

Children's Medical Services Network

Decision Making Experiences of Adolescents Enrolled in Children's Medical Services Network

June 2008



Institute for
CHILD HEALTH POLICY
UNIVERSITY OF FLORIDA

Prepared By:

**Caprice Knapp, PhD¹
Assistant Research Scientist
Institute for Child Health Policy
University of Florida**

**Vanessa Madden, BSc
Research Program Coordinator
Institute for Child Health Policy
University of Florida**

**Veronica Feeg, PhD
Professor, Department of Women's Children's & Family Nursing
Department of Nursing
University of Florida**

**I-Chan Huang
Assistant Professor
Departments of Epidemiology and Health Policy Research
University of Florida**

**Elizabeth Shenkman, PhD
Director,
Institute for Child Health Policy
Professor, Departments of Epidemiology and Health Policy Research
University of Florida**

¹ The authors thank Shivangi Khargonekar and Jodie Orozco for excellent research assistance.

Table of Contents

Executive Summary	4
Introduction	5
Data Collection and Evaluation Methods	7
Survey Design	7
Demographics and PedsQL Scores	8
Demographics	8
PedsQL Results	9
Adolescents' Experiences with SDM	10
Factors that Affect SDM	10
Maturity	10
Course of Treatment	10
Stages of SDM	11
Information Gathering	11
Deliberation	13
Decisional Control	14
Barriers to SDM	15
Lack of Options	15
Anxiety	15
Lack of Information about the Future	16
Poor Understanding of Diagnosis or Treatment	17
Assessment of SDM	18
SDM Narratives	19
Information Gathering	19
Deliberation	19
Decisional Control	19
Summary and Implications	21
Summary	21
Implications	21

List of Figures

Figure 1. Triadic SDM	6
Figure 2. PedsQL Fatigue Composite Scores	9
Figure 3. PedsQL Generic Composite Scores	9
Figure 4. SDM Decision Tree for Adolescents	18

List of Tables

Table 1. Adolescents' Characteristics, n=35	8
Table 2. Adolescent Diagnoses Represented in the Study	8

EXECUTIVE SUMMARY

Introduction

The past three decades have witnessed a change in patient-provider communication. Although traditionally paternalistic, the patient-provider relationship has moved towards a more interactive model. Physicians are encouraged to include patients in medical decision making and many health plans and government agencies view increased involvement in decision making as a cost effective enterprise to improve satisfaction and quality. Policymakers, clinicians, and researchers all refer to this updated model of communication as shared decision making (SDM). Currently, there is little to no information on of the SDM views and experiences of adolescents.

Data and Evaluation Instruments

Qualitative methods were used to explore the SDM experiences of adolescents who have a wide range of special health care needs. Thirty-five adolescents participated in the survey. All of the adolescents are enrolled in the Children's Medical Services Network (CMSN) program. The constant comparative method was used to analyze the interview transcripts and identify overarching themes that are important to adolescents in SDM.

Aims

The aims of this report are to:

- Explore adolescents involvement in and preferences about SDM,
- Identify perceived barriers to SDM, and
- Group adolescents into active versus inactive participants.

Findings

Key findings for adolescents were:

- Two factors that affect SDM are maturity and course of treatment
- Three distinct stage of SDM are: information gathering, deliberation, and final decision making.
- There are several barriers to SDM including:
 - Lack of options
 - Little to no opportunities to interact with other adolescents
 - Poor understanding about diagnosis and treatment, and
 - Lack of information about the future
- 46% of adolescents were active participants versus 54% inactive participants in SDM.

Recommendations

The primary recommendations for CMSN are:

- Nurse Care Coordinators (NCC) should help teach adolescents about the concepts of SDM and how to engage in SDM, and
- NCC should assess the level of understanding of diagnosis and treatment with each adolescent.

INTRODUCTION

Since the 1980s a shift has occurred in medicine concerning patient-provider interactions.^{1 2 3} Healthcare providers have been encouraged to move from a paternalistic approach in their interactions with patients to a more interactive approach.⁴ This approach is important when disseminating medical information and making medical decisions. Shared decision making (SDM) is often defined as both agents taking steps to participate in the decision making by expressing their preferences and coming to a mutually agreed upon decision.⁵ Health care providers, policymakers, and researchers use this term to describe this interactive approach.

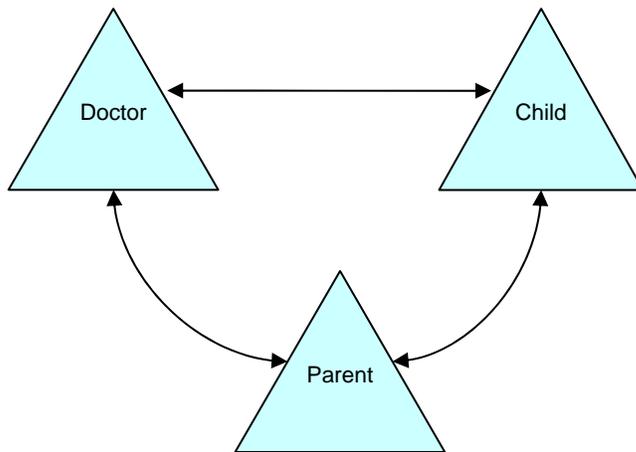
Existing findings about the relationship between SDM and patient satisfaction are inconclusive. Several studies show that patients who experience a more interactive approach to decision making are more likely to report that they are satisfied with their health care and more likely to adhere to medicine regimes.^{6 7 8} These studies suggest that improving the SDM interactions between providers and patients could be a cost effective way to improve quality of care since high levels of patient satisfaction are correlated with high quality health care.⁹ Moreover, if high levels of SDM lead to higher adherence to medicine regimes, then SDM can be used as a preventive approach to reduce costs associated with noncompliance and medical complications. However, other studies show that patient satisfaction is not correlated with SDM.¹⁰

The findings related to patient preferences for SDM are also inconclusive. Some studies show that patients desire to have a more autonomous role in SDM while others conclude that a more paternalistic role is preferred.^{11 12 13} Other studies have found that perceptions about SDM preferences vary when measuring the congruence between provider and patient reports.^{14 15} Patient preference also seems to be conditioned on the type of decision. Evidence suggests that patients faced with more acute or severe health care decisions prefer a paternalistic approach compared to those who have less acute health care concerns.¹⁶

Based on the available evidence, no clear conclusions can be made about what type of SDM is most beneficial. However, this lack of a consensus might be directly related to the complicated nature of medical decisions where one-size does not fit all.

Triadic SDM is a model that describes an approach where children, parents, and providers all play a role in SDM. Triadic interactions can be hierarchical or shared. Shared triadic interaction infers that all three participants have equal influence in medical decision making. However, this rarely occurs. Hierarchical triadic SDM occurs when the physician or parent contribute more than the child.

Figure 1. Triadic SDM



Studies show that children have little involvement in triadic SDM during primary care consultations.¹⁷ A review of 21 studies concluded that children aged 6-12 are not likely to participate in discussions during consultations, and if they do, it tends to be focused on information gathering, not decision making.¹⁸ These studies conclude that physicians dominate the conversation in the consultation most of the time (about 60%)¹⁹ and children least (2%-14% of the time).^{20 21} Children are more likely to speak after their caregivers have spoken and when the physician addressed the child by name and looked directly at him.²²

Qualitative evidence found that girls participated more in pediatric consultations than boys. Furthermore, children were more likely to participate in the consultation when accompanied by their mothers as opposed to their fathers, and more likely to participate the longer the visit.²³ In a national survey of adolescent health, gender was a significant factor in patient-provider preferences for confidentiality. Younger girls preferred their parent to be in the exam room with them, but not younger boys. Older boys and girls preferred that their parents did not accompany them to the exam room.²⁴

Survey evidence also suggests that adolescents with certain chronic illnesses (rheumatoid arthritis, sickle cell disease, cystic fibrosis, and inflammatory bowel disease) prefer that physicians communicate directly with them, versus bypassing them and communicating with the parent. Adolescents participating in the study did not have significant preferences as to whether they wanted to discuss personal issues, such as sexuality, with their physician.²⁵

DATA COLLECTION AND EVALUATION METHODS

Adolescents aged 14 to 21 who are enrolled in CMSN and have a special health care need were included in the sample. Adolescents with special health care needs are more likely to have faced medical decisions in the past, as opposed to healthy adolescents where the number of medical decisions might be less.

Adolescents in the sample resided in one of four geographic areas in Florida: Gainesville, Jacksonville, St. Petersburg, and Lakeland. Purposive sampling was done so that participants would represent a wide range of sociodemographic and medical conditions. The number of completed surveys (n=35) met the goals of diversification and saturation.

Survey Design

A semi-structured questionnaire was used. Surveys were audio taped and subsequently transcribed. Given the lack of existing evidence on adolescents' experiences with SDM, and the lack of information on SDM experiences over a diverse array of medical conditions, the primary purpose of the survey was to explore the themes that are important to adolescents in SDM and their perceived barriers to SDM. Moreover, the surveys were not designed to focus on one particular decision, but rather general experiences with SDM. Whenever possible adolescents were asked to provide specific examples where decisions were made.²

A focused interviewing method was used for developing the survey questions.²⁶ This method allows the surveyor to limit the questions to aspects known to be important to the SDM process from the existing literature. The survey instrument asked questions about the process of, their involvement in, and preferences about SDM. All adolescents were asked about each of the topic areas, and additional probes were asked if the respondent was not clear or did not provide enough substantive information.

Audiotapes were transcribed verbatim. The constant comparative method was used to analyze the transcripts.²⁷ All transcripts were read and the analysis was conducted using NVivo software.²⁸ Codes and labels were constructed that identified common experiences and concerns across the respondents. Once the codes were created, each transcript was queried and code matches were highlighted. The highlighted data were used to create a hierarchical framework. Based on that framework, overarching themes were identified. An iterated approach was then used to ensure that the codes were consistent with the thematic findings. Any discrepancies were discussed and the codes were further refined if necessary.

Adolescents also completed two standardized survey instruments designed to measure quality of life and fatigue: Pediatric Quality of Life (PedsQL) generic and Pediatric Quality of Life fatigue scale.²⁹ Respondents are asked how much of a problem they have had in the past month performing daily activities in four domains: physical, social, school, and emotional. Respondents can choose between several answers that range from almost always a problem to never a problem. Items are then reverse scored resulting in an average score from 0 to 100 with 100 being the highest level of functioning ability.

The survey did include a final section of questions on transitioning to the adult health care system. Two of the participants responded to these questions. However, it should be noted that this sample was purposive and not randomly selected; therefore, presenting the results might be misleading. In addition, we performed a literature review and found that while decision making is most likely an important component of transitioning, no formal evidence exists that measures that association.

DEMOGRAPHICS AND PEDSQL SCORES

Demographics

Tables 1 and 2 summarize the adolescents' demographic and diagnostic characteristics and their parents' household, marital, and education characteristics. Average age of the adolescents was 16.9 years (standard deviation 2.1 years).

Although the listed diagnoses in Table 2 demonstrates that adolescents were purposively chosen so that a diverse set of diagnoses would be represented, it should be noted that many of the adolescents had secondary and even tertiary diagnoses that further complicated their medical condition.

Table 1. Adolescents' Characteristics, n=35

	Percent of Sample
<i>Gender of Adolescent</i>	
Male	45%
Female	55%
<i>Household Type</i>	
Single-Parent Household	60%
Two-Parent Household	40%
<i>Parental Education</i>	
Less than High School	23%
High School	42%
Some College	27%
College Graduate	8%
<i>Parental Marital Status</i>	
Married	31%
Common Law	6%
Divorced	31%
Separated	9%
Single	22%
<i>Race of Adolescent</i>	
Non-Minorities	47%
Minorities	53%

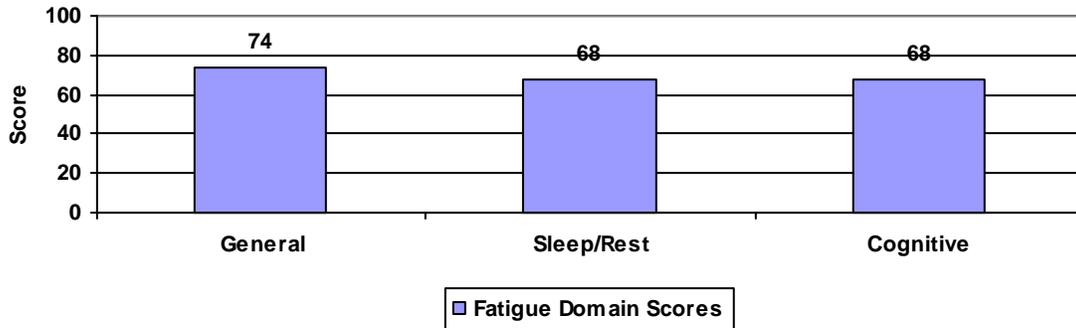
Table 2. Adolescent Diagnoses Represented in the Study

Diagnosis	Number	Percent of Sample
Acute Renal Failure	1	3%
Cerebral Palsy	3	9%
Congenital Heart Disorder	3	9%
Encephalopathy	1	3%
Hemophilia	1	3%
HIV	11	31%
Immunity Disorder	4	11%
Microcephalus	1	3%
Muscular Dystrophy	4	11%
Neoplasm	3	9%
Neurofibromatosis	1	3%
Panhypopituitarism	1	3%
Pituitary Dwarfism	1	3%

PedsQL Results

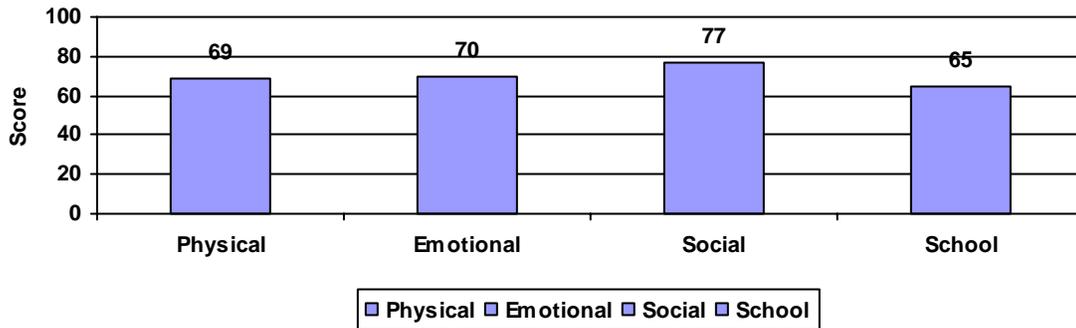
Results for the adolescent reported PedsQL fatigue and generic composites are presented to provide supplemental information on self-reported quality of life. There are three fatigue composites: general fatigue, sleep/rest fatigue, and cognitive fatigue. The chart below shows that adolescents scored themselves highest on general fatigue and had the same average score for cognitive and sleep/rest on a scale of 0 to 100 (Figure 2). Lower scores indicate more fatigue.

Figure 2. PedsQL Fatigue Composite Scores



The PedsQL Generic Scale has the following domains: physical, emotional, social, and school functioning. Figure 3 shows the average adolescent self-reported scores ranging from 77 on social to 65 on school functioning.

Figure 3. PedsQL Generic Composite Scores



ADOLESCENTS' EXPERIENCES WITH SDM

Factors that Affect SDM

Overall, there were two factors that affected SDM for adolescents: maturity and course of treatment.

Maturity

It was clear throughout the interview process that older teens had an easier time engaging in SDM with their parents and providers. We defined older adolescents as those aged 18-21 and younger adolescents aged 14-17. This was compounded by the fact that several of the adolescents, particularly those with HIV, were AIDS orphans and living on their own or with extended family members and had been in total control of their medical decisions for quite some time. A few of the older adolescents had children themselves, some living in their parents' home and some living independently. Older adolescents were planning for the future and accounting for their diagnoses when contemplating their future plans. Most seemed focused on housing, education, and employment planning. Younger adolescents were focused more on short term decisions. For example, older adolescents had a greater understanding that failure to adhere to medicine regimes might affect their overall health, whereas younger adolescents indicated that they did not adhere to medicines because they tasted bad or made them feel abnormal.

Course of Treatment

Course of treatment played the largest role in SDM, not only in the types of decisions that were made, but also the adolescents' involvement in SDM. Adolescents primarily underwent three treatment types: pharmacy, surgery, and therapy. Therapy was used the least by the adolescents, with only two indicating that they had physical therapy. However, the SDM experiences were strikingly different for adolescents who primarily experienced a pharmacy versus surgical regime. Adolescents whose primary treatments were pharmacy regimes were more involved in SDM. Adolescents who had undergone surgeries felt as if there were no choices and that their physicians left them out of the SDM process. Even if the surgery was viewed as *'a life or death thing....'* adolescents indicated that they still would like some input into the decision. One adolescent recalled how important it was that he was at least able to pick the date of his surgery, and that small gesture allowed him to feel as if he were involved in SDM. Adolescents on pharmaceutical treatments felt they had more control over medical decisions by refusing to take prescribed medications, thereby causing physicians to recommend a different medication or dosage, or working with their parents and providers to find a medication that was better suited to their circumstances.

"They suggested it to me because at that time I just didn't even want to take any medicines. I had just quit taking them. But they just suggested, they asked me well what can we do to make you start taking medicine, you know, do you want your medicine to be changed? You want a different regime type thing? I was like well at that point I didn't really wanna take any medicine but I was like sure why not, I'll give it a try. And once I heard it was only 3 pills a day, once a day, I was like yeah you know that sounds good, I'll try it..."

“Well basically I had no decision in it – I had to have surgery, cause it was getting bad then. I was going into kidney failure when I had to have surgery. So it was like basically I had no decision, no choice to make. It was just something that I had to get done.”

Stages of SDM

Adolescents described the three stages of SDM as found in the Charles et al. framework: information gathering, deliberation, and final decision making.⁵

Information Gathering

All adolescents indicated that they were involved in information gathering to some degree. For the adolescents in the sample who were diagnosed after birth, most recalled receiving verbal and written information from their physician about their diagnoses. Several adolescents indicated that their providers also drew pictures or showed them models of body parts that helped them understand what was happening to their body. However, receiving information about their diagnosis was not reported as a positive experience for several adolescents who were diagnosed with cancer and HIV. In particular, adolescents diagnosed with cancer were angry about the manner in which they received the diagnostic information and the amount of information they received.

“...after about 8 hours of waiting I finally got a CAT scan. And I sat for another hour and a half to two hours and finally they put me in a room and told me they had found a tumor in my brain. And the intern was like, ‘it’s a brain tumor, it can either be this or that. One of them is good and one of them is OK, I don’t know for sure which one is which, but we’re going to assume that it’s the worst one’... I don’t know how to say this but when it first happened to me, they asked my mother why I was never given a CAT scan. They asked her why she never brought me to have a CAT scan. You know, why did we let it go on so long? Well for one, I didn’t know. It really made us mad...”

“...I don’t think I’ve had one good experience yet...they didn’t really explain much of anything. They just said you know, ‘you got a brain tumor’ and that was pretty much it. My dad had to tell me everything. He said he didn’t really know what to say I guess, he didn’t know how to explain it.”

Adolescents with HIV also had less than positive experiences with learning about their diagnosis. This was primarily because some parents chose not to disclose their diagnosis, although the adolescents had been taking medications throughout the course of their lives. Adolescents with HIV expressed negative feelings on learning their diagnosis later in life and several reported that they learned about their diagnosis because they had negative encounters with other children at school or neighbors.

“The doctor said it and then my brother, who I lived with, he was just nodding ‘yup, yup, yup’. And I was like, well how come you didn’t tell me before? And he was like, you weren’t mature enough. And I was like so?... (adolescent with HIV)”

Beyond information related to diagnosis, adolescents expanded on the information they received about their treatment options. Again, adolescents that underwent surgery as their primary treatment felt that they received little to no information about the surgery itself or the relevant options. One adolescent who had undergone about 40 surgeries in

his life commented that, *'I love 'em, but they need to give me more options. Which, you don't blame me, do you?'*

Adolescents with pharmaceutical regimes as their primary course of treatment received more information about the options they had, but few recalled receiving information on the side-effects of the medications. Furthermore, very few adolescent could recite the names of their medications or the associated side-effects. When asked to describe their understanding of the information they had been given, most adolescents revealed that they understood all the information. However, when probed further, a few indicated that they could not comprehend the physician provided information and one adolescent described that he wanted more practical information.

"...Well the long words I can't understand"

"She was trying to explain things to me because I wasn't really comprehending a lot, because I, you know, had a brain tumor. But (nurse) would explain it to us and she (mom) would just relay it back to me. She would mostly explain things to me."

"My mom explains it laymen terms, I'm like oh OK, OK good... I tell him (physician) speak English please, I don't want to hear no mumbo jumbo."

"Sometimes the papers really doesn't help me because some of these medicines you just can't do a lot with, because like if you want to get a job or something like that, the papers don't describe enough to tell you what you should do if you want to get a job or if you want to play sports or something like that (adolescent with HIV)."

Several adolescents report finding useful information sources beyond their physician's office. The Internet was the primary source that adolescents used to find information about their diagnosis.

"Oh yeah, I go on the internet and surf the net. Like if there's a medicine, I've surfed, I've seen Cymbalta think I've looked up, Remiron [sic], the one pill I was on. I looked that up to try to see more information on it because when I was having bad dreams and stuff my mom had mentioned, well, my sister was on that and that might be causing you. So I looked it up. So I use the internet."

Adolescents were computer savvy and one adolescent had used www.myspace.com to locate an adolescent with his same diagnosis and develop a friendship. However, having contact with another adolescent with a similar diagnosis was a rare occurrence. Those who were able to share with another adolescent through attending camps or support groups were positive about those experiences and felt less isolated.

"I went to camp and I'm going to a little team thing and we going to talk about our daily experiences and we go out and have us a good time."

Other sources that adolescents gained information from were television (*"I watch a lot of medical shows..."*) and being allowed to review their own medical charts.

Interaction with others might also allow for adolescents to share information and feel more connected to a larger community of adolescents with SHCN. When asked what they would tell another adolescent who has been diagnosed with the same condition,

“... no matter what kind of condition you’re in, you can still do the things that everybody else do.”

“...you just got to listen to the doctors and you can’t slag you got to take your medicines on time, you can’t mess up.”

“Just try to live like a normal teenager, don’t think that you’re weird or different. Yeah, if we could talk about our problems and what you’re going, I think it would go a lot better.”

“Yeah, just fight through what you can. Just get through it, you know....it’s been hard – I have cerebral palsy. It’s kinda hard having cerebral palsy.”

“If they’re not on medicines, then to get onto medicines because it’s the most important thing. And just to go see a doctor as soon as possible, because if you let it grow inside of you then it could turn into AIDS and then you can die from the infections of AIDS. So just to go get help as soon as possible.”

“Basically, you’ve got to eat and stuff keep your body up, and everything good, because if you don’t you get even sicker. Keep your body up, while you’re in there, ‘cause that stuff, it’s crazy...Just expect having a lot of responsibility as a person with kind of disease, and missing some stuff...”

Deliberation

Once information was gathered, adolescents then engaged in deliberation with their parents and providers. Most adolescents described the deliberation process as the physician providing them information in the consultations, which sometimes included options, and very little deliberation occurring between themselves and their parent and physician. Again, those who primarily underwent surgeries alluded to little to no deliberation, even though they would prefer that deliberation had occurred. Adolescents also reported that the deliberation usually occurred in the office, and that decisions were made quickly thereafter.

“They don’t ever say to you, ‘you guys go home, have a think about it ...and call me tomorrow’ which I hate that.”

This was the stage of SDM where several adolescents described disagreements they had with their parents or physicians. Most adolescents who disagreed with the course of treatment did not want to take the suggested medications. They were tired of being abnormal, their medication caused seizures, or the medication tasted bad. In most of these instances, the physician ultimately changed the medication regime; however, a few adolescents with HIV report they still refused to take their medications regardless of what their physician prescribed.

“... I was sitting in my room, ‘cause I was on Sustiva [sic] and I was looking at the paper and I read it could kill me! And, that was shocking to me, so I had to stop my pill on my own.... It made me have seizures and everything.”

“I was the one that wanted to switch because I was getting tired of taking so many pills, so I was the one that actually wanted to look into switching to the once a day pills so that I could remember easily because with taking all those pills I ended up getting off track

sometimes for awhile and wouldn't take it. So now that it's once a day it's easier to keep up with. I normally tend to remember at night than first thing in the morning."

"But it was my fault that it led that way because the medicine that I was on, Fuzeon [sic] I think, I made my body become resistant to it sooner because I couldn't handle the shots anymore. I took myself off the shots."

Involvement in deliberation was not affected by race of provider, although a few female adolescents were uncomfortable with their male providers and felt that this inhibited their involvement in SDM.

Involvement in deliberation could also have been affected by whether or not a parent accompanied the adolescents in the exam room. Overwhelmingly, adolescents wanted their parent to accompany them, and all but one adolescent wanted their mother to be that parent. Even adolescents who indicated that they wanted all of the decisional control wanted their parent in the exam room with them. The only exception was that as adolescents get older they are less comfortable discussing sexual activity or family planning with their physician in front of their parent, and they would like the option to spend some time at the beginning or the end of the appointment without their parent in the room.

Decisional Control

The last stage of SDM focused on decisional control between the adolescent, parent, and/or provider. In other words, who the adolescent felt made the final decision. This series of questions provided the most conflicting information. Although most adolescents report that they are always involved in SDM, very few report they have the most decisional control in the triad, or even want to have the most control over the decision.

"... I just let him make it because I'm not really good with making decisions."

"Well they don't listen to me at all, so I would probably say never (involved in decision making)."

"By them being the doctor, it seems like they know what they're talking about."

Even when adolescents alluded to the idea that they could not be forced to undergo surgeries or take medications ("*...Its my body...*"), they felt that they did not have the most decisional control. With the exception of the few adolescents who had been supporting themselves for a substantial period of time because their parents were deceased, adolescents strongly stated their desire to be independent, but very few were in terms of decisional control. When asked how involved she was in SDM, one adolescent who reported that she had little decisional control said,

"I think we always like discuss it a lot because I don't know, they're really good about putting in my opinion and everything and making sure it's actually something I want and not that they feel like they're forcing me to do or that my mom's telling me to do."

When asked at what age they think they should have complete decisional control, younger adolescents indicated 18 and older adolescents indicated 21. Finally,

adolescents were asked to describe their SDM preference. The majority of adolescents prefer triadic SDM.

Barriers to SDM

Based on the adolescents' experiences we identified several barriers to SDM including: adolescent anxiety, lack of information about the future, poor understanding of their diagnosis and/or treatment, and lack of options.

Lack of Options

Adolescents noted that they are prevented by participating in SDM because they are often not presented with options by which they can interject their opinion. Most adolescents who had either an active or passive role in SDM were often not given treatment options. Without options these adolescents felt that there was no SDM process. Even if the primary course of treatment is surgery, which could be viewed as necessary to sustain life, adolescents would still like to have options presented to them. It should be noted that although the adolescents were not directly asked if they assented to treatment regimens, which is particularly of interest to those adolescents older than 18, requesting assent by the adolescent is another way to show respect for adolescents and ensure them that their opinions are valued.

"... we never had options it was just, 'You need to do this or you're probably going to die'..."

One adolescent described a situation where she was presented with options in the past. This provided a good description of how being presented an option results in an adolescent feeling as if she had a part in SDM.

"...before there was an option...they'd put me in like an immobilizer for like a couple months and then like, when I got out, it'd keep it [knee] from popping out for a little while but it never really stopped it, so I had the operation. They tried ... all the options before surgery just so I don't like have to have one."

Anxiety

Involvement in SDM could be affected by a misunderstanding or a lack of recognition of the issues that cause anxiety for adolescents. Even without the presence of a SHCN adolescents struggle with self esteem, body acceptance, and acceptance by others. These issues are magnified for adolescents with a SHCN because medications and surgeries often exacerbate their anxiety. Adolescents discussed how these non-medical issues affected their adherence to medications and therapies.

"Because people are really prejudice about HIV and they might ban me out of the school, out of the pool and stuff like that "

"... I was looking bad, I was ugly. So it was kind of hurting my self esteem."

"... I have [leg] braces; I don't really like wearing them. But I don't know a teenager really would. I normally only wear them like if something actually goes wrong or if I'm like in pain."

“Well I didn’t want to take the Prednizone [sic] because it gives you pimples and stuff and it makes you gain a little weight, but besides that it’s been fine.”

“... I just wanted to feel normal type thing. I hated how I had, like if we were going off to eat, how I had to take my medicine with me, and take it in front of people, you know like I would always think to myself it’s none of their business what I have to do ...”

Lack of Information about the Future

SDM could be hampered when physicians and parents do not provide information to adolescents on future expectations. However, because the survey was from the adolescents’ perspectives, it did not address how physicians and parents decide which information and how much information to release to adolescents. Adolescents were asked to explain what they had been told to expect in the future. Twenty-four out of 35 adolescents replied that no one had discussed the future with them. For the adolescents who did express that their parent or physician discussed the future with them, they were told:

“...just to have some more surgeries.”

“... before they told me like by now I wouldn’t be able to walk, but like I do a lot of the physical therapy just because that worries me. Like, that’s a scary thought. And so like now they tell me like, they basically give me an expectancy on like how long they think like I’ll be able to walk or like how long they think I can go without having another operation ...I mean like sometimes it’s not always what I want to hear, but it’s still, it’s good to know.”

“... you need to be on the lookout for, you know, maybe if you see something on your skin or maybe you start to feel dizzy.”

“I think she (mom) just wants to be open and honest but sometimes like I don’t know, I don’t sometimes want to hear it from her. I might want to hear it from someone else, because she’s (mom) always talking to me, talking to me about that stuff.”

“She (doctor) has told me that wheelchair was going to be my most like easiest means of transportation throughout my life. So kind of shitty news...”

“She (doctor) tells me that I should never get used to this one medicine because it will always change as I get older and older.”

“She (mom) just says it might get worse, and it might not...”

Poor Understanding of Diagnosis or Treatment

It is difficult for adolescents to be involved in SDM when they are receiving insufficient information or their level of understanding about their diagnosis and/or treatment is limited. When asked to explain what their diagnosis was, the adolescents' answers indicated that further patient education might be helpful to enhance SDM.

"It's just like an illness that causes tumors to form on the nervous system and bumps will come under your skin and then like you get like birthmarks on all over your body and causes bone disfigurement and learning disabilities and stuff like that."

"Well first thing, I already know that it's not my fault...I don't feel different from other people. I feel the same. And other people who have it, you know I wouldn't go against it or anything because I know what it's like. It's a little disease in your body; it's nothing really big. You know, you can't catch it by hugging or just kissing someone."

"So after six weeks I finally understand what I have..."

More concerning was the phenomenon that most adolescents did not know the names of the medications they were taking, the purpose of those medications, or the side-effects.

"Well, it's kind of always had to take medications, but I didn't know what it was for."

"Like, um, I forgot what it's called, but it's some white liquid, and she was showing it to me. She was like 'you do this like that' and I was like...she was like 'that's for when stuff is real real bad' like they're going to the next step to AIDS. I was like we'll do that milestone when we get there. Cause I was askin' about pills only, but I didn't ask that question. I was like are pills the only thing that can cure this, or treat this or whatever. I even asked about a cure too. I think there were a number of times when I asked about a cure too. She was like 'well they got the liquid, they got the pills, they got the shots.' But I remember one time I was taking the liquid and I was standing up and my mom and I was trying the liquid, and it smelled like sewage! And I had to drink it and it would not stay down! Oh my goodness, that's when they had to put me on the pills."

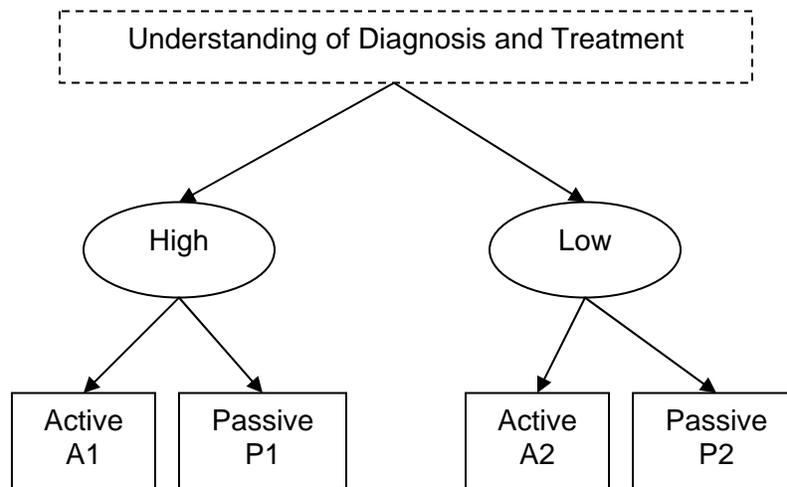
"I didn't get that, the uh, side effect talk, cause I'm not allergic to nothing, I guess. So I didn't get side effect talk. If I did get the side effect talk, I would know that was wrong [laughter]."

One adolescent had a higher level of understanding about her medications and responded that, *"They put me on these new drugs that aren't really out on the market for sale. They're Prezista maverick [sic] or something like that. And some other drugs like Trizivir [sic] and Norvir [sic]. But it's like different forms, like I was resistant to it before, but I'm able to take it now. So that's a big change and then they added some depression pills because I was going through a lot of depression and stuff. And so that's the biggest change recently."*

Assessment of SDM

The experiences of the adolescents were analyzed to determine if SDM had occurred and whether the adolescent was actively or passively participating in SDM. Further analysis of the transcriptions suggested that adolescents could be further grouped based on their level of understanding of their diagnosis and treatment into whether their decision making was active or passive (Figure 4).

Figure 4. SDM Decision Tree for Adolescents



We classified adolescents with a high level of understanding as either active or passive participants in SDM as follows:

- Informed active participants (A1) were involved in SDM even if they did not make the final decision, and were generally making decisions that did not have potentially negative long term health impacts (such as adherence to medications). N=13
- Informed passive participants (P1) were passively involved in SDM due to factors beyond their control. This was either because (1) their parent did not support their involvement in SDM, or (2) they felt like they had little or no options because their primary course of treatment was surgery. N=3

We classified adolescents with a low level of understanding as either active or passive participants in SDM as follows:

- Uninformed active participants (A2) were the final decision makers but were making decisions that could have negatively impacted their long term health (such as failure to adhere to medications). N=4
- Uninformed passive participants (P2) made no attempt, or had no desire, to be involved in SDM. N=15

SDM Narratives

Several adolescents told stories about SDM experiences. These stories provided additional insight into the varied experiences of the adolescents and help understand the framework in which they are making decisions. Excerpts from two adolescents with the same diagnosis are provided below that illustrate strengths and weaknesses of their SDM experiences. Excerpts are stratified by the three stages of SDM so that the reader should be able to follow each adolescent's story chronologically.

Information Gathering

(Adolescent 1) "Like booklets, you can go to any health department, or you could go get them from a doctor's office or anything like that. There are like booklets on HIV and AIDS and they tell you what it is, and where you can go get help, like resources and stuff like that, and that helped me learn as I get older or whatever, you know I was looking at pamphlets and stuff. That helped to get me to know more about the disease and what it does to your body and stuff. It helps."

(Adolescent 2) "We talk about my medicine and stuff."

Deliberation

(Adolescent 1) "They suggested it [changing medicines] to me because at that time I just didn't even want to take any medicines. I had just quit taking them. But they just suggested, they asked me well what can we do to make you start taking medicine, you know, do you want your medicine to be changed? You want a different regime type thing? I was like well at that point I didn't really wanna take any medicine but I was like sure why not I'll give it a try. And once I heard it was only 3 pills a day, once a day, I was like yeah you know that sounds good I'll try it. So, and it's been working. They did, they told me like every single time I go like I would always have some type of problem, like I would miss a dose or something, and they'd always...tell me well you know how important it is to take your medicine and how serious it is and if you quit taking it that you know you could become resistant to that drug you know your body wouldn't be able to handle it anymore. So you know I would know how important it is, I just chose not to take it, that was my fault even though I knew how important it was to take it. They made a lot of suggestions you know about medicines and stuff."

(Adolescent 2) "Then I stopped taking my pills, so they put me on this... other pill. I think it's a white pill – I don't know what it is. And then I had some other pink pill and then got me on that 'cause I stopped taking my medicine for awhile....I was just getting sick of it. I didn't like taking it no more.... When I switched medicines he told me about it. Or whatever – tells me if it's going to make me feel dizzy or something like that..."

Decisional Control

(Adolescent 1) "... when she (mom) found I wasn't taking my medicine of course she was really disappointed ...and it took me awhile to really wanna start back on medicine again before I went in to go see my doctor, and my mom's like you really need to call them up and tell them that you know you wanna try something different or you know you really need to do it before it's too late. And I listened to her, but then it's just like you know what 'I don't wanna feel nauseous' or 'I don't wanna take all them pills', or 'I'm just tired of being abnormal' and all this kind of stuff. And you know just doctors appointments getting in the way of everything like my social life and stuff. And it took me

awhile for me to actually, you know, when I seen my results come back from the doctor, my blood test, like I seen how my viral load just went up drastically and it scared me. And my CD4's went down and I got really scared because I was almost developing full blow AIDS or whatever and I didn't want that to happen so ... that really changed my mind."

(Adolescent 2) "He (doctor) didn't let me choose what I wanted to take."

SUMMARY AND IMPLICATIONS

Summary

There are four summary points.

First, adolescents expressed that two factors affect SDM: maturity and course of treatment. The latter finding is consistent with studies showing that adult patients with more acute or severe conditions tend to be less involved in SDM.¹⁶

Second, consistent with the Charles et al. framework of decision making, the adolescents described three distinct phases of SDM: information gathering, deliberation, and decisional control.⁵ All adolescents had been given some information about their diagnosis and treatment. When asked to describe the deliberation process, most adolescents told stories of their physician talking to them during the consultation about changes to their treatment. Most adolescents described a paternalistic approach whereby the physician was informing the adolescent and their parent what the best course of treatment was and why. Adolescents did not describe the Charles et al. deliberation scenario whereby the patient discusses his goals and values and the physician provides medical information and describes the risks and benefits.⁵ Few adolescents indicated that they had decisional control. Most report that their mother or their physician had the most decisional control. However, many of the adolescents did not want the decisional control, especially for decisions with potential consequences to their health.

Third, adolescents identified five barriers to SDM. They noted that there are little to no opportunities to learn from other adolescents with similar diagnoses, they are sometime anxious about common teenage issues (such as appearance) which may influence them not engage in the SDM process, they may not be presented with treatment options about which to make a decision, they described a lack of discussion about the future, and about two-thirds of the adolescents in the survey have a poor understanding of their diagnosis and/or treatment.

Fourth, four types of SDM participation were identified based on the adolescent's understanding of his diagnosis and treatment: active informed participation (A1, 37%), active uninformed participation (A2, 9%), passive informed participation (P1, 11%), and passive uninformed participation (P2, 43%).

Implications

CMSN has a unique opportunity to improve parent and child involvement in SDM through nurse care coordinators (NCC). The following recommendations can be employed by the CMSN NCC to improve SDM with CMSN families:

- NCC should be trained on the concept and importance of SDM and begin to incorporate those concepts into practice. Training modules and simulations could be developed for this purpose.
- NCC should assess the level of understanding of diagnosis and treatment by asking the adolescent to explain his diagnosis and treatment regime. NCC can emphasize SDM as part of their normal transition planning process. Adolescents

on a pharmacy regime should know their medications and possible side-effects. Communication about drug safety is especially important in pediatrics. Communication between providers, parents, and patients can help to prevent medication errors.³⁰

- All adolescents, regardless of treatment regime, should be taught how to engage in SDM by asking a few questions to their parents and physicians, such as:
 - *What are my options to the treatment that is being suggested?*
 - *What are the risks and benefits of those options?*
 - *Do I need more information to make a decision?*
 - *Have I informed my parent and physician what option I think is best and why?*
 - *What should I expect after the treatment has occurred (side-effects, complications, length of stay in hospital, long term health effects)?*
 - *What are my long term health care goals?*
- Once the NCC assesses the adolescents' level of understanding, NCC can develop a task in the care plan to improve SDM if needed. Examples by SDM type are presented below:
 - Active, informed (A1) adolescents require little training, but can be encouraged to continue participating in SDM.
 - Passive, informed (P1) adolescents can be empowered by discussing with them what to expect when they go in for surgery, what is important for their quality of life, and if there are any pain management issues that need to be addressed. P1 adolescents need to retain some amount of control and the NCC can help them prepare for surgeries by discussing what they can bring to the hospital or help them prepare a list of questions to ask prior to surgery.
 - Active, yet uninformed (A2) adolescents are in control of their decision making, but are making bad decisions. NCC can provide additional information to these adolescents on the cumulative effect that their decisions can have on their health and well being. NCC have an advantage that general practitioners may not in that they understand the psychosocial issues of the family and can tailor their SDM training to the adolescents specific situation.
 - Passive, uninformed (P2) adolescents are not involved in SDM and do not want to be involved in SDM. NCC can work with parents to discuss with the adolescent how to be involved in SDM which can lead to increased empowerment. Parents can work with the NCCs to make inroads with the adolescent.
- CMSN should consider implementing more formal interventions designed to empower adolescents in the SDM process. Some examples of such interventions would be: creation of decisional aids (workbooks, flow charts, or booklets), NCC-adolescent education sessions, or community forums that would allow for adolescents to meet in a social setting and support each other. Other SDM interventions are role playing and turn-taking.

-
- ¹ Brody, D. The patient's role in clinical decision-making. *Ann Int Med* 1980;93:718-722.
- ² Levenstein J., E. McCracken, I. McWhinney, M. Stewart, and J. Brown. The patient-centered clinical method. 1. A model for the doctor-patient interaction in family medicine. *Fam Pract*. 1986;3(1):24-30.
- ³ McWhinney I. Why we need a new clinical method? *Scand J Prim Health Care*. 1993;11:3-7.
- ⁴ Brown, J., M. Stewart, E. McCracken, and I. McWhinney. The patient centered clinical method.2. Definition and application. *Fam Pract* 1986;3(2):75-9.
- ⁵ Charles, C., A. Gafni, T. Whelan. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci and Med* 1999;49:651-61.
- ⁶ Merenstein, D., M. Diener-West, A. Krist, M. Pinneger, and L. Cooper. An Assessment of the Shared Decision Model in Parents of Children with Acute Otitis Media. *Pediatrics* 2005;116:1267-75.
- ⁷ Brody, D., S. Miller, C. Lerman, D. Smith, and G. Caputo. Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *J Gen Inter Med* 1989;4:506-511.
- ⁸ Swanson, K., R. Bastani, L. Rubenstein, L. Meredith, and D. Ford. Effect of mental health care and shared decision making on patient satisfaction in a community sample of patients with depression. *Med Care Res Rev*. 2007;64(4):416-30.
- ⁹ Loh, A., D. Simon, C. Wills, L. Kriston, W. Neibling, and M. Harter. The effects of a shared decision making intervention in primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns*. 2007; 67(3):324-32. Epub 2007 May 10.
- ¹⁰ Ende, J., L. Kazis, A. Ash, and M. Moskowitz. Measuring patients desire for autonomy: decision making and information seeking preferences among medical patients. *J Gen Inter Med* 1989;4(1):23-30.
- ¹¹ Briel, M., J. Young, C. Hugenschmidt, H. Bucher, and W. Langewitz. Shared-decision making in general practice: do patients with respiratory infections actually want it? *Swiss Med Wkly* 2007;137(33-34):483-5.
- ¹² Levinson, W., A. Kao, A. Kuby, and R. Thisted. Not all patients want to participate in decision making. A national study of public preferences. *J Gen Inter Med*. 2005;20(6):531-5.
- ¹³ Deber, R., N. Kraetschmer, S. Urowitz, and N. Sharpe. Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expect* 2007;10(3):248-58.
- ¹⁴ Elkin, E., S. Kim, E. Casper, D. Kissane, and D. Schrag. Desire for information and involvement in treatment decisions; elderly cancer patient's preferences and their physician's perceptions. *J Clin Onc* 2007;25(33):5275-80.
- ¹⁵ Strull, W., B. Lo, and G. Charles. Do patients want to participate in medical decision making? *JAMA* 1984;252(21):2990-4.
- ¹⁶ McKinstry, B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ* 2000;321:867-71.
- ¹⁷ Bates, K., and L. Meeuwesen. Doctor-patient-child communication. A (re)view of the literature. *Soc Sci and Med* 2001;52:839-51.
- ¹⁸ Cahill, P., and A. Papageorgiou. Triadic communication in the primary care consultation: a review of the literature. *Br J Gen Pract* 2007;57(544):904-11.
- ¹⁹ Wassmer, E., G. Minnaar, N. Abdel Aal, M. Atkinson, E. Gupta, S. Yuen, and G. Rylance. How do paediatricians communicate with children and parents? *Acta Paediatrica* 2004;93(11):1501-6.
- ²⁰ Aronsson, K., and B. Rundstrom. Child discourse and parental control in paediatric consultation. *Text* 1988; 8:159-84.
- ²¹ Pantell, R., T. Stewart, J. Dias, P. Wells, and A. Ross. Physician communication with children and parents. *Pediatrics* 1982; 70:396-402.
- ²² Cahill, P., and A. Papageorhiou. Video analysis of communication in paediatric consultations in primary care. *Br J Gen Pract* 2007;57(544):866-71.
- ²³ Cox, E., M. Smith, R. Brown, and M. Fitzpatrick. Effect of gender and visit length on participation in pediatric visits. *Pat Educ Couns*. 2007 Mar;65(3):320-8.
- ²⁴ Kappahahn, C., K. Wilson, and J. Klein. Adolescent girls' and boys' preferences for provider gender and confidentiality in their health care. *J Adolesc Health*. 1999;25(2):131-42.

²⁵ Britto, M., R. DeVellis, R. Hornung, G. DeFriese, H. Atherton, and G. Slap. Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics* 2004;114(5):1272-80.

²⁶ Merton, R., M. Fiske, and P. Kendall. *The Focused Interview: A Manual of Problems and Procedures*. Glencoe, IL: The Free Press, 1990.

²⁷ Strauss, A., and J. Corbin. *The Basics of Qualitative Research: Techniques and Procedure for Developing Grounded Theory*, 2nd e. Sage, Thousand Oaks, CA. 1998.

²⁸ Richards, L. *Using NVivo in Qualitative Research*. QSR International, Melbourne Australia. 2002.

²⁹ Varni, J., M. Seide, and C. Rode. The PedsQL: Measurement model for the Pediatric Quality of Life. *Med Care*. 1999;37(2):126-39.

³⁰ Stebbing, C., I. Wong, R. Kaushal, and A. Jaffe. The role of communication in paediatric drug safety. *Arch Dis Child* 2007;92(5):440-5.