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Relationships of Shared Decision Making with Parental Perceptions of Child Mental Health Functioning and Care

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Abstract

Experts encourage parents and practitioners to engage in shared decision making (SDM) to provide high quality child mental health care. However, little is known regarding SDM among families of children with common mental health conditions. The objectives of this study were to examine associations between parental report of SDM and parental perceptions of (a) receiving child mental health care and (b) child mental health functioning. We analyzed cross-sectional data on children with a common mental health condition (attention-deficit hyperactivity disorder, oppositional-defiant or conduct disorder, anxiety, or depression) from the 2009/2010 National Survey of Children with Special Healthcare Needs (N = 9,434). The primary independent variable was parent-reported SDM, and the dependent variables were parental perception of (a) their child receiving all needed mental health care (b) their children's impairment in school attendance and extracurricular activity participation, and (c) severity of their children's mental health condition. Multivariate logistic and multinomial regression analyses were conducted. Greater parent-reported SDM was associated with parental perceptions of receiving all needed child mental health care and children not having school or extracurricular impairment. Greater SDM was also associated with perceptions of children having a mild mental health condition compared to children having a moderate or severe condition. Findings provide a basis for future longitudinal and intervention studies to examine the benefit of SDM for improving parental perceptions of the quality of child mental health care and mental health functioning among children with common mental health conditions.

Keywords

Child; Shared decision making; Mental health; Mental health functioning; Mental health impairment

Introduction

A significant portion of children in the U.S. have a mental health condition that causes impairment in functioning, with estimates indicating approximately 20 % of children have a mental health disorder. (Costello et al. 2005) Prevalence estimates for common disorders among children, including attention-deficit hyperactivity disorder, depression, conduct disorder, and anxiety are 9, 4, 2, and 1 %, respectively. (Merikangas et al. 2010) Yet, approximately half of children with a mental health disorder are under treated for their condition. (Merikangas et al. 2010) Such statistics highlight the need to identify practices that may improve the quality and outcomes of children's mental health care.

According to the Substance Abuse and Mental Health Services Administration, shared decision making (SDM) can improve the quality and outcomes of children's mental health care. (2010) SDM occurs when both parents and providers take steps to participate in the treatment decision-making process by sharing information and agreeing on treatment decisions. (Charles et al. 1997) SDM occurs when providers discuss treatment options, provide parents with opportunities to ask questions and indicate concerns, and explore parent ideas for how the mental health condition should be managed. (Fiks et al. 2010; Brinkman et al. 2011).

Research in adult mental health care showed SDM practices improve patients' activation and retention in mental health services.(Alegria et al. 2008) In pediatrics, SDM has largely examined the care of children with chronic physical conditions and care to prevent physical illness. Specifically, findings indicate SDM practices are associated with improvement in children's clinical outcomes and better parental perceptions of care, as well as lower parental decisional conflict related to preventive intervention options.(Shourie et al. 2013) The anticipated benefits of SDM in child mental health care include improved treatment engagement and better child mental health functioning.(2010; Zima et al. 2013; Fiks et al. 2012) Yet, few studies have examined the associations between SDM and parental perceptions of child mental health care or child mental health functioning. No study has examined the association between SDM and parental perceptions of child mental health care. The limited literature on the relationship between SDM and parent-reported functioning among children with a mental health condition has focused on children with ADHD. (Fiks et al. 2012; Brinkman et al. 2013) In particular, research showed that increases in SDM are associated with decreases in parent-reported impairment among a nationally representative sample that included children with ADHD (Fiks et al. 2012). Additional research that examines associations between SDM and perceptions of functioning among parents of children with diverse common mental health conditions will provide a stronger foundation for longitudinal and intervention studies focused on SDM and changes in perceptions of children's mental health functioning. Furthermore, it is important that research on SDM control for family sociodemographic factors given their association with SDM.(Butler et al. 2014).

The objectives of the present study were to examine associations between parental reported SDM and parental perceptions of (a) children receiving all their needed mental health care (b) children's impairment, and (c) the severity children's mental health conditions among a

nationally representative sample of children with common mental health conditions. Based on previous research conducted with children ADHD, research focused on physical illness, and research on adult mental health care, we hypothesized that greater SDM would be associated with parental perceptions of: a) children receiving all needed mental health care, b) lower impairment in children's school attendance and extracurricular activity participation, and c) lower child mental health severity.

Method

Data Source

We conducted secondary analysis of data from parents and guardians of children 5–17 years of age who participated in the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN; Child and Adolescent Health Measurement Initiative, 2012). The NS-CSHCN is a cross-sectional, telephone-based survey of a nationally representative sample of children with special health care needs in the United States. Children with special health care needs are defined as those who have or who are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al. 1998). The survey is sponsored by the Maternal Child Health Bureau (MCHB) and has been conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics every 4 years since 2001.

Design and Study Population

In the 2009–2010 sample, a random digit dial procedure identified 372,698 children under the age of 18 years residing in 196,159 households across the U.S. These households were screened to identify children who met the federal MCHB qualification for designation as a child with special health care needs. Households with either a landline telephone or cell phone were included in the 2009/2010 survey. A total of 40,242 interviews were completed with parents of a child with a special health care need (Child and Adolescent Health Measurement Initiative, 2012). The interviews were available in multiple languages that consisted of English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean. The Baylor College of Medicine Institutional Review Board approved the current study.

The current study used a subset of the survey population. In particular, the sample was restricted to children with a current diagnosis of ADHD, conduct disorder or oppositional defiant disorder, anxiety, or depression, and who had received treatment or counseling for a mental health condition ($N = 9,434$). These disorders were selected because they represent the two most common dimensions of child mental disorders among children. These dimensions are externalizing (ADHD and disruptive behavior disorders) and internalizing disorders (depression, anxiety), and disorders within each category are highly correlated. (Cosgrove et al. 2011).

In this study, to determine the presence of a mental health diagnosis, the following three survey questions were used: “Does your child have any kind of emotional, developmental, or behavioral problem for which (‘he/she needs’/‘they need’) *treatment or counseling*?”; “Has a

doctor or other health care provider ever told you that [child] had [condition], even if he/she does not have the condition now?"; and "Does [child] currently have the [condition]?" The response options for these questions were yes or no. The conditions were the following: attention deficit disorder or attention deficit hyperactive disorder (ADHD), behavioral or conduct problems such as oppositional defiant disorder or conduct disorder, depression, or anxiety problems. Parents who responded "yes" to the question related to treatment/counseling and *both* questions related to any of the conditions were included in this study.

Dependent Variables

Receipt of All Needed Mental Health Care—Receipt of all needed child mental health care was assessed by a two-part question. Parents were first asked: "During the past 12 months, was there any time when [Child] needed mental health care or counseling"? Parents who responded "yes" to this first question were then asked a second question: "Did [Child] receive all the mental health care or counseling that he/she needed"? Parents' responses of "yes" or "no" to this second question were used to assess receipt of all needed mental health care. It is important to note that only a subset of our sample were asked the second question to determine receipt of mental health care (n = 6,940).

Impairment—The following two questions were used to assess impairment in school attendance and participation in extracurricular activities, respectively: 1) "Do [Child]'s (medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems) interfere with [his/her] ability to attend school on a regular basis" and 2) "Do [Child]'s (medical, behavioral, or other health conditions/emotional, developmental, or behavioral problems) interfere with [his/her] ability to participate in sports, clubs, or other organized activities? Parental responses were coded as "yes" or "no."

Mental Health Severity—For each mental health condition endorsed (ADHD, oppositional defiant disorder or conduct disorder, depression, and anxiety), parents were asked: "Is that condition, mild, moderate, or severe"? If the child had more than one disorder and severity rating, the parent's most severe rating was used. Mental health severity was scored as mild, moderate, or severe.

Independent Variable

Shared Decision Making (SDM)—Table 1 includes the four questions that assess SDM in the NS-CSHCN. Survey developers used an expert panel, cognitive interviews testing a number of items, and item pretesting with 132 parents to develop the four questions. Cognitive testing showed the instructions and four questions had face validity and were understood as intended and reliable. Family focus groups before and during item development confirmed the four items represented the most essential components of SDM. Individual item correlations show different information assessed by each item, with item-total correlations ranging from 0.59–0.69 (Richard LeDonne from the Child and Adolescent Measurement Initiative, personal communication, July 12, 2012). The internal consistency coefficient for the questions has been reported at .87, indicating high internal consistency. Parents respond to each question on a 4-category Likert scale (1 = Never, 2 = Sometimes, 3

= Usually, or 4 = Always), and an average score was calculated for each participant (possible range of scores is 1–4).

Covariates

We included the following covariates: child gender, child age, child race/ethnicity, household poverty status, insurance status, parent education, household primary language, and having a personal doctor/nurse. Race/ethnicity was assessed using mutually-exclusive race/ethnicity categories: non-Latino white, non-Latino black, Latino, and Other. Parents who indicated their child was currently insured and there was not any time during the past 12-months that their child was not covered by insurance were categorized insured; all others were categorized as uninsured. Income data relative to the Federal Poverty Level (FPL) was assessed. Parental education was categorized as less than high school, 12 years/high school graduate, and more than high school. Household primary language was categorized as English versus Not English. Having a personal doctor or nurse was assessed by the question “Do you have one or more persons you think of as [Child]’s personal doctor or nurse?”, and dichotomous responses were categorized as yes or no.

Data Analysis

SAS 9.2 (SAS Institute Inc 2008) was used to conduct descriptive statistics and four logistic regression models for each of the following outcomes: receipt of all needed mental health care, impairment in school attendance, impairment in extracurricular activity participation, and mental health severity. Logistic regression was used because the outcome variables were categorical (either dichotomous or three-levels). Ordinary Least Squares was not used because it could produce bias standard errors given categorical dependent variables violate the assumptions of homoscedasticity. (Long JS. 1997) Proc logistic using the descending was conducted to examine the association between SDM and receipt of mental health care, child impairment, and child mental health severity. Proportional odd assumption was examined to determine whether an ordinal or multinomial model was most appropriate to examine the association between SDM and mental health severity.

Results

Sample Characteristics

Approximately 79 % (n = 5,685) of parents perceived their children received all needed mental health care. Twenty-seven percent (27 %; n = 2,208) and 43 % (n = 3,835) of parents perceived their child had impairment in school attendance and extracurricular activity participation, respectively. Finally, 23 % (n = 2,295) of children’s parents perceived them to have a mild mental health condition, 46 % (n = 4,408) were perceived to have a moderate condition, and 31 % (n = 2,610) were perceived to have a severe mental health condition. The mean SDM score was 3.37 (range = 1–4; SD = 0.77).

Descriptive statistics and weighted percentages are presented in Table 2. Females comprised the highest proportion of children (64 %). The majority of the parents achieved more than a high school education (64 %) and reported their primary household language was English

(95 %). Finally, high proportions of children were insured (90 %) and had a personal doctor or nurse (92 %).

Associations Between SDM and Receipt of Child Mental Health Care, Impairment, and Mental Health Severity

Results from the multivariate logistic regression analyses are presented in Tables 3, 4. Table 2 shows that greater SDM was associated with higher odds of parent-report of children receiving all needed mental health care while controlling for sociodemographic factors, insurance status, and whether or not the child had a personal doctor or nurse. Table 3 further indicates greater SDM was also associated with lower odds of parent-report of children having impairment in school attendance and lower odds of children having impairment in extracurricular activity participation.

We conducted multinomial logistic regression to examine the association between SDM and perceived mental health severity because the test for the proportional odds assumption was significant in the model using ordinal logistic regression ((Merikangas et al. 2010) $\chi^2 = 33421.10$, $df = 16$, $p < 0.01$). Table 4 presents results from the multinomial logistic regression model. Results showed that greater SDM was associated with lower odds of parental perception of children having a moderate mental health condition compared to children having a mild mental health condition. Similarly, greater SDM was associated with lower odds of parental perception of children having a severe mental health condition compared to having a mild mental health condition.

Tables 3 and 4 also show that some sociodemographic factors were associated with parent-report of receipt of mental health care, child impairment, and child mental health severity. Male gender was associated with lower odds of perceived impairment in extracurricular activity participation and lower odds of parent-report of having a severe mental health condition compared to a mild condition. Children ages 12–14 years compared to children ages 5–8 years had higher odds of parental perceived impairment in extracurricular activity participation. Parents whose highest level of education is high school reported higher odds of receiving all needed mental health care compared to parents who obtained greater than a high school education. Having a lower household income compared to a higher income of 400 % FPL or greater was associated with a) lower odds of parent-report of receiving all needed mental health care and b) higher odds of parental perceived impairment in school attendance, extracurricular activity participation, and having a severe compared to a mild mental health condition. Finally, children living in a household where the primary language was other than English had lower odds of parent-report of having a moderate mental health condition compared to a mild condition. Uninsured status was associated with lower odds of parental perception of receiving all needed mental health care.

Discussion

This is the first study to examine associations between shared decision making (SDM) and receipt of mental health care and mental health functioning among children with various common mental health conditions. As predicted, greater SDM was associated with parental perceptions of receiving all needed mental health care for their child. This finding aligns

with previous studies focused on childhood physical illness which showed SDM is associated with greater parental satisfaction with care.(Wilson et al. 2010; Porter et al. 2006) Examination of interventions to improve SDM as a strategy to increase parent-report of receipt of needed child mental health care is a viable direction for future research.

Findings from this study also indicate that SDM is associated with parental perceptions of children's mental health impairment and severity. These findings align with two previous studies. One previous study demonstrated that increases in SDM were associated with decreases in parent-reported impairment among a nationally representative sample of children with attention deficit hyperactivity disorder (ADHD) (Fiks et al. 2012). A second previous study conducted in a primary care clinic among parents of children with ADHD and disruptive behaviors showed that greater SDM was associated with parental report of lower mental health severity and impairment.(Butler 2014) Our preliminary findings build on the previous literature by demonstrating an association between SDM and parental perception of mental health impairment and severity among children with various common mental health conditions that include oppositional defiant/conduct disorders, anxiety, and depression. Thus, our findings call for future longitudinal examination of the association between SDM and changes in mental health impairment and severity among children with diverse mental health conditions.

Finally, household income was consistently associated with perceived care and child mental health functioning. In accord with previous studies examining mental health service use and standardized measures child mental health functioning(Merikangas et al. 2011; Amone-P'Olak et al. 2010) lower household income was associated with greater perceived impairment in children's mental health functioning, report of lower severity, and report of not receiving all needed mental health care. The results underscore the importance of examining family household income in future studies that examine SDM and child mental health care and outcomes.

The present study also has some implications for practice. Effective strategies to improve SDM among parents may include decision aids to help parents understand and clarify their choices and preferences for mental health treatment, peer-delivered workshops to increase parental SDM skills, or web-based communication skills training for parents (Center for Mental Health Services 2010). Similarly, effective practices to increase providers' SDM include mental health communication skills training or training in the implementation of decision aids

Study Limitations

The study design is cross-sectional, thus we are unable to conclude whether SDM influences parental perceptions of receiving all needed mental health care, child mental health impairment, or children's mental health severity. This study involves secondary data analysis, which limits the study to examination of previously collected data. Additional variables that may contribute to SDM were not available in the dataset, such as, parental health literacy or the length of parental relationships with providers. Further, clinician report or a standardized assessment of impairment would have expanded our options for assessing

the association between SDM and impairment. Experiences of SDM were assessed using parent report, which may be associated with recall bias. Parent-report of SDM may not reflect children's experience of SDM with providers. The generalizability of the findings to parents whose primary language is not English may be limited given the relatively small percentage of parents in the study sample whose primary language is not English. Finally, there is a paucity of standardized parent-report measures that assess SDM; measures are only beginning to be developed.(Elwyn et al. 2001; Weiss and Peters 2008) Despite these limitations, the study includes a large nationally representative sample of children with common mental health conditions, which maximizes the generalizability of the findings.

Conclusions

Experts have emphasized SDM to improve the quality and outcomes of child mental health care (Center for Mental Health Services 2010). Results from this study show that SDM is associated with parental perception of receiving all needed child mental health care, lower impairment, and lower mental health severity. Our findings call for future examination of the potential benefits of SDM for children with various mental health conditions. Research on decision aids for improving SDM making among parents of children with suggest future research should examine the effectiveness of SDM for improve care among parents of children with other common mental health conditions(Brinkman et al. 2013).

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Table 1
Survey questions for measurement of shared decision making

1	During the past 12 months, how often did [child]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment? Would you say never, sometimes, usually, or always?
2	How often did they encourage you to ask questions or raise concerns?
3	How often did they make it easy for you to ask questions or raise concerns?
4	How often did they consider and respect what health care and treatment choices you thought would work best for [child]?

Data Source: National Center for Health Statistics and Maternal and Child Health Bureau, National Survey of Children with Special Health Care Needs, 2009/2010

Table 2**Demographic characteristics**

Variable	Overall N (Weighted %)
Gender	
Female	6,262 (64.34)
Male	3,162 (35.66)
Child's age, years	
5–8	1,971 (20.86)
9–11	2,499 (25.98)
12–14	2,426 (26.49)
15–17	2,538 (26.66)
Poverty level	
400 % FPL or greater	2,493 (22.06)
0–99 % FPL	2,085 (27.05)
100–199 %	2,073 (24.03)
200–399 % FPL	2,783 (26.85)
Parent's education	
More than high school	7,135 (64.64)
12 years/high school graduate	1,664 (21.94)
Less than high school	635 (13.42)
Parent's primary language	
English	9,184 (95.05)
Language other than English	250 (4.95)
Race	
White, non-Hispanic	6,609 (62.04)
Black, non-Hispanic	918 (14.32)
Other	873 (7.86)
Hispanic	1,034 (15.79)
Insurance	
Insured	8,569 (89.80)
Uninsured	818 (10.20)
Personal doctor/nurse	
No	645 (7.94)
Yes	8,777 (92.06)

FPL federal poverty level

Table 3
Associations between shared decision making and receipt of mental health care

Variable	Received All Needed Mental Health Care Adjusted OR (95 % CI)
Shared decision making	2.04 (1.78–2.35) **
Gender (ref: Female)	
Male	0.95 (0.75–1.23)
Child's age, years (ref: 5–8)	
9–11	1.08 (0.74–1.56)
12–14	0.77 (0.54–1.11)
15–17	0.86 (0.60–1.23)
Poverty level (ref: 400 % FPL or greater)	
0–99 % FPL	0.63 (0.42–0.94) *
100–199 %	0.71 (0.48–1.04) †
200–399 % FPL	0.69 (0.48–0.98) *
Parent's education (ref: More than high school)	
12 years/high school graduate	1.58 (1.14–2.18) **
Less than high school	1.29 (0.83–2.02)
Parent's primary language (ref: English)	
Language other than English	1.53 (0.69–3.40)
Race (ref: White, non-Latino)	
Black, non-Latino	1.10 (0.73–1.66)
Other	1.24 (0.79–1.93)
Latino	1.13 (0.76–1.66)
Insurance (ref: Uninsured)	
Insured	0.39 (0.28–0.55) **
Personal doctor/nurse (ref: No)	
Yes	1.26 (0.80–1.98)

FPL federal poverty level; *OR* Odds Ratio; *CI* Confidence Interval.

**
p < 0.01,

*
p < 0.05,

†
p < 0.10

Table 4
Associations between shared decision making and child mental health impairment and mental health severity

Variable	Impairment in school attendance Adjusted OR (95 % CI)	Impairment in extracurricular activity participation Adjusted OR (95 % CI)	Moderate versus mild mental health condition Adjusted OR (95 % CI)	Severe versus mild mental health condition Adjusted OR (95 % CI)
Shared decision making	0.66 (0.59–0.74) **	0.62 (0.56–0.69) **	0.76 (0.66–0.86) **	0.66 (0.57–0.76) **
Gender (ref: Female)				
Male	1.02 (0.84–1.22)	0.78 (0.67–0.91) **	0.87 (0.72–1.05)	0.79 (0.64–0.97) *
Child's age, years (ref: 5-8)				
9–11	1.21 (0.91–1.60)	1.04 (0.84–1.29)	1.06 (0.81–1.38)	1.11 (0.82–1.50)
12–14	1.84 (1.42–2.39) **	1.25 (1.01–1.55) *	1.09 (0.83–1.44)	1.08 (0.80–1.46)
15–17	2.58 (2.01–3.32) **	1.65 (1.33–2.05) **	0.96 (0.73–1.24)	0.98 (0.73–1.32)
Poverty level (ref: 400 % FPL or greater)				
0–99 % FPL	2.88 (2.20–3.78) **	1.87 (1.47–2.38) **	1.22 (0.91–1.64)	3.16 (2.31–4.33) **
100–199 %	1.82 (1.39–2.38) **	1.48 (1.18–1.85) **	1.18 (0.90–1.54)	2.05 (1.51–2.77) **
200–399 % FPL	1.51 (1.15–1.98) **	1.31 (1.07–1.61) **	1.10 (0.86–1.39)	1.35 (1.01–1.81) *
Parent's education (ref: More than high school)				
12 years/high school graduate	1.04 (0.83–1.30)	0.85 (0.69–1.04)	1.18 (0.92–1.51)	0.99 (0.76–1.29)
Less than high school	1.07 (0.78–1.47)	0.68 (0.51–0.91) **	1.20 (0.83–1.73)	1.04 (0.72–1.49)
Parent's primary language (ref: English)				
Language other than English	1.11 (0.64–1.91)	0.73 (0.45–1.18)	0.57 (0.33–0.97) *	1.01 (0.52–1.96)
Race (ref: White, non- Latino)				
Black, non-Hispanic	1.07 (0.83–1.40)	0.86 (0.68–1.09)	0.76 (0.57–1.03) †	0.89 (0.65–1.20)
Other	1.21 (0.80–1.83)	1.23 (0.92–1.64)	0.74 (0.54–1.01) †	1.21 (0.80–1.81)
Latino	1.15 (0.85–1.54)	0.92 (0.71–1.20)	1.05 (0.77–1.43)	0.84 (0.59–1.19)
Insurance (ref: Uninsured)				
Insured	1.86 (1.39–2.48) **	1.33 (1.02–1.73) *	1.09 (0.80–1.51)	1.14 (0.81–1.61)
Personal doctor/nurse (ref: No)				
Yes	1.34 (0.91–1.98)	1.75 (1.27–2.41) **	1.30 (0.89–1.88)	1.68 (1.15–2.46) **

FPL federal poverty level; OR Odds Ratio; CI Confidence Interval.

**
p < 0.01,

*
p < 0.05,

†
p < 0.10