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Adolescent and Caregiver Perspectives on Medical Decision-Making for Chronic Illness

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Abstract

Objective—To assess correlates of adolescent and parent perceptions of their involvement in medical decision-making (MDM).

Methods—Study participants included 28 pairs of pediatric patients with chronic rheumatologic illnesses and their parents presenting to an outpatient rheumatology clinic. Participants completed measures assessing perceptions of MDM involvement, health consciousness, and decisional conflict.

Results—Adolescent health consciousness correlated positively with parent health consciousness and adolescent valuing involvement. There was a significant positive correlation between adolescents valuing involvement in medical decisions and perception of actual involvement. Adolescents who perceived themselves as more involved in their care reported less decisional conflict. Parents who wanted to participate in MDM reported greater actual involvement.

Discussion—Adolescents who value participation in MDM reported higher levels of actual participation, suggesting their preferences may be considered by providers. Greater engagement in MDM was related to lower decisional conflict for adolescents, suggesting that including adolescents in the MDM process does not necessarily result in confusion or distress.

Keywords

Adolescent health; chronic illness; medical decision-making

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Introduction

Medical decision-making (MDM) is the umbrella term for the dynamic and evolving process of making a medical decision (McCabe, 1996). MDM is a complex construct, comprising factors including adherence, self-management, patient activation, health consciousness, and patient empowerment (Drotar, Crawford, & Bonner, 2010; Zikmund-Fisher et al., 2010). Although previous research has demonstrated that pediatric patients are motivated to be engaged in care when educated about their diseases, patient and family engagement is rarely realized in clinical settings (Alderson, Sutcliffe, & Curtis, 2006; Drotar et al., 2010). It is understood that adolescents value their involvement, and as such it is essential to understand MDM processes in pediatric populations to develop better strategies for effecting meaningful engagement (Miller & Harris, 2011).

Methods

Participants and Procedure

Participants were 28 adolescents ($M_{\text{Age}} = 16.1$ years; $SD_{\text{Age}} = 2.5$ years) and their parents who presented to an urban pediatric hospital's outpatient rheumatology clinic. The sample was composed of 20 (71%) female, 6 (21%) male, and 2 (7%) adolescents who did not report their gender, and their parents (23 (82.1%) mothers, 2 (7.1%) fathers, and 3 (10.7%) unknown). Sixteen (57.1%) adolescents were diagnosed with Juvenile Idiopathic Arthritis, 4 (14.3%) with Lupus, 7 (25%) with Other (including skin morphea and chronic recurrent multifocal osteomyelitis), and 1 (3.6%) who did not report a diagnosis. Adolescents reported a mean disease length of 6.59 years ($SD = 5.26$ years). Research staff invited potential participants who presented to the clinic for outpatient visits to participate in a survey study. The survey was designed to be brief and anonymous to protect patient confidentiality, and as a result it included limited items pertaining to disease activity. Eligible participants were 11–21 year-old English-speaking youths who were patients with chronic rheumatologic disease. All procedures were approved by the relevant hospital and university institutional review boards. Participants were asked to identify a recent medical decision at the beginning of the survey and to answer the study measures accordingly. Adolescents and parents were instructed to complete the surveys separately.

Measures

Survey measures included the Health Consciousness Scale (HCS) to assess thoughts and actions regarding positive health behaviors (Gould, 1990), the Decisional Conflict Scale (DCS) to measure feelings of conflict and uncertainty related to a medical decision (O'Connor, 1993), and the Decision Participants Interview, which included a scale for Actual Involvement (AI) and Desired Involvement (DI) and was created for this study. The AI scale assessed the degree to which each participant perceived himself/herself to be involved in making a medical decision; the DI scale assessed each participant's desired involvement.

Statistical analyses

Pearson bivariate correlations between relevant constructs are the primary analytic technique. Effect sizes (r values) and significance levels are reported below.

Results

Decision type, frequency, and examples of recent medical decisions identified by adolescents and parents can be found in Table 1. Adolescents' report of actual and desired involvement, measured on a 5-point Likert scale (from 1 to 5) with higher values representing more actual or desired involvement, was high, with adolescents both desiring involvement ($M = 4.2$, $SD = 1.1$) and perceiving themselves as being involved ($M = 4$, $SD = 1.2$). On these scales, a 4 corresponds to "a lot."

Table 2 details the bivariate correlations and significance levels between all variables of interest. Adolescent and parent health consciousness levels were positively and significantly related ($r(26) = .43$, $p = .027$). There were also significant positive correlations between adolescents valuing involvement in medical decisions and their perception of their actual involvement ($r(26) = .39$, $p = .042$), and between adolescents valuing involvement and their level of health consciousness ($r(26) = .48$, $p = .009$). A significant negative correlation was found between adolescents' perception of their actual involvement in medical decisions and feelings of decisional conflict ($r(26) = -.64$, $p < .001$). Lastly, parents who wanted to participate in MDM reported more actual participation, $r(26) = .82$, $p < 0.001$.

Discussion

This study suggests that the constructs of desired and actual involvement, decisional conflict, health consciousness, and how much adolescents value involvement are consistently related. Considering health consciousness findings first, it appears that parents who are more health-conscious have adolescents who are also more health-conscious. It is possible that as adolescents with chronic illness become more attuned to changes in their health, parents adaptively become sensitive to their adolescents' verbalizations of health concerns. Alternatively, parents with greater levels of health consciousness may set an example (or otherwise compel) adolescents to focus more on their health and well-being. This could be explored further by comparing health consciousness ratings of a chronically ill sample to a non-chronically ill sample to evaluate the relationship between parent and adolescent health consciousness in the absence of chronic illness.

Adolescents with more health consciousness levels were also more likely to value involvement in care. Perhaps increased adolescent health consciousness represents a positive coping mechanism that leads youth to believe their participation in MDM is important. In turn, adolescents who valued MDM participation reported that they were more likely to actually *want* to participate and that they actually *have* participated in MDM. This relationship held even more strongly for parents; when parents reported wanting to participate in MDM, they were highly more likely to report actual participation. As a potential clinical tool, increasing an adolescent's health consciousness may also increase disease comprehension, desire for actual involvement, and actual involvement. Alternatively,

facilitating adolescent participation in MDM may help increase adolescent health consciousness.

One potential downside of adolescent participation in MDM is the potential for the adolescent to be dissatisfied or conflicted over the eventual decision, possibly caused by the stress of MDM or the awareness of other appealing options not chosen (i.e., decisional regret) (Coyne, O'Mathuna, Gibson, Shields, & Sheaf, 2013). Fortunately, these results suggest that adolescents who perceived themselves as being more involved in MDM experienced *less* decisional conflict. Thus, adolescent involvement in MDM carries less of a risk of negative effects while still having a potential positive influence on treatment adherence and psychosocial stress (Coyne et al., 2013).

It should be noted that there were several limitations in the current study, including a small sample size, mostly female respondents (both adolescents and parents), and cross-sectional self-report measures, so results are strictly correlational and causal relationships cannot be assumed. The role of gender in medical decision-making preferences is not currently understood within pediatric chronic illness, but remains an important area to investigate in future research. Additionally, adolescents with chronic illnesses may be more health conscious and more engaged in their healthcare than peers given the longstanding need for intervention, and results should be interpreted within the framework of pediatric chronic illness. Further, this sample of adolescents with chronic rheumatologic illnesses is not necessarily generalizable to adolescents with other chronic diseases.

Conclusion

Results suggest that adolescents desire involvement and perceive themselves as being involved in MDM. Furthermore, adolescents who pay closer attention to their health value their participation in MDM more, and adolescents who value their participation in MDM report higher levels of actual participation. Parents who desired greater involvement also reported higher levels of actual participation. Collectively, these results support continued research on youth-focused MDM to further the field's efforts to provide patient-centered care that is responsive to both adolescent and parent perspectives and goals.

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Table 1

Decision Types and Examples.

Cohort	Decision Type	n(%)	Example
Adolescents	<i>Escalation of therapy</i>	8(28.6)	"I had been very sick for several months the meds I was taking were not working. We all agreed I should start Rituxan."
	<i>Switching therapies due to side effects</i>	1(3.6)	"My family and I decided to put myself on Celcept instead of my previous one because it gave me constant headaches."
	<i>Switching therapies (unspecified reason)</i>	5(17.9)	"Switching from Enbrel shots to Humira."
	<i>Weaning therapy</i>	3(10.7)	"As my JRA got better we decided to lower my medication. My doctor and family had to decide how to go about doing this that would be the best for me. The doctor made the decision that seemed to work out great."
Parents	<i>Other</i>	3(10.7)	"Decide whether to try physical therapy or biopsy to see if an infection who tried it."
	<i>Missing</i>	8(28.6)	
	<i>Escalation of therapy</i>	10(35.7)	"Her knees were swollen and methotrexate and prednisone did not help. Drained knees and put on Humira."
	<i>Switching therapies due to side effects</i>	2(7.1)	"Change in medication for scleroderma. The medication methotrexate was giving her headaches."
	<i>Switching therapies (unspecified reason)</i>	2(7.1)	"We were discussing a change in medication to help make It easier for my daughter to be consistent in taking her medication. Also discussed auto-injection versus self-injecting."
	<i>Weaning therapy</i>	4(14.3)	"The decision to begin weaning off methotrexate as she was starting college. This due to concerns about the general use of alcohol on college campuses."
	<i>Other</i>	5(17.9)	"Decision about whether to go to physical therapy or not. Drs recommended it as a solution to pain, only downside was time involved when she already has many apps."
	<i>Missing</i>	5(17.9)	

Escalation of therapy: Escalating therapy, to include whether to start new therapy, as well as selection of new therapy*Switching therapies due to side effects:* Switching therapies because of unwanted or intolerable side effects*Switching therapies (unspecified reason):* Switching therapies due to an unknown reason*Weaning therapy:* Weaning or discontinuation of therapy*Other:* Non-pharmacologic therapy decisions or medication decisions where escalation/weaning was not specified by participant*Missing:* Missing responses as well as responses that did not clearly describe a decision

Table 2

Correlations among measure variables.

	Mean (SD)	1	2	3	4	5	6	7	8	9
1. Adolescent Actual Involvement	4.00 (1.18)	--								
2. Adolescent Desired Involvement	4.22 (1.21)	0.49**	--							
3. Adolescent Valuing Involvement	4.46 (0.64)	0.39*	0.64**							
4. Caregiver Actual Involvement	4.31 (0.84)	-0.19	-0.22	-0.11	--					
5. Caregiver Desired Involvement	4.42 (0.72)	-0.13	-0.13	-0.25**	0.82**	--				
6. Adolescent DCS	40.12 (11.21)	-0.64**	-0.47*	-0.51**	0.28	0.29	--			
7. Caregiver DCS	36.56 (11.56)	-0.34	-0.10	0.07	-0.11	-0.38 [†]	0.26	--		
8. Adolescent HC	15.71 (5.26)	0.25	0.06	0.48**	0.25	-0.14	-0.37 [†]	-0.03	--	
9. Caregiver HC	19.04 (3.90)	0.33	-0.13	0.24	0.29	0.15	-0.02	-0.15	0.43*	--

[†] p < 0.1

* p < 0.05

** p < 0.01