the goals of a successful health care transition outlined in the "Six Core Elements of Health Care Transitions," we did not perform cognitive testing to assess participants' understanding. Furthermore, these questions may not wholly account for someone's ability to independently manage their health care.

Conclusion

Our large-scale mixed method study showed that many youth want to independently manage their care and should be viewed by their providers as allies in health care transitions instead of barriers. At the same time, an important minority of young adults may be at risk for unsuccessfully transitioning to adult care. Primary care providers and specialists who care for youth in outpatient settings can facilitate successful transitions by routinely screening them for their current levels of engagement in care and desire to be more involved. For youth identified as being at high risk for poor transitions during screening, providers must use the youth's perspectives to empower them to take control of their care and schedule follow-up visits specifically aimed at monitoring progress toward successful transitions. Youth-informed health care transitions will promote health care independence among youth, identify barriers that prevent them from taking ownership of their care, and set them up for success as adults.

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