

Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study

Jennifer M. Knopf MA,* Richard W. Hornung Dr PH,† Gail B. Slap MD MS,‡ Robert F. DeVellis PhD§ and Maria T. Britto MD MPH¶

*Project Specialist, Division of Adolescent Medicine, Center for Innovation in Chronic Disease Care, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, †Professor of Environmental Health, Division of General and Community Pediatrics, Cincinnati Children's Hospital Medical Center and the University of Cincinnati School of Medicine, Cincinnati, OH, ‡Professor of Pediatrics and Internal Medicine, Office of Fellowship Programs, Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine, Philadelphia, PA, §Research Professor, Department of Health Behavior and Health Education, School of Public Health, Thurston Arthritis Research Center, University of North Carolina at Chapel Hill, Chapel Hill, NC and ¶Professor of Pediatrics, Division of Adolescent Medicine, Center for Innovation in Chronic Disease Care, Cincinnati Children's Hospital Medical Center and the University of Cincinnati School of Medicine, Cincinnati, OH, USA

Abstract

Correspondence

Jennifer M. Knopf
Division of Adolescent Medicine
Center for Innovation in Chronic
Disease Care
Cincinnati Children's Hospital Medical
Center
MLC 7027, 3333 Burnet Avenue
Cincinnati, OH 45229-3039
USA
E-mail: jennifer.knopf@cchmc.org

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Objective Shared decision making may increase satisfaction with health care and improve outcomes, but little is known about adolescents' decision-making preferences. The primary purpose of this study is to describe the decision-making preferences of adolescents with chronic illnesses and their parents, and the extent to which they agree.

Design Survey.

Setting and participants Participants were 82 adolescents seen at one of four paediatric chronic illness subspecialty clinics and 62 of their parents.

Main variables Predictor variables include sociodemographics, health parameters, risk behaviour, and physical and cognitive development. The main outcome variable is preferences for decision-making style.

Results and conclusions When collapsed into three response categories, nearly equal percentages of adolescents (37%) and parents (36%) preferred shared decision making. Overall, the largest proportion of adolescents (46%) and parents (53%) preferred passive decision making compared to active or shared decision making. Across five response choices, 33% of pairs agreed. Agreement was slight and not significant. Improved general health perceptions (OR = 0.76, 95% CI = 0.59–0.99) and improved behaviour (OR = 0.75, 95% CI = 0.56–0.99) were significantly associated with parents' preferences for less active decision making. Older age was significantly associated with agreement (OR 1.58, 95% CI = 1.09–2.30) between parents and adolescents. The paucity of significant predictor variables may indicate physicians need to inquire directly about patient and parent preferences.

Introduction

Shared decision making between adults and physicians has been shown to increase satisfaction with health care.¹⁻³ In addition, there is evidence that compared to patients who were relatively inactive in making treatment decisions, those who experienced a more active role had fewer physical, social and emotional problems following surgery, less fatigue and a better quality of life.^{4,5} The majority of the literature focuses on adult preferences for decision making with comparatively little directed towards adolescents' preferences.

The definition of shared decision making varies in the literature,⁶ but it most frequently refers to the structure elucidated by Charles *et al.*⁷ In this model, the doctor and the patient work together to come to a decision. The characteristics of this model are that the interaction must take place between a doctor and a patient, both of whom must share information and contribute to the process of decision making. The process is complete when both agree on a treatment option.^{7,8} The shared decision making model was initially described in the context of treatment decisions for a life-threatening illness,⁷ but it has also been described in the context of primary care,^{9,10} care of chronic conditions,^{11,12} and paediatric care.¹³

The shared decision making model falls in between the extremes of two other models: paternalistic and informed-decision making. In the paternalistic model, or passive model, the physician assumes an authoritative role in which he or she informs the patient about the selected treatment without the patients' input or eliciting patient preferences. In an extension of this model, the 'physician-as-perfect-agent' model, the physician elicits the patients' lifestyle preferences, goals, and values to choose a treatment option equal to what the patient would choose. At the opposite end of the spectrum is the active, or informed decision-making model. In this model the physician transfers clinical knowledge to the patient who then is able to make an independent decision.

There is a great deal of literature surrounding preferred decision-making styles on the passive-active spectrum, but reported preferences vary

widely. Those who cite shared decision making as their preference range from 27% of patients with various types of cancer¹⁴ to 68% of those reading a vignette about an invasive medical procedure.¹⁵ Those preferring passive decision making range from 20% of patients with breast cancer¹⁶ to 69% of patients with chronic disease.¹⁷ In general, very few people want to make decisions on their own. The reported variation in preferences is generally ascribed to varying methodology (i.e. predicted experience vs. vignette), specific scale employed, participant population (i.e. healthy vs. ill), and to the type of decision being made. For example, patients reading mortality vignettes preferred more physician-led decision making than when reading morbidity and quality of life vignettes.¹⁸ Patients also may prefer a more shared approach when considering lifestyle and behaviour choices.¹⁹

Age is the most consistent predictor of decision-making preferences, with younger individuals preferring a more active role than older individuals.^{3,14,17,20-23} Adult patients who prefer shared decision making are also more likely to be female, white, in better health, and have more education.^{3,14,17,24-26} The magnitude of these associations is typically small, however, and some studies are contradictory.^{27,28} In addition, qualitative studies have found that influences on decision-making preferences include: knowledge about diagnosis, a longer time since diagnosis, the chronicity of a disease, wanting control over one's body, lack of trust in a physician, and personal characteristics (i.e. curiosity and assertiveness).²⁹⁻³²

While there is a multitude of research about adult patients and decision-making preferences, there is relatively little research involving child and adolescent patients. Further, most of the existing studies focus on parents' preferences or are based on data collected from health-care providers, record review and observational data collection,³³⁻³⁶ rather than data generated by adolescents themselves. This is an especially important area to understand in respect to adolescents with chronic illnesses because their treatment decisions may impact their long-term care and adherence.

Similar to the adult patient literature, there is variation in parents' reported preferences. Those preferring a shared approach range from 43.5% considering the method of anaesthetic administration³⁷ to nearly 60% of parents of children with cancer.³⁸ Those preferring passive decision-making range from 13.6% of parents of children with cancer³⁸ to 45.5% of parents managing postoperative nausea and vomiting.³⁷ In general, preferences for active decision making is low,³⁷⁻³⁹ but when dichotomized into passive and active preferences, 72% of parents preferred an active approach when treating a child's acute otitis media. In addition, parents preferences varied by decision type. For example, parents of children scheduled for elective surgery preferred that physicians lead decision making for intra-operative pain management, but preferred a shared or active role with regard to parent presence for anaesthesia induction and emergence.³⁷ In a qualitative study of decision making during physical therapy, parents perceived that the therapists made technical decisions, while the therapists perceived that parents made lifestyle and value decisions.⁴⁰

In addition, only one 2001 study found that any demographic variable predicted parents' decision-making preferences. Similar to adult patients, African-American parents were significantly more likely to prefer passive decision making than white parents.³⁷ A 1999 study did not find any demographic variables associated with preferences.³⁹

Few studies have addressed the perspective of the child or adolescent, but those suggest many children and adolescents do want to participate in their health care. One qualitative study in the United Kingdom focused on adolescents and young adults with diabetes aged 16-25 years. The findings suggested that adolescents and young adults are willing to participate during consultations and in decision making.⁴¹ A 1996 study qualitatively investigated the roles of parents and their children and adolescents while making health-care decisions. All children in the study with scoliosis were 'involved' in the decision-making process, but involvement ranged from discussions with parents and health-care

providers to making the final decision regarding surgery. In three of the eight cases, the child's input was either the final decision, or it convinced parents to consent to surgery. The patients and parents all reported being satisfied and appreciating involvement in the process. In the same study, parents of children with cystic fibrosis considered themselves to be 'involved' in decision making by having discussions with health-care providers and making decisions about at-home respiratory treatments. Parents reported that children were allowed to make some decisions about daily management of their illness or when hospitalizations might be necessary. Some parents waited for health-care providers to include their children in decision making, while others did not want their children to make the final decision because of concerns for potentially negative consequences.⁴² Similarly, in a study of parents and patients from 3 to 18 years of age with cancer, both patients and parents expressed a desire to be included in bedside rounds. Parents, however, often preferred that their children not be included out of concern that the information was upsetting, a perception that was not consistent with children's self-report.⁴³ In addition to demonstrating that children and adolescents desire participation, these studies indicate that parent and patient preferences for involvement in decision making may not always be in agreement.

Minimal agreement for decision making is not unusual in the literature.^{44,45} However, most of the published literature has focused on agreement of patients and proxies for medical decisions or health-related quality of life, or on physicians' understanding of patient's decision-making preferences. For example, in one study, less than 40% of physician and patient dyads were in agreement when given decision-making options identical to the ones provided in our study.⁴⁴ Similarly, Janz *et al.* found agreement in less than 40% of dyads consisting of physicians and breast cancer patients when asked what level of decision making was used.⁴⁵ To our knowledge, there are no published data on the agreement of parents and adolescents for

various modes of medical decision making. This study addresses this gap.

Adolescents with chronic illnesses will soon be adults with chronic illnesses who will be responsible for their own health-care decisions. Based on available evidence in the adult literature¹⁻⁵ it seems likely that involvement in decision making may also benefit adolescents. This may be especially true for adolescents with chronic illnesses, who are responsible for the day-to-day management of their health. However, since their parents must consent to treatment for minor children, and parents often provide guidance for young adults with chronic illnesses, it is important to understand parent and patient agreement about decision making. It is also important for health-care providers to understand the nature of adolescent and parent decision making given the triadic nature of the relationship.^{13,46}

The primary aim of this paper is to describe the decision-making preferences of adolescents with chronic illnesses and the preferences of their parents, as well as the extent to which they agree on adolescent decision making. Based on adolescent desire for autonomy and the literature suggesting younger people prefer more active decision making,^{3,14,17,20-23} we hypothesized that adolescents would prefer shared decision making. The secondary aim of the paper is to explore demographic, health, and developmental factors that influence patient and parent preferences, as well as agreement about decision making.

Method

This study is part of a larger, observational cohort study examining health-care preferences of adolescents with chronic illnesses. The single-item scale of decision-making preferences was added to the larger, existing study, which was not created for this particular research question. Therefore, it should be considered a pilot study. Data were collected from the last 82 participants recruited for the larger study and from the parents of those same participants who were < 18 years of age. Participants completed this

item at the first visit only. Therefore, only data from this visit were analysed. The study was approved by the Committee for the Protection of Human Subjects. Details of recruitment and data collection have been previously reported⁴⁷ and are summarized below.

Participants

This study occurred at a large, urban children's hospital in the Midwestern United States. Participants were being treated by paediatric specialists at one of four subspecialty clinics: cystic fibrosis, juvenile rheumatoid arthritis, inflammatory bowel disease and sickle cell disease. These four chronic illnesses were chosen because they are well-defined, and there are multiple intensive treatment options requiring the cooperation and adherence of the adolescent. For example, all patients with cystic fibrosis must do airway clearance at home, but different methods (i.e. pneumatic vest, flutter device, manual chest physiotherapy) are available. Patients diagnosed less than 2 years prior were excluded to ensure that participants had substantial experience as health-care consumers. Adolescents gave written assent or consent, as did guardians of those < 18 years of age.

Measures

Preferences for decision-making involvement

Adolescents and guardians completed a previously validated ordinal scale item, measuring preferences for adolescent involvement in medical decision making.⁴⁸ This scale was selected because it is widely used,^{14,25,37,39,44} thus facilitating comparison with other populations, and because it assesses decision-making preferences in general, rather than preferences for one type of decision. For the parents, the original wording was changed from 'I' to 'my adolescent'. There were five possible response options: (1) The doctor should make the decisions using all that he/she knows about the treatment; (2) The doctor should make the decision by strongly considering my (my adolescent's) opinion; (3) The doctor and I (my adolescent) should make

the decisions together on an equal basis; (4) I (My adolescent) should make the decisions but strongly consider the doctor's opinion; and (5) I (My adolescent) should make the decisions, using all that I (he/she) know(s) and learn(s) about the treatments.

Demographic, health and developmental factors The following factors were included based on a previously demonstrated relationship to decision-making preferences (sociodemographics, health parameters, cognitive development) or due to their relationship with adolescent preferences for communication with health-care providers (risk behaviour, physical development).

Sociodemographics Participants self-reported gender, age, race and ethnicity. Health insurance status, parental education and household income were self-reported by those ≥ 18 years of age and by guardians of minor participants.

Health parameters Adolescent preferences for involvement may vary by physical and psychosocial functioning. We used three single-item measures from the previously validated Child Health Questionnaire⁴⁹ to assess general health status, global behaviour and change in health status, as well as two multi-item scales to assess general health perceptions and mental health.

Risk behaviour Discussing risk behaviours with health-care providers is more likely to be preferred by adolescents who have already engaged in those behaviours.^{50,51} The *Youth Risk Behaviour Survey (YRBS)*⁵² assessed selected previous and current risk behaviours (i.e. alcohol, tobacco and marijuana use, sexual intercourse, school performance and seatbelt use). This measure has been used repeatedly and found to be reliable.⁵³ A total risk score, ranging from 0 to 6, was calculated for each adolescent by awarding one point for each reported risk behaviour.

Physical development Pubertal maturation correlates with adolescents' expressed preferences for information and counseling.^{50,54} Adolescents' determined their pubertal stage using self-assessment techniques⁵⁵ that correlate with physical assessment.^{56,57}

Cognitive development Adolescents generally transition during early or middle adolescence from the third to fourth stage of cognitive

development (concrete to formal operational thinking) resulting in greater ability to understand abstract concepts and unexplored possibilities. Adolescents who have reached the final stage, formal operational thinking, may express more concerns about future health and desire a different level of involvement in decision making. The *How is your logic?* Scale⁵⁸ measures qualitative cognitive development through 13 items measuring concrete and formal thought. Adolescents were classified in one of three categories representing the final three stages of cognitive development (i.e. concrete operational thought or earlier, transitional, or formal operational thought).

Statistical analysis

Analyses were conducted using SPSS version 12.0 (SPSS Inc., Chicago, IL, USA) and SAS version 9.1 (SAS Institute, Inc., Cary, NC, USA). Means and simple proportions were used to describe the study population. A chi-squared test was used to determine if within-group and between-group preferences were significantly different. The *k* statistic was used to determine the chance adjusted agreement between adolescents and parent responses.⁵⁹ A McNemar-Bowker test, a generalized version of the McNemar's test for the analysis of matched pairs, was performed to indicate the significance of concordance in a particular direction. In these analyses, only data from adolescents whose parents also provided data were included.

To explore the associations between demographic, health and developmental factors and the adolescent and parent preferences, univariable and multivariable analyses were conducted. To facilitate further analyses, the five initial response categories were collapsed into three categories as has been done in multiple other studies:^{14,25,37,39} Passive (option 1 or 2), Shared (option 3), or Active (option 4 or 5). To avoid arbitrarily categorizing many continuous variables, ordinal logistic regression was used to assess the associations between the collapsed response categories and the categorical and continuous predictor variables.

Finally, to investigate factors associated with exact adolescent-parent agreement, pairs of responses were coded as either agree or disagree on the five-point scale. Agreement was defined as the adolescent and parent indicating the same decision-making preference on the five initial response categories. Univariable and multivariable logistic regression was repeated to assess the association between agreement and predictor variables.

The proportional odds assumption was tested and met for all reported ordinal logistic regression analyses. For both multivariable models, variables were added and removed until all included variables were significant at the 0.1 significance level.

Results

Participant characteristics

The mean age of adolescents was 15.4 years, 45% were male, and 84% had commercial health insurance. In addition, pubertal development was skewed toward maturity, while only 25% of respondents reached formal operations or full cognitive maturity. Parents were evenly divided in their education, with nearly one-third obtaining a college degree. (See Table 1).

Decision-making preferences

All analysis was carried out for both the 5-point and the collapsed 3-point scales, but there was no difference in significance. Therefore, only the analysis of the 3-point scales are reported here, as is common in the literature.^{14,25,37,39}

When the scale is collapsed to the three point scale and group responses are examined, both adolescents (46%) and parents (53%) preferred passive decision making, followed by shared decision making (adolescents: 37%; parents: 36%). Only 17% of adolescents and 11% of parents preferred active decision making.

There was a significant difference in the preferences of adolescents ($\chi^2 = 10.92$, $P = 0.004$) and in the preferences of parents ($\chi^2 = 16.48$, $P = 0 < 0.001$). When comparing the prefer-

Table 1 Participant characteristics

Mean (\pm SD), age, years	15.4 (\pm 2.33)
Male, <i>n</i> (%)	37 (45)
Race, <i>n</i> (%)	
White	68 (83)
Black	14 (17)
Diagnosis, <i>n</i> (%)	
Cystic fibrosis	12 (15)
Inflammatory bowel disease	22 (27)
Juvenile rheumatoid arthritis	35 (43)
Sickle cell anaemia	13 (16)
Parent/guardian education, <i>n</i> (%)	
High school graduate or less	31 (39)
Some college	23 (29)
College graduate or more	25 (31)
Income, <i>n</i> (%)	
< \$25 000	7 (9)
\$25 000–\$50 000	20 (25)
\$50 000–\$75 000	19 (24)
> \$75 000	21 (26)
Don't know	14 (17)
Health insurance, <i>n</i> (%)	
Commercial	69 (84)
Public	10 (12)
Other	2 (3)
None	1 (1)
Self-assessed pubertal stage, <i>n</i> (%)	
Prepuberty or early puberty	13 (16)
Middle puberty	40 (50)
Mature	27 (34)
Cognitive development, <i>n</i> (%)	
Concrete operations or earlier	33 (41)
Transitional	26 (33)
Formal operations	21 (26)
Risk Behaviours, %	
Tobacco use ever	23 (28)
Marijuana use ever	10 (12)
Alcohol use ever	35 (43)
Sexual intercourse ever (\geq 13 years of age only)	17 (27)
Grades lower than average	17 (21)
Seatbelt use less than always	34 (42)
Quality of life score (\pm SD)	
Single item for general health	72 (\pm 25)
Single item for behaviour	81 (\pm 18)
Mental health	74 (\pm 14)
General health perceptions	59 (\pm 21)

ences of adolescents as a group to the preferences of parents as a group, there was no significant difference ($\chi^2 = 1.16$, $P = 0.5$). (See Table 2).

When comparing individual pairs of adolescent and parent responses, only 33% of the pairs were in agreement. Using the criteria of Landis

Table 2 Group responses of adolescent and parent pairs for preferences for decision making ($n = 62$ pairs)

	Adolescent preferences			
	Passive (%)	Shared (%)	Active (%)	Total (%)
Parent preferences				
Passive (%)	16 (26)	9 (15)	8 (13)	33 (53)
Shared (%)	8 (13)	11 (18)	3 (18)	22 (36)
Active (%)	2 (3)	4 (6)	1 (2)	7 (11)
Total (%)	26 (42)	24 (39)	12 (19)	62

and Koch,⁶⁰ agreement was slight when adjusted for chance and not significant ($k = 0.076$, $P = 0.10$). In addition, the McNemar-Bowker test was calculated and it was not significant in either instance (McNemar-Bowker $\chi^2 = 3.97$, $P = 0.27$) indicating no substantial association of responses between parents and adolescents.

Decision-making preferences and participant characteristics (univariable)

Univariable analyses between decision-making preferences and patient characteristics are summarized in Table 3. There were no significant associations between demographic and developmental factors and adolescent preferences, although cognitive level was marginally associated ($P = 0.06$). This would suggest that

advancement in cognitive level is associated with a 40% decrease in the odds of preferring active decision making (OR = 0.60, 95% CI = 0.35–1.01). Three factors were significantly associated with parental preferences for adolescents' involvement in decision making: general health perceptions ($P = 0.04$), global behaviour ($P = 0.05$), and pubertal stage ($P = 0.05$). With a 10-point improvement in general health (on a 100-point scale), there is a 24% decrease in the odds of preferring active decision-making (OR = 0.76, 95% CI = 0.59–0.99). With a 10-point improvement in behaviour (on a 100-point scale), there is a 25% decrease in the odds of preferring active decision-making (OR = 0.75, 95% CI = 0.56–0.99). For each level of advancement in pubertal stage, the odds of parents preferring active decision making approximately doubles (OR = 2.05, 95% CI = .997–4.21).

Decision-making preferences and participant characteristics (multivariable)

To assess factors independently associated with preferences for shared decision-making, we conducted separate ordinal regressions for adolescents and parents. Since there was a significant relationship ($r = 0.665$, $P < .01$) between general health perception and the single-item

Table 3 Univariable associations for adolescent and parent preferences

	Adolescent			Parent		
	β	SE	P -value*	β	SE	P -value*
Age	0.004	0.09	0.96	0.228	0.13	0.09
Behaviour	0.006	0.01	0.63	-0.029	0.02	0.05
Change in health status	0.187	0.19	0.32	-0.088	0.23	0.71
Cognitive development	-0.518	0.27	0.06	-0.16	0.33	0.62
General health perceptions	-0.005	0.01	0.64	-0.027	0.01	0.04
Health insurance	-0.464	0.56	0.41	0.095	0.70	0.89
Mental health	-0.024	0.02	0.10	-0.011	0.02	0.55
Parental education	-0.212	0.43	0.62	-0.678	0.54	0.21
Parental income	-0.326	0.24	0.17	-0.222	0.29	0.44
Pubertal stage	0.105	0.31	0.73	0.718	0.37	0.05
Race	0.292	0.55	0.59	-0.66	0.68	0.34
Sex	-0.102	0.42	0.81	-0.408	0.50	0.41
Single-item assessment of global health	-0.001	0.01	0.94	-0.001	0.01	0.42
Total risk score	0.038	0.13	0.77	0.259	0.16	0.11

*Test for trend in ordinal categorical variables.

assessment of global health, only multi-item scale general health perception was entered into the regression model.

No adolescent model is reported as only one variable, cognitive development, ever reached the 0.1 significance level. For the parent model, only two factors approached significance: global behaviour ($P = 0.07$) and pubertal stage ($P = 0.08$). A 10-point improvement in behaviour (on a 100-point scale) was associated with a 25% decrease in the odds of preferring active decision making (OR = 0.75, 95% CI = 0.56–1.01). With each advance in adolescents' pubertal stage, there was an approximate doubling of the odds that parents would prefer active decision making (OR = 1.95, 95% CI = 0.93–4.05).

Agreement in decision-making preferences and participant characteristics

Finally, we examined factors associated with adolescent and parent agreement. There were no significant univariable associations (Table 4). However, in the multivariable model, age ($P = 0.02$) and pubertal stage ($P = 0.02$) were both significant. With each increasing year of age the odds of agreement increased by 58% (OR = 1.58, 95% CI = 1.09–2.30). As adolescents advance one pubertal stage there is a 72%

Table 4 Univariable associations for adolescent and parent agreement

	β	SE	<i>P</i> -value
Age	0.160	0.14	0.26
Behaviour	-0.014	0.02	0.37
Change in health status	0.015	0.25	0.95
Cognitive development	0.223	0.35	0.52
General health perceptions	-0.015	0.01	0.29
Health insurance	-1.700	1.09	0.12
Mental health	-0.017	0.02	0.38
Parental education	0.185	0.59	0.75
Parental income	0.584	0.34	0.09
Pubertal stage	-0.706	0.40	0.08
Race	-1.833	1.09	0.09
Sex	0.693	0.56	0.21
Single-item assessment of global health	-0.010	0.01	0.39
Total risk score	-0.051	0.18	0.77

decrease in agreement (OR = 0.28, 95% CI = 0.10–0.82). Because the effect of pubertal stage was unexpected, and because pubertal stage is correlated with age ($r = 0.45$, $P < 0.001$), we examined the possibility that collinearity was responsible for the unexpected effect. However, when pubertal stage was entered into the model alone, the direction of the effect remained the same ($\beta = 0.49$, $P = 0.078$), although somewhat diminished. Finally, there is an 88% decrease in the odds of agreement for public insurance compared to private insurance (OR = 0.12, 95% CI = 0.01–1.22).

Conclusions

We had hypothesized adolescents and parents would prefer shared decision making, but both groups preferred passive decision making on a 3-point scale, followed closely by shared decision making. Similar to the adult patient and parent literature, very few adolescents or parents wanted adolescents to make treatment decisions independently.

In examining parents' preferences for their adolescents' participation in decision making, parents as a group tended to prefer a lesser degree of participation for their adolescents than the adolescents desired, though this difference was not statistically significant. When we compared pairs, the results were not even marginally significant, but this was likely because the study was a pilot and our sample size was modest. A larger study would help determine if real but small differences exist. Parents in our study preferred that their adolescent children primarily allow physicians to make decisions while considering the adolescent's opinion. In our study, only 33% of the parent and adolescent dyads agreed on a decision-making style, but minimal agreement on decision making is not unusual in the literature.^{44,45}

Based on the adult literature and adolescent developmental theory, we had anticipated that age, parental education and general health would be associated significantly with preferences. However, in our exploratory analysis, cognitive development was only marginally

associated with adolescent preferences, while general health perceptions, global behaviour, and pubertal stage had marginal associations with parental preferences. Although we had limited statistical power to detect these associations, other published studies have also found few, if any, significant associations between demographic factors and parents' decision-making preferences.^{37, 39} Furthermore, in a 1998 review of adult patient preferences for clinical decision making, approximately 80% of the variance in decision-making preferences remained unaccounted.²⁷

Though marginal, the association of advanced cognitive development and preferences for passive decision making were unexpected. It is possible that as adolescents begin to grasp the complexities of medical decision making, they may prefer their parents and physicians to lead the decision-making process. A second unexpected finding is the opposite effects of increasing age and pubertal stage on parent-adolescent agreement. This finding cannot be explained by collinearity, nor can it be explained by any previously published research. If these findings are replicated in future studies, further exploration would be warranted.

Many of the inconclusive findings in our study are likely due to our small sample size of 82 adolescents and 62 parents. The adult literature suggests that hundreds of participants are needed to detect an association between demographic factors and decision-making preferences. Our study, however, can provide guidance to other investigators about the larger sample size that will likely be needed to detect these associations in adolescents.

Despite the previous validation of our measure,^{14,48} and its use in a number of published studies,^{25,37,39,44} it uses only a single, general question about decision-making preferences. The question was asked without additional context as part of a broader research study. The limitations of this methodology are threefold: There is no consideration of what 'involvement' means to the adolescent and parent; what preferences would be for different types of decisions; or whether adolescents would have chosen the

same option if they could consider their parents' input as well.

There is much debate in the literature as to what constitutes 'involvement' in decision making. The seven domains of involvement in decision making proposed by Entwistle and Watt demonstrate the complexity of decision making.⁶¹ Our single-item question does not capture the intricacies of doctor-patient communication, the state of a patient when involved in medical decision-making, nor the feelings of adolescents and parents regarding their participation in decision making. Entwistle and Watt also suggest that when considering patient preferences for decision making, a range of tasks should be considered from 'recognition and clarification of a problem' to 'the evaluation of the solution adopted'. Similarly, Wirtz *et al.* suggested that patient participation should not be limited to making a decision based on a set of treatment options, but also on deciding what those treatment options should be.⁶²

Furthermore, our item does not allow for any analysis as to how the adolescent and parent interpreted the question. We do not know what they believe their role in being a passive, collaborative, or active participant constitutes. Previous research has demonstrated that patient participation of decision making does not always match objective measures or qualitative interviews,^{40,63,64} patients feel that the question responses do not match their roles,⁶⁵ and that patients feel that some decisions such as obtaining a diagnostic test do not require a decision.⁶⁶ In addition, receiving information may be sufficient involvement for some patients. Deber *et al.* found a high desire for information in nearly 80% of patients, although many wanted more physician control for problem-solving tasks.¹⁸ Similarly, nearly 100% of respondents surveyed by Levinson *et al.* wanted to be asked their opinion and presented with options, but just over 50% preferred that the physician make the final decision.²⁴ Although we cannot separate decision-making preferences and preferences for involvement, it is possible that adolescents may not possess the cognitive maturity necessary to conceptualize and

distinguish various type of decision making. Further study of parents is certainly warranted as well. Qualitative studies may also help illuminate adolescent reasoning and expressed preferences for decision making.

Participants in our study may have preferred a different level of decision making if they could indicate to what degree their parents could participate as well. This transitional developmental pattern is likely the reality in many clinical settings. To our knowledge, there is no investigation into the decision making process when an additional individual is introduced to the process and all complexities are magnified. Finally, our intent was to examine the decision-making preferences of adolescents with chronic illnesses as they are more frequent health-care consumers than healthy adolescents. Therefore, our findings should not be generalized to the general adolescent population.

In addition to a study with a larger sample size and qualitative research for adolescent preferences in decision making, other areas merit future study. These should be conducted in a manner suited to understanding the complexities of the process. First, is an investigation of adolescents' preferences for specific types of decisions, such as one time medical decisions vs. those addressing chronic problems, rather than decision-making preferences in general. Second, it is important to understand whether adolescents' actual experience of participating in medical decisions matches their stated preference. Finally, because parents are important sources of advice and support for adolescents with chronic illnesses and because they are responsible for consenting to treatment until the adolescent reaches legal age, it is important to understand how the level of parental involvement affects adolescents' decision-making preferences.

The present study provides the first data regarding adolescent-parent agreement regarding decision making and provides preliminary insights into the decision-making preferences of adolescents with chronic illnesses, as well as into the level of involvement parents prefer for their adolescents. It adds to the growing body of knowledge suggesting that patients' values for

their treatment and outcomes are highly personal. Providers are unlikely to be able to infer their patients' values or preferences based on demographic or development factors and the adult literature. Hence, it is a reasonable first step for physicians to directly ask adolescents and their parents about their wishes. This may help improve adolescents' satisfaction with the health-care system, as well as their transition into the adult health-care system.

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