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Predictors of health literacy and numeracy concordance among adolescent with special health care needs and their parents

Deena J Chisolm, PhD^{1,2}, Madhurima Sarkar, PhD¹, Kelly J. Kelleher, MD^{1,2}, and Lee M. Sanders, MD, MPH²

¹The Research Institute at Nationwide Children's Hospital, Columbus OH

²Department of Pediatrics, The Ohio State University, Columbus OH

³Department of Pediatrics, Stanford University, Stanford CA

Abstract

Background—Parent and teen health literacies (HL) are employed as teens with chronic illnesses transition to health self-management and the adult health system. This study explores the relationships between parent and teen HL.

Methods—Teens ages 12-18 with chronic conditions and their parents, sampled from a pediatric Medicaid ACO, completed an interview assessing HL and self-reported competence with written and numeric health information. Rates of teen and parent HL, degree of concordance, and relationship between concordance and teen-reported competence with health materials were measured.

Results—Half (52%) of teens had adequate HL. 62% of teens reported competence with written health materials and 69% with numeric information. Correlation between parent and teen HL was modest but significant ($\phi=0.13$; $p=0.03$). 47% of parent-teen dyads were concordant for adequate HL while 10% were concordant inadequate. Adequate teen HL was associated with parental adequate HL and parental education. Discordance was associated with self-reported competence with written material and numeric material.

Conclusion—Over half of parent-teen dyads had at least one member with less than adequate health literacy and parent-teen HL concordance were associated with teen perception of health literacy. These findings support the consideration of both independent and dyad HL levels in adolescent care.

Keywords

health literacy; transition; adolescent health

Introduction

Adolescence is a pivotal time in an individual's life course. As teens transition into adulthood, they begin to make independent decisions about their healthcare and begin managing various aspects of their health. The habits and skills that emerging adults will ultimately need to make accurate healthcare decisions are established during adolescence and can shape health and healthcare throughout life (Giedd et al., 1999; Sawyer et al., 2012; Wolf et al., 2009a). The adolescent health care transition process generally includes a gradual shift from parental control of health-related activities and decisions to empowerment of the youth to take on those roles (American Academy of Pediatrics, American Academy of Family, & American College of Physicians-American Society of Internal, 2002). During this process, teen and parental health literacies likely interact to generate health outcomes. Unfortunately, over 21 million parents in the US have low health literacy (Yin et al., 2009), defined as “the ability to understand, communicate, and use health information to function effectively in the healthcare system”(Nutbeam, 2000). Independently, limitations in teen and parent/caregiver health literacy have been shown to be associated with poor health behaviors and outcomes (Sanders, Federico, Klass, Abrams, & Dreyer, 2009) but little is known about the link between teen and parent health literacy.

Parents of children with special health care needs (CHSCN) face substantial health literacy-related challenges associated with their responsibility to facilitate their child's care, to assert their child's rights, and to forcefully pursue required health care. In fact, these parents often see themselves as their child's primary care coordinator, a role that requires complex cognitive processing including understanding, evaluating, applying, and remembering health information (Pizur-Barnekow, Darragh, & Johnston, 2011). Having a parent with these skills can make a difference in a youth's health. For example, research in children with asthma has shown that parental health literacy is associated with reduced emergency department use, improved asthma control, and higher health-related quality of life (Gandhi et al., 2013; Morrison, Myrvik, Brousseau, Hoffmann, & Stanley, 2013).

As CHSCN age, however, the parent's role is diminished as teens begin taking on responsibility for their own disease management and care coordination. While this transition is developmentally appropriate, it does not always yield positive health outcomes. Often teens may take on more responsibility than their maturity level and health literacy can support (Schilling, Knafl, & Grey, 2006) resulting in a period of increased teen personal responsibility but decreased adherence to disease management regimens sometimes resulting in increased mortality and morbidity (Kyngas, Kroll, & Duffy, 2000).

The intersection of parent and teen health literacy is of particular importance during this transition period because both teens with SHCN and their parents require adequate health literacy to understand information regarding management and care of the teen's illness and symptoms (Manganello, 2013). Communication within clinical visits for adolescents with special health care needs can be challenging because clinicians must communicate complex information at a level understandable by both the teen and the parent. While universal health literacy precautions can help with the challenge, it is also important for clinicians and health educators to recognize situations where health literacy discordance may interfere with

communication and yield poor symptom management, poor adherence to disease management instructions, and/or inappropriate service utilization. In this analysis, we assess parent-teen concordance on health literacy measures and test the effect of parent health literacy on adolescent health literacy, competence with written material and competence with numerical information in teens with special healthcare needs.

Methods

Sample

The Teen Literacy in Transition (TeenLIT) Study is exploring relationships between parent health literacy, teen health literacy, and readiness to transition to adult care among teens with special health care needs (TSHCN) enrolled in a Medicaid accountable care organization (ACO). TSHCN are identified in a two stage process. First, claims data from a large pediatric Medicaid ACO are queried to identify teens, ages 12-18, with one of the 15 diagnoses most commonly found in children with special healthcare needs. Potentially eligible families are sent a letter offering them the opportunity to opt out of the study sample. Households sampled from the remaining population are called to confirm eligibility and to schedule a study appointment for the youth and the parent/guardian (referred to a parent in this paper) most responsible for the youth's healthcare. Eligibility is confirmed if the child's age remains within the study criteria (12-18 years) and if the youth meets the definition of TSHCN based on the Questionnaire for Identifying Children with Chronic Conditions (QuICCC screener) (Stein, Westbrook, & Bauman, 1997). The QuICCC is an interviewer-administered instrument for identifying children with chronic or disabling conditions. It consists of 16-item sequences and has been validated for use in a pediatric Medicaid population. Each sequence begins with a stem that asks if a child has experienced a specific consequence (e.g., use of prescription medication, use of specialized therapy). If the response is yes, the respondent is asked if the condition is caused by a medical, behavioral, or other health condition and if the consequence is expected to last more than one year. Teens are considered to have a special health care need if they answer yes to any stem AND its two follow-up questions (Stein, Silver, & Bauman, 2001).

Interviews are conducted either in a clinical facility in conjunction with a scheduled medical visit or in the participant's home or community based on the participant's wishes. Both parent and teen each receive a gift card in thanks for their participation. All elements of the study have been approved by the Nationwide Children's Hospital Institutional Review Board.

Health Literacy Assessment

Teen and parent health literacy is assessed using a combination of interviewer administered and self-administered scales. Our primary measure of health literacy is the Rapid Estimate of Adult Literacy in Medicine (REALM), standard (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) and teen version (Davis et al., 2006) as appropriate. The REALM is an interviewer administered tool in which respondents are asked to read 66 health-related terms aloud. Scoring is based on the number of words read correctly as assessed by the trained interviewer. Consistent with previous literature, those scoring between 0 and 61 are

classified as having less than adequate health literacy and those scoring 62 or above are classified as having adequate health literacy. While the REALM directly measures health-related word recognition, it has also shown a substantial correlation with the Test of Functional Health Literacy in Adults, which measures the understanding of health related terms in context and is often cited as the gold standard of health literacy research (Baker, 2006).

In addition to the REALM, we use items from two questionnaire based tools: the Brief Health Literacy Screener (Chew, Bradley, & Boyko, 2004) and the Health Information National Trends Survey (HINTS) (National Cancer Institute) to assess self-reported competence with written and numeric health information. For self-reported competence with written material, we use the Brief Health Literacy Screener item: “How often do you have someone help you read health care materials.” Individuals are coded as competent with written material if they respond “never” or “occasionally”. Self-reported competence with numerical information is measured using the HINTS item “In general, how easy or hard do you find it to understand medical statistics.” Individuals are coded as competent if they respond “easy” or “very easy.”

Independent Variables

Demographic characteristics for the parent and the youth are collected on the parent survey. These include teen age, race, and gender, and parent age, race, gender, and educational attainment. For this analysis, teen age is categorized as ≤ 16 or ≥ 17 , race is categorized as White or non-White, and parent education is categorized as having a “high school diploma or less” or having “some college or more”. We note that this study is conducted in a Medicaid ACO, therefore, socioeconomic status and insurance status are consistent across the population. An additional predictor of interest is the teen's level of functional limitation. Functional limitation for this study is stratified into three levels: no limitation, some limitation, and severe limitation (Nageswaran, Silver, & Stein, 2008). Limitation is determined by the parent's response to the following questions: (1) “how often does your child's condition affect his or her ability to do the things other children of the same age do?” with response categories “never,” “sometimes,” “usually,” “always,” and (2) “If so, to what degree does the condition affect the child's ability to do those things?” with response categories “a great deal”, “some”, “very little.” Participants who respond “never” to question 1 are coded as having no functional limitations. A response of “sometimes” to question 1 and “some” or “very little” to the second item, yields a classification of “some limitation”. Those classified as severe limitation have either a response of “usually” or “always” to question 1 OR a response of “sometimes” to question 1 followed by “a great deal” to question 2.

Analysis

For this analysis, data were analyzed using SAS software (version 9.2; SAS Inc, Cary, NC). Health literacy differences among demographic groups were tested using the chi-squared test. We then explored concordance between parent and teen outcomes on each scale. Significance of concordance was tested using the phi statistic (adequate vs. not adequate). Next, we built logistic regression models to test significance of parent literacy as a predictor

of teen literacy controlling for demographic characteristics. Finally we classified all parent-teen dyads into four categories by REALM-measured health literacy concordance as follows: concordant high, parent high/teen low, parent low/teen high, and concordant low to test the role of health literacy concordance on the teen's competence with written material, competence with numeric information, and satisfaction with communication. An analysis of primary language at home was also intended but the non-English group was not large enough for reliable analysis.

Results

The opt out rate for the combined Year 1 and Year 2 sample was less than 1%. To date, 43 percent of families reached and deemed eligible have chosen to participate. Families choosing not to participate did not differ by child gender or age. Differential refusal by race cannot be tested due to unreliable race data on the claims data from which the sample is drawn.

A total of 278 parent-TSHCN dyads were recruited between 2012 and 2014. Approximately half of the teens (51%) were female and 63% were White (Table 1). 72% reported at least some functional limitation as a result of their chronic condition. 52% of teens had adequate HL as measured by the REALM-teen. Significantly lower REALM scores were seen in teens whose parents had a high school diploma or less education and whose parent had less than adequate REALM score. Teen demographic characteristics were not significantly associated with teen adequate REALM score.

Overall, 62% of teens reported competence with written health materials. Teens with functional limitations reported significantly lower written material competence than those without limitations. Interestingly, competence with numerical health information was slightly higher than with written information (69%). Again lower rates of competence were seen in teens with functional limitations. Female gender and less than adequate parent health literacy were also associated with lower competence with numerical information.

Eighty-three percent of parents (of whom 95% were mothers) had adequate health literacy. Concordance between parent and teen health literacy was statistically significant but modest ($\phi=0.13$; $p=0.03$). Nearly half (47%) of the parent-teen dyads were concordant for adequate health literacy while 10% were concordant for inadequate health literacy (Table 2). Nearly a quarter of teens with inadequate health literacy (29/125; 23%) had a parent who also evidenced less than adequate health literacy. 52% and 55% of parent-teen dyads reported concordant high competence with written material and numeric material respectively. As with health literacy, a notable number of teens with low competence to use written or numerical information also had parents with self-reported low competence (17% and 29% respectively).

Multivariate modeling shows that significant correlations between parent health literacy and teen health literacy remain even after controlling for teen demographic factors and functional levels (Table 3). Odds of a teen having adequate health literacy were twice as

high when the parent had adequate health literacy and when the parent had post high school education.

Finally, when parent-teen dyads were categorized by health literacy concordance, we found that, after controlling for covariates, teens in concordant high dyads were more likely to report competence with written material and with numeric material than teens from concordant low dyads or parent high/teen low dyads. Self-reported competence with numerical information was significantly lower than the concordant high category for concordant low and both categories of discordance.

Discussion

The analysis demonstrates that 2 in 5 low-income parent-teen dyads seeking care for chronic illness will have non-concordant health literacy levels and that over 20% of low literacy teens also have a low literacy parent taking responsibility for the teen's health. These literacy detriments may negatively affect the family's ability to use health information, follow medical instructions, and successfully navigate the teen's transition to adulthood, which requires developmentally appropriate increased responsibility for self-care and medical decision-making.

Parent health literacy and parent self-reported competence with written information are strongly associated with teen health literacy, even after controlling for the teens' demographic characteristics. The significant relationship between parent and teen health literacy aligns well with literature on parental general literacy, home literacy environments and child cognitive development. Early shared-reading by children and parents has been shown to promote vocabulary acceptance and cognitive development (Duursma, 2008; Payne, 1994; DeBaryshe 1993). Positive cognitive outcomes are also associated with number of books in the home, parental attitudes toward reading, and reading promotion interventions (Bingham, 2007; Rodriguez et.al, 2009; Mendelsohn 2001). Even newborns in the neonatal intensive care unit have been shown to gain cognitive and emotional benefit from early shared reading (Jones, 2004; Lariviere, 2011). Given the likelihood that health literacy is aligned with general literacy and with positive literacy home environments, it is not unexpected that children of higher health literacy parents would have higher health literacy themselves.

While it is heartening that many teens are part of concordant adequate dyads, it is a concern that the remainder are not. It is often assumed that youths with lower health literacy can rely on the support of their parents to interpret and utilize health information but 23 percent of teens with less than adequate health literacy also have a healthcare responsible parent or guardian with less than adequate health literacy. These teens, who are expected to develop health literacy and disease management skills through interaction with their caregivers along with the educational system and the health care system, are at a significant disadvantage without functional role models. This issue must be taken into consideration in the process of patient education and engagement to maximize results (Sanders, Shaw, Guez, Baur, & Rudd, 2009; Wolf et al., 2009b). Although the importance of parental health literacy is evident, the role of concordance is also notable. Teens in parent high/teen low dyads reported lower

competence with written material than concordant high dyads and teen in parent low/teen high dyads also reported lower competence with numeric material.

To date, there have been no studies examining parent-teen discordance in health literacy; however, existing research suggests that discordance on other cognitive factors can yield negative health outcomes. Existing literature suggests that when adolescents and parents have incongruous skills or beliefs, service providers can find it difficult to develop treatment plans and goals (Hawley & Weisz, 2003). For example, parent-child discordance in beliefs about mental health has been found to be associated with poorer outcomes and lower utilization of mental health services (Lewis et al., 2012; Williams, Lindsey, & Joe, 2011). Approaches to addressing health literacy challenges in teens with special health care needs are complex because of the needs of providing understandable information to both the youth and the parent. Our findings show that both independent and conjoint health literacy limitations must be considered. Programs that maximize parent general literacy, health literacy, and shared reading while children are still young (e.g., Reach Out and Read) may increase teen health literacy and parent teen concordance by the time children reach adolescence. Additionally, youth health education programs that engage parents and their children together may aid the conjoint development of health literacy among families (Gest, Freeman, Domitrovich, & Welsh, 2004). Additional research is underway to explore the relationship between concordance and outcomes and to test factors that may moderate or mediate any identified relationships.

One particular limitation of the study should be mentioned. This study was conducted in a chronically ill Medicaid population and results may not be generalizable to higher SES, privately insured, or healthier populations. We selected this population for research, however, because of their high level of interaction with the healthcare system and higher risk of low educational attainment and health literacy. Interestingly, we also note that the parental health literacy level in our sample appears higher than that found in other studies of adult Medicaid populations (Pasche-orlow, Parker, Gazmararian, Nielsen-Bohlman & Rudd, 2005; Moon, Cheng, Patel, Baumhaft & Scheidt 1998; Rosenthal et.al, 2007). This may be reflective of several issues: 1) the Hispanic/low English proficiency population in our area is relatively low; 2) individuals with reading levels below 3rd grade were excluded because of literacy expectations in the full questionnaire; and 3) low literacy individuals may have differentially declined participation in the study. Given these issue, these results may not be generalizable to very low literacy parental populations.

Overall, these findings demonstrate that, within a generally low SES population of TSHCN, over half of parent-teen dyads have at least one member with less than adequate health literacy. Parent and teens were non-concordant over 40 percent of dyads. Both non-concordant and inadequate health literacy have the potential to interfere with effective three way communication among the parent, the teen and the clinician. This is a significant concern given that teens with special health care needs face a perfect storm of rising health-literacy burden (increased societal responsibility for consuming health information) and rising health risks (risky health behaviors and decreased use of and access to health services). Continued attention to literacy-tailored health communication is needed.

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Table 1
Sample demographics and teen health literacy and numeracy rates by demographic category (n=278)

	N (%)	% Adequate Realm	% Competent with written material	% Competent with numerical information
Total	278	145	175	190
Sex				
Male	133 (47.84)	47.37	63.16	75.94*
Female	143 (51.44)	57.34	63.64	62.24
Age				
17-18	206 (74.10)	54.85	65.53	69.42
<17	62 (22.30)	50.00	59.68	72.58
Race				
White	175 (62.95)	57.14	61.14	72.57
Non-White	101 (36.33)	44.55	67.33	62.38
Parent education				
<=HS diploma	106 (38.13)	45.28*	56.60	66.04
Some college	170 (61.15)	57.06	67.65	70.59
Parent health literacy				
Adequate REALM	230 (82.73)	55.65*	64.78	72.61**
Less than adequate REALM	47 (16.91)	36.17	55.32	48.94
Functional level				
No limitation	76 (27.34)	55.26	76.32**	78.95*
Some/severe limitation	201 (72.30)	51.24	58.21	64.68

* χ^2 p-value <0.05

** χ^2 p-value<0.001

Table 2**Parent teen concordance on teen literacy measures[†]**

	Concordant adequateN (%)	Concordant not adequateN (%)	Parent High/ Teen LowN (%)	Parent Low/ Teen HighN (%)	Overall correlationPhi (p)
REALM	128 (47.4)	29 (10.7)	96 (35.6)	17 (6.3)	0.128 (0.03)*
Self-Report Written	152 (55.1)	17 (6.2)	84 (30.4)	23 (8.3)	0.056 (0.36)
Self-Report Numerical	144 (52.4)	25 (9.1)	60 (21.8)	46 (16.7)	0.070 (0.25)

[†]Totals for each measure differ due to missing responses for parent or teen

* Significant correlation $p < 0.05$

Table 3
Simple and adjusted odds ratios for parental predictors of TSHCN health literacy measures

	Teen Adequate REALM		Teen Reported Competence Written Material		Teen Reported Competence Numeric Material	
	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)
Parent REALM						
<Adequate	Reference		Reference		Ref	
Adequate	2.3 (1.18-4.38) *	2.1 (1.10-4.16) *	1.5 (0.80-2.84)	1.7 (0.86-3.22)	2.9 (1.50-5.43) *	3.3 (1.65-6.45) *
Parent Written						
Low	Reference		Reference		Ref	
High	2.7 (1.30-5.45) *	3.0 (1.43-6.28) *	1.3 (0.68-2.64)	1.2 (0.60-2.41)	2.1 (1.03-4.07) *	1.9 (0.95-3.93)
Parent Numerical						
Low	Reference		Reference		Ref	
High	1.1 (0.66-1.95)	1.2 (0.68-2.10)	0.7 (0.44-1.38)	0.7 (0.38-1.23)	1.3 (0.74-2.31)	1.3 (0.70-2.28)
Parent education						
HS	Reference		Reference		Ref	
Some college	1.7 (1.03-2.78) *	1.8 (1.08-3.00) *	1.6 (0.97-2.65)	1.5 (0.91-2.54)	1.5 (0.91-2.53)	1.3 (0.76-2.25)

Note: Adjusted for Teen race, age, sex and functional level

* p<0.05

Discordance in REALM score (Parent/teen)	Teen self-reported competence with written material		Teen self-reported competence with numeric material	
	n (%)	AOR (95% CI)	n (%)	AOR (95% CI)
Parent Realm high/Teen Realm high	107 (75.9)	Reference	111 (78.7)	Reference
Parent Realm high/Teen Realm low	54 (52.4)	0.4 (0.19-0.58) *	66 (64.7)	0.5 (0.26-0.87) *
Parent Realm low/Teen Realm high	13 (65.0)	0.5 (0.19-1.48)	10 (50.0)	0.3 (0.11-0.82) *
Parent Realm low/Teen Realm low	15 (44.1)	0.2 (0.11-0.53) *	16 (47.1)	0.2 (0.10-0.52) *

Note: Adjusted for Teen race, age, sex and functional level

*
p<0.05