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Benefits of medical home care reaching beyond chronically ill teens: Exploring parent health-related quality of life

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Abstract

Background—Caring for teens with special health care needs places physical and mental health burdens on parents, which can be exacerbated by the stresses of transitions to independence. Medical homes can improve teen transitions to greater self-management and reduce health care-related time and financial burdens for families. This analysis examines the association between parent-reported teen medical home status and caregiver health-related quality of life (HRQOL).

Methods—The study sample included parents/caregivers of teens with special health care needs, ages 15–18, recruited from a pediatric Medicaid accountable care organization who participated in a survey (response rate=40.5%). The primary outcome was parent HRQOL scores (0–100 points) measured using the PedsQL Family Impact Module. Medical home status was based on parent report of teen's health care meeting medical home criteria. Linear regression models were used to estimate HRQOL scores, adjusted for demographic characteristics, health literacy, and teen functional limitation

Results—Among 488 parents, 27% reported their teen received care consistent with a medical home. Adjusted parent HRQOL scores were significantly higher among those whose teens had a medical home (74.40; 95% CI 71.31–77.48), relative to those whose teens did not (65.78; 95% CI 63.92–67.65). Medical home subscale analyses showed HRQOL scores had significant positive associations with family-centered care and coordinated care, but not other subscales.

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Conclusions—Teen medical home status was positively associated with caregiver HRQOL, suggesting that the medical home may benefit overall caregiver well-being. In particular, receiving care that was family centered and coordinated appeared to be the most beneficial.

Keywords

Medical Home; Health Care Quality; Caregivers; Quality of Life

Introduction

Children who have “chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally,” are commonly classified as children with special health care needs (CSHCN).¹ Parents of CSHCN face many burdens in caring for and advocating for their children’s health needs and have been shown to experience stress,² financial burdens,³ and caregiving demands⁴ that may negatively impact their own physical and mental health. More than half of parents of CSHCN report spending at least an hour each week coordinating medical care for their children.⁵ Parents of adolescents with special health care needs may experience additional stress due to conflicts with chronically ill teens who are transitioning to assuming more responsibility for self-care.⁶ The combined financial and family-life stresses of parents of CSHCN may adversely affect the overall health-related quality of life (HRQOL) of parents.

The medical home is a model of health care delivery that is designed to be “accessible, continuous, family-centered, coordinated, compassionate, and culturally effective,”⁷ and has been found to be associated with improved access to care,⁸ lower emergency department use,^{9,10} and improved health status¹¹ among CSHCN. Evidence also suggests that care from a medical home may have positive effects on parents, including reduced caregiver time and financial burdens.^{9,12} However, it is not known whether a teen’s receipt of care that is consistent with a medical home is associated with parent’s overall HRQOL or whether specific aspects of the medical home, such as care coordination or family-centered care, are associated with HRQOL. Clinicians may be further motivated to provide family-centered care to adolescents¹³ if such care could provide additional benefits to caregivers, such as improved HRQOL.

When evaluating the association between adolescent’s receipt of care consistent with a medical home and parent HRQOL, it is also important to consider youth and parental characteristics that may modify such an association. One potential modifier is the parent’s level of health literacy (HL), which is defined as “the ability to understand, communicate, and use health information to function effectively in the health care system.”¹⁴ Parents with lower HL have been shown to have more difficulty understanding medication instructions and have less health knowledge related to their child’s condition,^{15,16} which could interfere with their ability to take full advantage of the enhanced quality of care offered through the medical home. Another potential effect modifier is the youth’s level of functional limitation. Prior research has suggested that particularly for children with severe physical limitations,

the potential for the medical home to positively influence outcomes such as emergency department visits may be more limited than in other children.¹⁷

The present study's objectives were to describe the association between parent report of youth's receipt of care consistent with a medical home and parent/caregiver HRQOL, and to examine characteristics that may modify the association in a sample of parents/caregivers of adolescents with special health care needs. Specifically, the present study sought to determine whether medical home status was associated with parent HRQOL, to determine which of the five core components of the medical home (having a personal physician, getting referrals when needed, having a usual source of care, receiving family-centered care, and receiving effective care coordination) were associated with HRQOL, and to assess whether the association between youth's medical home status and parent HRQOL was modified by parent HL or youth limitation level.

Methods

Study Sample and Setting

The study sample included the caregivers of mid-adolescent teens (15–18 years) with special health care needs who were enrolled in the “Teen Literacy in Transition” or “TeenLIT” study, which was designed to explore the relationship among transition readiness, parent and teen health literacy, and racial disparities in adolescents with special healthcare needs. Caregiver was defined as the person with primary healthcare responsibility for the teen and could include parents, grandparents, foster parents, or other custodial caregivers. Because over 90% of the caregivers in our sample are parents, we will use the word “parent” in the remainder of the manuscript. The teens were recruited over four years from 2012–2016 from a Medicaid accountable care organization (ACO), Partners for Kids (PFK), which serves children ages 19 and under in a 33 county region in central and southeastern Ohio. In the study's first year, PFK data systems were queried to identify potentially eligible teens with a diagnosis of one of the sixteen most common health conditions reported by youths in the National Survey for Children with Special Health Care Needs (NS-CSHCN) (Appendix 1),¹⁸ or who attended a cerebral palsy outpatient clinic. Identified families were sent a letter describing the study and given the opportunity to opt-out from being contacted by study staff by calling a study phone number or sending an e-mail. This process was repeated in each successive year to capture newly eligible patients. Based on the initial data query, participants who were identified in a previous year, had an enrolled sibling, were non-English speaking, aged out before recruitment, were members of an MCO that limited research contact, or were ward of the state were excluded prior to further screening contact. Study staff called the parents of remaining potentially eligible teens and described the study. If parents expressed interest in participating, staff administered the Questionnaire for Identifying Children with Chronic Conditions– Revised (QuICCC-R)¹⁹ to confirm the teen's CSHCN status. The parents and teens who were eligible were invited to the study interview. Both teens who provided assent and parents who consented to participate completed self-administered assessments of demographics, HRQOL, medical home status, health literacy, and health care transition planning. However, for the present analyses, only completed parent surveys were used. Among 4,086 potentially eligible teens identified for recruitment,

25 parents opted-out of initial contact and 970 teens did not meet inclusion criteria of initial data query. Among 3,091 remaining teens, 152 teens were excluded based on parent responses to the phone screen (age, QuICCC-R, or death) and 1,735 parents could not be reached (i.e., no functional phone number). Ultimately 488 parent-teen dyads of the 1,204 who were both reachable by study staff and eligible were interviewed (response rate 40.5%). This study was approved by the Institutional Review Board at Nationwide Children's Hospital.

Measures

The primary outcome of the study was parent HRQOL, which was assessed with the Family Impact Module questions of the Pediatric Quality of Life Inventory™ (PedsQL™) 2.0.²⁰ A subset of the PedsQL Family Impact Module questions (20 of 36 items, across 4 domains) has been validated to measure HRQOL among parents/caregivers.²⁰ These items can be used to generate an overall HRQOL summary score for the parent (0–100 points) and domain scores, with increasing scores indicating better HRQOL.²⁰ The total score is the average combined score across the 4 domains: physical, emotional, social, and cognitive functioning. Each domain includes 5 items with 5-point Likert scale response options, in which parents report how much of a problem in the past-month they have had with each item (“never” to “almost always”) as a result of their child's health. Each domain has a domain score (0–100 points) in which individual item scores are averaged across the number of items completed.

Whether or not teens received care consistent with a medical home, referred to as “medical home status” hereafter, was the primary independent variable of interest. Medical home status was determined based on parent responses to the 2005/2006 NS-CSHCN medical home questions.²¹ The NS-CSHCN assesses 5 sub-components of the medical home: 1) access to a personal doctor, 2) family-centered care (FCC), 3) getting referrals when needed, 4) having a usual source of sick and well care, and 5) receiving effective care coordination. All medical home sub-components must be satisfied in order for care to be considered consistent with a medical home. To satisfy FCC, respondents must report that their teen's personal doctor or other health care provider “usually/always” spent enough time with them, listened carefully, was sensitive to family values, provided needed information, made them feel like a partner, and (if needed) provided an interpreter. To satisfy effective care coordination, respondents must report receiving enough help with care coordination and being “very satisfied” with care coordination. For all items, the present study included an additional response option of “unsure” and if individuals indicated being “unsure” about an item, this was considered to be a “no” response.

Health literacy was assessed with the Rapid Estimate of Adult Literacy in Medicine (REALM).²² The REALM was administered by study staff during the study visit. Following the REALM protocol, staff gave parents a list of 66 medical terms to read out loud that were ordered in increasing difficulty. The REALM score is based on the number of items read correctly. Parental health literacy was scored as adequate if the respondent achieved a score of 62.²²

Teen's limitation level was categorized as “some,” “severe,” or “no” limitation, based on two questions used in the NS-CSHCN. The first asks, “In the past 12 months, how often has the

child's medical, behavioral, or other health conditions behavioral, or other health conditions or emotional, developmental, or behavioral problems affected his or her ability to do things other children his or her age do?" The second asks, "Does child's condition affect his or her ability to do things a great deal, some, or very little?" Consistent with methods used in prior research,^{23,24} teens were assigned to limitation categories based on parent responses as follows: 1) "some limitation" if the youth's health "sometimes" affected his/her ability to do things and their ability was affected "some" or "very little;" 2) "severe limitation" if the youth's health "usually/always" affected their ability to do things and their ability was affected "a great deal;" and 3) "no limitation" for all other responses.

Demographic characteristics included parent age, gender, race/ethnicity (White Non-Hispanic, Black Non-Hispanic, Hispanic, and Other), education (less than high school, high school/GED, some college, college or more), and place of residence (Central Ohio or Appalachia).

Analyses

Descriptive statistics were used to describe the study sample and chi-square tests compared characteristics across medical home status. Separate multivariable linear regression models were fit to examine associations between HRQOL overall, as well as for each HRQOL domain (physical, emotional, social, and cognitive functioning), and whether or not teens received care consistent with a medical home, adjusting for characteristics that had known associations with both health care quality and HRQOL and could act as potential confounders, including demographics, health literacy, and teen limitation. Post-estimation predictive margins²⁵ were used to estimate adjusted overall HRQOL and domain scores for those who did/did not receive care consistent with a medical home, or those meeting/not meeting the five specific medical home components. Interactions between medical home status and limitation, as well as medical home status and health literacy were also individually tested in adjusted models to determine whether the association between overall HRQOL and medical home status depended on these factors. Post-estimation Wald tests were used to determine whether interactions were significant. Analyses were conducted using Stata version 14.0.²⁶

Results

Among 488 parents enrolled in TeenLIT who completed study assessments, only a minority (27%) reported their teen received care meeting medical home criteria (Table 1). Overall, 79.7% reported their teen had a personal doctor, 56.8% reported family-centered care, 86.5% reported receiving a referral was not a problem (or was not needed), 84.0% reported having a usual source of care, and 48.6% reported effective care coordination. Most parents were female, age <50 years, White Non-Hispanic, and had at least some college education. There were no significant differences in individual characteristics across medical home status, with the exception of whether or not the parent had adequate health literacy. A significantly lower proportion of parents with less than adequate HL reported care consistent with a medical home (18%) compared to parents with adequate HL (29%) ($p<0.05$).

The unadjusted mean HRQOL scores in the sample for parents whose teen did/did not have care consistent with a medical home were 75.4 (SD= 19.1) and 65.4 (SD=19.8), respectively. After adjustment for covariates, there was a significant difference in adjusted HRQOL scores for parents whose teen had a medical home, relative to parents whose teen did not have a medical home, 74.40 vs. 65.78 ($p<0.001$) (Table 2). Significant differences in HRQOL based on medical home status were also observed across all HRQOL domains. However, among the five medical home components, only FCC and coordinated care were significantly associated with overall HRQOL score, p -values <0.001 (Figure 1). Parents who reported their teen received FCC or coordinated care had significantly higher HRQOL than parents not reporting this care.

There were significant differences in HRQOL based on teen limitation level. Parents whose teen had no limitations had the highest HRQOL scores (81.4, SD=16.1), followed by parents whose teen had some limitation (66.8, SD=18.5), and severe limitation (59.2, SD=19.4). However, the interaction between teen limitation level and medical home status was not significant in adjusted models, suggesting that the association between medical home and parent HRQOL did not differ based on limitation level. The interaction between health literacy and medical home status was also not significant. Post-hoc sensitivity analyses examined the association between HRQOL and meeting at least 4 of the medical home components (as compared to all 5 components), and found that results were similar to main findings.

Discussion

In this sample of parents of teens with special health care needs, parents whose teens had care consistent with a medical home had significantly higher HRQOL scores than parents whose teens did not, and these findings were consistent across all domains of HRQOL. In particular, parental reports of the medical home components of FCC and having coordinated care appeared to be the most important to the relationship between HRQOL and medical home status. However, only a minority of parents reported care for their teens consistent with a medical home (27%). This rate was even lower for parents with less than adequate health literacy of whom 18% reported care meeting medical home criteria. These findings highlight the importance of considering the potential positive association of the medical home with higher quality of life for family members of teens with special health care needs and highlight some vulnerable groups with lower access to care consistent with a medical home.

Numerous studies of the medical home in pediatric populations have examined associations of receipt of medical home services with child health status, and many have found positive associations.¹¹ However, this is the first study, to our knowledge, to evaluate the association of parental reporting of care consistent with a medical home and parent HRQOL. The positive association of parent-reported medical home consistent care with parent HRQOL observed in this study suggests that there may be additional benefits of the medical home, above and beyond the benefits of reduced acute care utilization and costs which are typically the focus of economic evaluations of medical homes.²⁷ HRQOL is an important outcome for parents and findings suggest improved health care quality for teens with special health care

needs provided through care that is consistent with a medical home may in turn have positive spillover effects on parent quality of life. As a result, health systems might observe positive differences in HRQOL among caregiver's of CSHCN as well as reduced costs. In addition, the medical home appeared to have a positive association among all parents equally, regardless of their level of health literacy or their teen's limitation level.

There are several mechanisms through which the medical home may improve parent HRQOL. Previous studies have highlighted the reduced time burden for parents in coordinating their child's care when their CSHCN have access to a medical home.^{5,9,12} The time needed to follow-up with obtaining needed care can be substantial for families with CSHCN, and this coupled with at-home care requirements can result in missed time from work or needing to quit work.^{12,28} The medical home may reduce time burden for parents through improved care coordination. In addition, the medical home has been associated with lower unmet health care needs among CSHCN,⁹ which may also reduce healthcare-related burdens on families. The medical home has also been associated with improved family functioning and coping²⁹ among caregivers. Together, these reduced burdens on families may relieve stress and improve well-being.

Interestingly, but not surprisingly, the medical home sub-components significantly associated with parents' HRQOL were care coordination and family-centered care. These domains in particular have been associated with reduced burdens among caregivers in prior research.^{5,30} It is possible that, for parent "peace of mind," the instrumental value of assistance arranging care, provision of needed information, and attentive listening offered through care coordination and family-centered care are more important than continuity with a specific provider. Given that many Medicaid enrolled children in the study sample received care from Nationwide Children's Hospital primary care clinics, which are not structured to provide continuity with a single provider (DJC, personal knowledge), this finding is informative. It argues that clinics that do not offer "personal physicians" can still provide care that enhances family quality of life if they design their systems in a way that is supportive and family centered.

The prevalence of parent-reported medical home consistent care among the study sample was surprisingly lower than what has been reported nationally: 43% of CSHCN in the NS-CSHCN had a medical home in the 2009/2010 survey,³¹ compared to 27% in the present study. Demographics may account for some of the discrepancy. The teens enrolled in the study were all publicly insured at the time they were identified and were identified through claims data, rather than a population-based national sample. The sample also included a larger proportion of Black Non-Hispanic parents and a lower proportion of White Non-Hispanic parents (30% and 61%, respectively) than is representative of the general population in the state of Ohio (13% and 83%, respectively).³² Among CSHCN, the prevalence of the medical home is 36.6% among Black children and 38.9% among publicly insured children, both lower than the national rate.²¹ The medical home prevalence ranges nationwide from 34.2% to 50.7% across all 50 states, highlighting the variability by geographic location.³³ Although the rate of medical homes among CSHCN in Ohio (46.4%) is higher than that observed in the present study,³³ the racial and socioeconomic differences in our sample could contribute to these differences.

There are several potential limitations to the present study. First, we cannot interpret a causal association between parent-reported teen medical home consistent care and parent HRQOL. Because this is cross-sectional data, we did not have a baseline measure of parent HRQOL before teens either received or did not receive care consistent with a medical home. There are possible alternative explanations for our findings. For example, it is possible that parents with higher HRQOL rate their teens' experiences with health care more favorably³⁴ and are more likely to report care consistent with a medical home. Second, we do not know whether the results of this study, conducted in central and southeastern Ohio, would generalize to other populations and it is possible that different associations would be observed in other areas. However, the present study included a diverse sample of teens and parents who were publicly insured, and who are likely targets for interventions such as the medical home. Third, we do not have demographic data on nonrespondents and were unable to account for differences in response by demographics through the use of survey weights or to assess the extent to which nonresponse bias may have influenced findings. Fourth, some teens who did not have a qualifying diagnosis may have met the QuICCC-R screener for CSHCN. However, the diagnoses selected as inclusion criteria have represented well over 90% of CSHNC.¹⁸ Finally, medical home status was based on parent self-report rather than practice certification as a medical home so we cannot say that care was delivered in a medical home in the structural sense. Patients were not truly nested within a specific primary care clinic, given that patients could move freely between clinics, and we were therefore also unable to explore practice variation in parent-reported medical home care. In addition, the self-report of medical home sub-components, such as care coordination, could reflect parents' reporting of services received outside the medical home depending on how broadly parents interpreted the questions. This self-reported medical home measure, however, has been used in numerous previous studies of pediatric populations^{12,28} and patient experiences of care are generally considered valid and important measures of the quality of care received.³⁵

Conclusion

In conclusion, the present study was the first, to our knowledge, to identify a positive association between parent HRQOL and parent-reported medical home consistent care among teens with special health care needs. The study findings highlight the potential for the medical home to indirectly benefit families, beyond the direct benefit offered to the teen through improved health care quality. The specific medical home components of family-centered care and care coordination appeared to be the most important to the association with HRQOL. Future studies should further evaluate these associations prospectively to build the case for investing in and sustaining the medical home model in vulnerable pediatric populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What's New

Parents of chronically ill teens face time and financial burdens. Teens' access to a medical home may alleviate burdens and improve parental HRQOL. This study identified a positive association between parent-reported care consistent with a medical home and parental HRQOL.

Figure 1. Adjusted Overall HRQOL Score by Medical Home Components

Adjusted for age, gender, race/ethnicity, region, teen limitation level, health literacy.

* $p < 0.001$, Wald test for differences in parental HRQOL scores for five medical home components.

Table 1

Characteristics of the Sample (n=488)

	No Medical Home N=356		Medical Home N=132		Total N=488	
	N	(%)	N	(%)	N	(%)
Parent Gender						
Female	340	(95.5%)	123	(93.2%)	463	(94.9%)
Male	16	(4.5%)	9	(6.8%)	25	(5.1%)
Parent Age Category						
40d	169	(47.5%)	56	(42.4%)	225	(46.1%)
41–50	118	(33.2%)	46	(34.9%)	164	(33.6%)
51–60	47	(13.2%)	26	(19.7%)	73	(15.0%)
>60	22	(6.2%)	4	(3.0%)	26	(5.3%)
Parent Race/Ethnicity						
White Non-Hispanic	217	(61.0%)	85	(64.4%)	302	(61.9%)
Black Non-Hispanic	105	(29.5%)	37	(28.0%)	142	(29.1%)
Hispanic	20	(5.6%)	2	(1.5%)	22	(4.5%)
Other	14	(3.9%)	8	(6.1%)	22	(4.5%)
Parental Education						
Less than High School	44	(12.4%)	8	(6.1%)	52	(10.7%)
High School/GED	99	(27.8%)	39	(29.6%)	138	(28.3%)
Some College	125	(35.1%)	54	(40.9%)	179	(36.7%)
College or More	88	(24.7%)	31	(23.5%)	119	(24.4%)
Parent Health Literacy (HL) *						
No Adequate HL	79	(22.2%)	17	(12.9%)	96	(19.7%)
Adequate HL	277	(77.8%)	115	(87.1%)	392	(80.3%)
Teen Limitation Level						
No Limitation	83	(23.3%)	44	(33.3%)	127	(26.0%)
Some Limitation	157	(44.1%)	50	(37.9%)	207	(42.4%)
Severe Limitation	116	(32.6%)	38	(28.8%)	154	(31.6%)
Region						

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	No Medical Home N=356		Medical Home N=132		Total N=488	
	N	(%)	N	(%)	N	(%)
Appalachia	49	(13.8%)	23	(17.4%)	72	(14.8%)
Central	307	(86.2%)	109	(82.6%)	416	(85.3%)

*
p<0.05,
Chi-Square test comparing no medical home to medical home

Table 2

Adjusted HRQOL Scores by Medical Home Status

	Overall			Medical Home Status					
				No Medical Home			Medical Home		
	Score	95% CI		Score	95% CI		Score	95% CI	
HRQOL	68.11	(66.50, 69.73)		65.78	(63.92, 67.65)		74.40 ^{**}	(71.31, 77.48)	
Physical	64.40	(62.56, 66.25)		62.59	(60.44, 64.74)		69.30 [*]	(65.73, 72.87)	
Emotional	65.35	(63.41, 67.29)		62.60	(60.36, 64.83)		72.77 ^{**}	(69.07, 76.48)	
Social	73.85	(71.83, 75.87)		71.18	(68.84, 73.51)		81.04 ^{**}	(77.18, 84.91)	
Cognitive	70.75	(68.77, 72.72)		68.49	(66.20, 70.79)		76.83 ^{**}	(73.02, 80.63)	

Adjusted for age, gender, race/ethnicity, region, teen limitation level, health literacy.

^{*} p<0.01,^{**} p<0.001,

Wald test for difference in HRQOL or HRQOL domain scores based on medical home status.