

Health Literacy and Health Outcomes among Children with Developmental Disabilities:
A Systematic Review

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Abstract

Developmental disabilities (DDs) are prevalent and associated with health disparities among children. Family health literacy of parents and/or children is one modifiable factor associated with child health; however, little is known about family health literacy for children with DDs. This systematic review was conducted to determine evidence on associations of health literacy with health outcomes among children with DDs. Medline, CINAHL, Embase, ERIC, PsycInfo, and Web of Science were searched through August 2018. Of 2,768 unique records, 53 full text articles were reviewed and four articles were included. Associations of family health literacy with health outcomes among children with DDs were mixed. Future research should include more diverse samples, greater breadth in health outcomes assessed, and increased methodological rigor.

Keywords: children, developmental disabilities, family, health literacy, health outcomes, parents, systematic review

Developmental disabilities (DDs) are a group of chronic health conditions (e.g., learning disabilities, attention deficit/hyperactivity disorder) that result from impairment in physical, learning, language, and/or behavior areas (CDC, 2018). Many US children are affected by developmental disabilities: approximately 18% have one or more developmental disability (Zablotsky et al., 2019). The prevalence of DDs has also increased in recent years, primarily driven by the rising prevalence of autism spectrum disorder (ASD) and to a lesser extent attention deficit/hyperactivity disorder (ADHD) and intellectual disability (Boyle et al., 2011; Zablotsky et al., 2019). Children with DDs and their families are likely to experience poor health and related outcomes relative to other children including lower quality of life (Ncube, Perry, & Weiss, 2018), poorer school attendance and performance (Wei, Blackorby, & Schiller, 2011; Wei, Lenz, & Blackorby, 2012), lower wages earned as adults (Queirós, Wehby, & Halpern, 2015), and reduced life expectancy (Lauer & McCallion, 2015).

From a public health perspective, it is essential to determine factors that can be intervened upon to optimize health for children with DDs given the increasing prevalence of DDs and the pronounced and persistent health disparities that this population experiences. Health literacy may be one such modifiable factor and is conceptualized as a family capacity that can promote health across the lifespan (Mistry et al., 2012). At an individual-level, health literacy refers to a person's ability to access, understand, appraise, and use needed health information and services to make appropriate health decisions (Sørensen et al., 2012).

Many US adults (~80 million) and more than one-quarter (~29%) of US parents have limited health literacy (Yin et al., 2009). Parents with lower education levels, who identify as black or Hispanic, and/or who have low household income are the most likely to have limited health literacy (Yin et al., 2009). Limited versus adequate parent health literacy is associated

with poor health outcomes that are applicable to the broad pediatric population, such as nonstandard medication dosing, decreased medication adherence, increased emergency department use, and missed school days (DeWalt & Hink, 2009; Keim-Malpass, Letzkus, & Kennedy, 2015). Less is known about the health literacy of children, themselves, and its relationship with their health outcomes.

As reflected in the HealthyPeople 2020 objectives (DHHS, 2019), understanding the role of health literacy in advancing population health—especially for groups at greater risk of poor health outcomes such as children with DDs—is a national health priority. Yet, little is known about family health literacy including that of parents and/or children and its relationship with health outcomes among children with DDs. Most health literacy research has focused on adult populations or on general pediatric populations, with some focus on children with asthma or type 1 diabetes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt & Hink, 2009).

Two past systematic reviews have focused on pediatric populations: one systematic review was on health literacy or literacy and health outcomes among children broadly (DeWalt & Hink, 2009) and another systematic review was focused on parent health literacy among children with special health care needs (Keim-Malpass et al., 2015). The systematic review conducted by DeWalt & Hink (2009) on health literacy or literacy and child health outcomes found the most evidence on the following associations: low parent health literacy or literacy with less knowledge of health outcomes, behaviors, and/or services for children; low adolescent health literacy or literacy and increased risk taking behaviors (e.g., smoking, lack of contraceptive use) by adolescents; and low parent health literacy or literacy and less optimal parent health behaviors (e.g., non-standard medication dosing for children, shorter time breastfeeding). From the systematic review conducted by Keim-Malpass and colleagues (2015)

on parent health literacy among children with special health care needs, most of the evidence found was focused on the relationship of parent health literacy with asthma- or diabetes-related health outcomes such as parent self-efficacy to manage the child's asthma. Only one study found in the systematic review by Keim-Malpass and colleagues (2015) focused on children with DDs (i.e., ADHD). Although results from these two past systematic reviews suggest that health literacy is related to health outcomes for children including some with special health care needs, the evidence gaps identified through these two prior systematic reviews demonstrate that additional research is needed to more fully understand how family (parent and/or child) health literacy contributes to health outcomes for children with DDs.

Furthermore, information on family health literacy for children with DDs is vital for taking steps to address health literacy in health promotion efforts for children with DDs. We, therefore, aimed to rigorously determine the state of evidence on associations of family health literacy with health outcomes among children with DDs by conducting a systematic review for which the methodology could be replicated and assessed (Moher, Stewart, & Shekelle, 2015). We focused on family health literacy as defined by health literacy of parents of and/or their children with DDs because parent and child health is inextricably linked.

Method

We conducted this systematic review per the guidelines by the Preferred Reporting Items for Systematic Review and Meta-Analyses Statement (PRISMA) (Moher, et al., 2015). This systematic review was registered in PROSPERO, registration number CRD4201913565. For most aspects of the review including title and abstract screening, full text review, data extraction, and quality assessment, we used the web-based software platform Covidence (*Covidence Systematic Review Software*, n.d.).

Eligibility Criteria

Randomized controlled trials, quasi-experimental studies, non-experimental studies, and qualitative studies among children with DDs published until August 2018 were considered. All inclusion criteria were determined a priori. Types of participants, concepts, context, and types of sources were also used as inclusion criteria and are briefly defined next.

Types of participants. Studies included children with DDs aged 0-21 years and their parents. As a starting point to determine keywords and search terms for our population, we used the following conditions (CDC, 2019): ASD, intellectual disability, down syndrome, cerebral palsy, ADHD, fetal alcohol spectrum disorders, kernicterus, fragile X syndromes, muscular dystrophies, Tourette syndrome, hearing loss including deafness, and vision disorders including blindness. We also expanded our keywords to be inclusive of neurodevelopmental and developmental disabilities generally (Table 1). To meet this criterion, studies needed to have explicitly included children with DDs as a subgroup of analytic interest or as the primary population examined.

Concepts. The two main concepts used to determine article inclusion for this review were family health literacy and health outcomes. Health literacy is a multifaceted construct that includes individuals' abilities to access, understand, appraise, and use health information and services to make appropriate health decisions (Sørensen et al., 2012). Parents often make health-related decisions for their children, particularly when children are young. For this reason, to be included in this systematic review, studies had to have explicitly assessed family "health literacy" quantitatively or qualitatively among children with DDs and/or their parents. Quantitative studies needed to have used one or more health literacy measures (e.g., Rapid Estimate of Adult Health Literacy [REALM], Test of Functional Health Literacy [TOFHLA]) to

be included. Qualitative studies needed to have directly addressed “health literacy” through the questions asked for data collection to be included. Health literacy-related concepts for children with DDs were also documented for all articles that underwent full-text review but were ultimately excluded because they did not explicitly assess the concept of health literacy (see evidence mapping section for additional details on this subset of articles).

Health or health-related outcomes (hereinafter referred to as health outcomes) needed to have been evaluated in children with DDs and/or their parents (e.g., parent knowledge of correct medication dosing for their child). Following from a prior systematic review conducted on health literacy and health outcomes among children broadly (DeWalt & Hink, 2009), studies that assessed the following health outcomes were considered for inclusion: health knowledge (e.g., knowledge about consent information for pediatric research studies, comprehension of vaccine brochures); health behaviors (e.g., medication adherence); measures of disease incidence, prevalence, morbidity, or mortality; self-reported general health status (e.g., missed school days); health services utilization (e.g., emergency department use); and costs of care.

Context. Health outcomes for children with DDs were sought from within the context of their health literacy, which could be in any health-related setting (e.g., in-patient healthcare setting, community-based setting such as home or school).

Types of sources. We excluded opinion pieces, editorials, book chapters, and reviews. We excluded prior reviews because we designed this systematic review to identify the same articles meeting the inclusion criteria; however, we checked that this was the case by examining the results from the prior two systematic reviews conducted on similar topics and populations (DeWalt & Hink, 2009; Keim-Malpass et al., 2015).

Search Strategy

Electronic database searches were conducted in Medline (Ovid), CINAHL, Embase, ERIC, PsycInfo, and Web of Science in December 2017 and then updated in August 2018 for records included from the date inception of each database through when each search occurred (i.e., December 2017, then August 2018). Search terms included controlled vocabulary and free text synonyms for four concepts: children, caregivers, literacy, and developmental disorders (Table 1). The search was limited to English language citations. The full search strategy for Medline is shown in Appendix A. Duplicate citations were removed using EndNote bibliographic management software (Clarivate Analytics, 2018). The reference lists of included articles were also examined, and Web of Science was used to identify articles that cited included articles.

Study Selection

Initially, 3,947 records were identified (Figure 1). After duplicate records were removed, 2,767 records remained including some dissertations. One source was manually added after a research team member became aware of an international dissertation of possible relevance through ResearchGate, bringing the total number of unique abstracts to 2,768. Titles and abstracts were each independently reviewed for eligibility by two authors using the inclusion criteria, and consensus was reached between two reviewers for each record. The full text of each eligible publication ($n = 53$) was then independently assessed by two research team members using the inclusion criteria. Consensus was reached among three authors regarding eligibility and the main reason for exclusion (e.g., no health literacy assessment).

Data Extraction and Study Quality Assessment

The information extracted from each article included author name(s), publication year, country, study design, sample size and characteristics, health literacy assessment(s) used, health

outcome(s) measured, and health literacy relevant results. The quality of each article was also assessed using a tool adopted with permission from Keim-Malpass (2015) and colleagues (Table 2). The quality assessment tool was used by Keim-Malpass and colleagues (2015) in a previous systematic review about parent health literacy among children with special health care needs. For the quality assessment, a level of I to IV was first assigned that indicated the type of study design (i.e., I = randomized controlled trial, IV = qualitative study). A letter grade of A to C was then assigned, which described the quality of the study and considered its generalizability of results, consistency with past research, sample size, and ability to draw conclusions from the results. Grade A indicated the highest quality, and grade C indicated the lowest quality. Two members of the research team completed independent data extraction and quality assessment for each article, and consensus regarding discrepancies was reached through discussion among three authors.

Evidence Mapping of Constructs Related to Family Health Literacy

Evidence mapping is a technique within the systematic review family that is commonly used to help identify gaps or future research areas from a body of literature (Miake-Lye, Hempel, Shanman, & Shekelle, 2016; Moher et al., 2015). We, therefore, sought to better understand constructs related to family health literacy that were previously examined in research among children with DDs by mapping the constructs examined in the 43 articles that underwent full text review but were excluded for not explicitly assessing health literacy. We mapped the constructs examined in these excluded articles by study design (i.e., qualitative study, non-experimental study, quasi-experimental study, randomized controlled trial) and the constructs assessed. The three authors who independently reviewed each of these 43 articles, then determined construct labels (e.g., attitudes, beliefs, knowledge, self-efficacy, information seeking) according to constructs included in commonly used health behavior theories (Bartholomew Eldredge et al.,

2016). That is, constructs such as self-efficacy or adaptive behavior that may influence or be influenced by family health literacy but are not necessarily considered health literacy per se. Each article was then assigned one or more construct(s) (i.e., some articles assessed multiple constructs) through consensus reached among the three authors. Consensus was also reached among the three authors about study design. Studies focused on parents and studies focused on children were separately mapped.

Results

Study Characteristics

Four studies met the systematic review inclusion criteria including one qualitative study, two non-experimental (i.e., cross-sectional survey) studies, and one randomized controlled trial (RCT). As shown in Figure 1, most full text articles were excluded because they did not explicitly assess family health literacy. Table 3 displays other key characteristics for the included studies. All included studies were published after 2010, with three of the four published after 2013 (Cheung, Davey, St John, Bydeveltdt, & Forsingdal, 2016; Dharmapuri et al., 2015; Smith & Samar, 2016). Three studies were conducted in the United States (Dharmapuri et al., 2015; Porter, Guo, Molino, Toomey, & Chan, 2012; Smith & Samar, 2016), and one study was conducted in Australia (Cheung et al., 2016). Nonprobability sampling was employed for all included studies, and three of four studies had sample sizes between 100 and 300 participants (Dharmapuri et al., 2015; Porter et al., 2012; Smith & Samar, 2016). Each study assessed a different developmental disability subgroup including ADHD (Porter et al., 2012), deaf or hearing impaired (Smith & Samar, 2016), developmental delay (Cheung et al., 2016), or learning disabilities (Dharmapuri et al., 2015).

Multiple measures and qualitative inquiry were used to assess health literacy. The Test of Functional Health Literacy in Adults (TOFHLA) was used to assess health literacy in two of the four studies (Porter et al., 2012; Smith & Samar, 2016), though, one of these two studies used the short (versus full) TOFHLA version (Smith & Samar, 2016). The Rapid Estimate of Adult Health Literacy in Medicine (REALM) was also used in one study (Dharmapuri et al., 2015), and the Health Literacy Skills Instrument Short Form (HLSI-SF) was used in another study (Smith & Samar, 2016). The health outcomes assessed across the four studies included: maternal application of health information in making decisions and using therapy services for young children with developmental delays (Cheung et al., 2016), general medication adherence assessed by the Adherence to Refills and Medications Scale (Dharmapuri et al., 2015), parent-reported ADHD data including on the child's ADHD symptoms and medication use (Porter et al., 2012), and interactive and critical health literacy outcomes (e.g., frequency of family discussions about family health history, ease of creating a healthy environment for self, ease of deciding the amount of exercise) (Smith & Samar, 2016).

Health Literacy and Health Outcomes among Children with DDs

Across the four included studies, findings regarding associations of health literacy with health outcomes among children with DDs were mixed. Study quality also varied widely: the highest rating (I, B) was given to the RCT (Porter et al., 2012), and the lowest rating (IV, C) was given to the qualitative study (Cheung et al., 2016) (Table 3). Two studies focused on parent health literacy and health outcomes relevant to children with DDs (e.g., parent-reported information on child's ADHD behaviors and medication use) (Cheung et al., 2016; Porter et al., 2012), and the other two studies focused on adolescent health literacy and health outcomes (e.g., youth medication adherence) (Dharmapuri et al., 2015; Smith & Samar, 2016).

Parent health literacy and health outcomes. In the RCT, Porter and colleagues (2012) examined if paper- or computer-based environments influence the accuracy and sufficiency of parent-reported data on their child's ADHD behaviors and medication use (i.e., ADHD data quality), as well as the impact of parent health literacy level on ADHD data quality (Porter et al., 2012). Only 10 (5.6%) of the 180 parents in the study sample, however, had limited health literacy as assessed by the TOFHLA. Parents with adequate (versus limited) health literacy had greater odds of providing accurate ADHD data (i.e., data on behavior or medication use) for their child; however, these adjusted associations were not statistically significant.

The qualitative study by Cheung and colleagues (2016) also examined parent health literacy. More specifically, this study used semi-structured interviews and grounded theory to explore how mothers use health information when children with developmental delays receive home-based intervention services. Results showed that clinician support impacted mothers' abilities to partner with clinicians to gain and apply health information for their child (e.g., level of collaboration with child's therapist and the mothers' learning preferences impacted mothers' acquisition and application of health information). This study also found that when information was complex, mothers were less likely to ask clinicians questions about it and apply it to their child's care including service use.

Given differences in purpose and design, these two studies received disparate quality ratings (Porter and colleagues (2012) study = I, B & Cheung and colleagues (2016) study = IV, C). Though not statistically significant, results from the study by Porter and colleagues (2012) show that adequate parent health literacy was associated with greater accuracy of information reporting by parents about their child's ADHD. The findings from the study by Cheung and colleagues (2016), however, suggest that parent health literacy in terms of processing and use of

health information about the child was influenced by clinician involvement and presentation of health information about the child.

Adolescent health literacy and health outcomes. The study by Dharmapuri and colleagues (2015) included adolescents, of whom 36% had a chronic illness and 20% had a learning disability. The study's objective was to determine associations between health literacy, measured by the REALM version for adolescents (REALM-TEEN), and general medication adherence, assessed by the Adherence to Medications and Refills Scale. The median score on the REALM-TEEN was 57, indicating a reading level of 6th to 7th grade among adolescents. Adolescents with both chronic illness and learning disability had poorer medication adherence than those without chronic illness and/or learning disability; however, health literacy level was not a significant correlate of adherence in this group.

The study by Smith and Samar (2016) also examined health literacy in adolescents, using multiple health literacy measures (i.e., HLSI-SF, TOFHLA short form, Comprehensive Heart Disease Knowledge Questionnaire) to compare health literacy between deaf or hard-of-hearing (D/HH) adolescents and hearing adolescents, and in relationship to interactive and critical health literacy outcomes (e.g., ease of deciding which foods are healthy). After controlling for demographic characteristics (e.g., race and ethnicity, socioeconomic status), D/HH adolescents had significantly lower health literacy scores, across the three measures, than hearing adolescents. In addition, limited versus adequate health literacy was associated with increased difficulty in certain interactive and critical health literacy outcomes among D/HH adolescents (e.g., ease of deciding when to see a doctor, ease of deciding the truth of printed health information), after controlling for demographic characteristics.

While results from the study by Dharmapuri and colleagues (2015) showed no statistically significant correlation between health literacy level and medication adherence among adolescents with chronic illness and learning disability, Smith and Samar (2016) did find statistically significant associations between health literacy level and certain health literacy outcomes among D/HH adolescents. Results from the study by Smith and Samar additionally suggest that health literacy is lower in adolescents who are D/HH versus those who are hearing. The study by Dharmapuri and colleagues (2015) did not directly compare health literacy scores between adolescents with learning disabilities versus those without learning disabilities. Due to similar study design characteristics, these two studies had similar quality ratings. Because the Smith and Samar (2016) study included a comparison group, its quality rating was slightly higher (III, B) than the study by Dharmapuri and colleagues (III, C).

Collective findings regarding family health literacy and health outcomes. Taken together, limited evidence was found on health literacy and health outcomes among children with DDs in this systematic review. Results from the studies by Smith and Samar (2016) and Cheung and colleagues (2016) suggest that health literacy may proximally influence health outcomes for children with DDs in terms of health literacy outcomes among adolescents who are D/HH or mothers' use of health information in the care of young children with developmental delays. Results from the studies by Dharmapuri and colleagues (2015) and Porter and colleagues (2012) did not show statistically significant associations of health literacy with health outcomes among children with DDs; however, unadjusted results from the study by Porter and colleagues (2012) suggest that parent health literacy may have some influence on the quality of ADHD data reported by parents but that mode of information reporting (i.e., paper-based versus computer-based) is a stronger predictor.

Constructs Related to Family Health Literacy: Evidence Mapping Results

To better understand constructs related to family health literacy that have been examined in past research on children with DDs, we additionally mapped health literacy-related constructs from the 43 articles that underwent full-text review but were excluded because they did not explicitly assess health literacy. Among these 43 articles, 35 focused on parents of children with DDs, 4 focused only on children with DDs, and 2 focused on both children with DDs and their parents. The publication dates for the 43 studies ranged from 1975 to 2018, with 18 studies published before 2011. Among the parent-focused studies, study designs were as follows: 20 were non-experimental, 7 were quasi-experimental (e.g., pre-test and post-test with or without a nonrandomized comparison group), 6 were qualitative, and 4 were RCTs. Among the child-focused studies, one was an RCT and the remaining 5 were quasi-experimental studies.

As shown in Figure 2a, the most commonly assessed constructs related to health literacy in the parent-focused studies included parent knowledge (e.g., knowledge about oral health and hygiene, knowledge about the management of child's behavioral aggression) (Bekiroglu, Acar, & Kargul, 2012), beliefs (e.g., beliefs about the etiology of ASD including whether immunization contributes to ASD risk) (Bazzano, Zeldin, Schuster, Barrett, & Lehrer, 2012), attitudes (e.g., maternal nutrition attitudes, attitudes about recommended services and benefits) (Caliendo, Booth, & Moser, 1982; Chauhan, Prasad, & Khurana, 2017), behavioral application of intervention strategies used (e.g., parent management of child's maladaptive behaviors, feeding a child with cerebral palsy) (Adams et al., 2012; Anderson, Avery, DiPietro, Edwards, & Christian, 1987), and self-efficacy (e.g., parent sense of competence, health-related self-efficacy) (García-López, Sarriá, & Pozo, 2016; Magaña, Li, Miranda, & Paradiso de Sayu, 2015). Parent satisfaction, information needs, information seeking, Internet literacy, treatment decision-

making, and service engagement were also assessed but to a lesser extent. Many studies developed their own measures rather than using existing measures to assess these constructs; however, 12 studies adopted or modified existing measures such as the Illness Perception Questionnaire (Gatzoyia et al., 2014; Mire, Gealy, & Kubiszyn, 2015), Chronic Disease Self-Efficacy Scales (Gatzoyia et al., 2014), and Social Position & Use of Social Services by Migrants and Natives Questionnaire (Tjiam et al., 2011).

Figure 2b displays the constructs related to health literacy from the six studies focused on children. Four studies assessed the child's academic achievement (e.g., wide-range achievement test) (Case, 1974; Edgerly, 1975; Leach & Swerissen, 1986; McDuffie et al., 2016), two studies assessed the child's behavior or functioning (e.g., adaptive behavior) (Adiwoso & Pilot, 1999; Scahill et al., 2016), and one study assessed the child's intelligence (i.e., intelligence quotient) (Edgerly, 1975). All child-focused studies employed previously used measures for the constructs assessed (e.g., oral health maintenance as measured by plaque scores in children, child adaptive behavior as measured by the Vineland II Adaptive Scales) (Adiwoso & Pilot, 1999; Scahill et al., 2016).

Discussion

This systematic review is one of the first to examine the evidence on associations of family health literacy and health outcomes among children with DDs. Because only four studies were included in the review, the breadth of evidence on this topic is currently very limited. Moreover, the quality ratings of the four included studies varied widely (i.e., I, B to IV,C), and findings regarding associations of health literacy and health outcomes among children with DDs were mixed across these studies. While findings from the studies by Cheung and colleagues (2016) and Smith & Samar (2016) suggest health literacy may exert some influence on more

proximal health outcomes (i.e., maternal health information use, critical and interactive health literacy outcomes such as knowing when to go to the doctor) among children with DDs, findings from the studies by Porter and colleagues (2012) and Dharmapuri and colleagues (2015) conversely suggest that neither parent nor adolescent health literacy is significantly related to health outcomes (i.e., youth medication adherence, accuracy of parent reported data on behavior and medication use for children with ADHD) among children with DDs. Due to the heterogeneity of these four studies with respect to the health literacy assessments used, health outcomes measured, and populations examined, it remains difficult to draw conclusions about the state of existing evidence on health literacy and health outcomes for children with DDs.

Findings from our systematic review and past research (DeWalt & Hink, 2009; Keim-Malpass et al., 2015) highlight significant gaps remaining in the evidence base on family health literacy and health outcomes for children, particularly vulnerable subpopulations such as children with DDs. Nevertheless, the evidence gaps identified through this systematic review and past research provide clear direction for the future research to more fully understand how family health literacy contributes to health outcomes among children including those with DDs. Research gaps and future directions may be considered in relation to the following three issues: diversity of the populations studied, health-related outcomes examined, and methodological rigor including health literacy assessment.

To more fully understand relationships of health literacy and health outcomes among children with DDs greater diversity in the populations studied is needed. The four studies included in this systematic review each focused on a different subgroup of children with DDs including those with ADHD, developmental delays, D/HH, or learning disability. Evidence on health literacy for other subgroups of children with DDs—particularly DDs that may be

increasing in prevalence and/or may require a greater array of services (e.g., ASD, intellectual disability)—is consequently needed. Moreover, the small percent of parents with low health literacy in the study by Porter and colleagues (2012) suggests that future research in this area must attempt to oversample families by certain characteristics that are correlated with limited health literacy (e.g., less than high school education, low household income, limited English proficiency) (Yin et al., 2009).

Further research examining relationships of family health literacy with more distal health-related outcomes, such as health behaviors (e.g., services utilization, physical activity, healthy diet) and health status (e.g., parent distress), is also warranted. Past research on parent health literacy and health outcomes among children has shown that parent knowledge, attitudes, and beliefs related to their child's health are assessed more frequently than health services utilization and other longer-term health outcomes (e.g., quality of life) (DeWalt & Hink, 2009; Keim-Malpass et al., 2015). This systematic review similarly found that studies most commonly assessed attitudes, knowledge, and/or beliefs as health outcomes potentially related to health literacy, except for the study by Dharmapuri and colleagues (2015) that examined youth medication adherence. This may be due, in part, to the cross-sectional design of three of the four studies included in the systematic review (Cheung et al., 2016; Dharmapuri et al., 2015; Smith & Samar, 2016) and the relatively short three-month time frame of the study by Porter and colleagues (2012). Because children with DDs are known to experience persistent healthcare and health disparities, future research on family health literacy for this population may seek examine healthcare access (e.g., use of evidence-based services, emergency department visits, well-child visit receipt) and quality of care (e.g., shared decision-making, care coordination receipt) in

addition to health behavior (e.g., physical activity, healthy diet, screen time) and health outcomes (e.g., quality of life, functional impairment, body mass index).

Increased methodological rigor in future research examining relationships of family health literacy and health outcomes is needed. Only the study conducted by Porter and colleagues (2012) used an RCT. Similarly, past research has shown there have been a dearth of studies published on family health literacy and health outcomes among children that have employed rigorous designs (DeWalt & Hink, 2009; Keim-Malpass et al., 2015). Future research may, therefore, seek to study relationships of family health literacy with health outcomes among children with DDs by using longitudinal designs such as prospective cohort or time series studies or by including health literacy assessments in baseline data collection for RCTs. Further research is also needed to rigorously adapt valid and reliable health literacy measures that can be administered long-distance (e.g., via computer or telephone), which could be used with individuals who might be more challenging to engage in research and potentially lower in their health literacy (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014).

From mapping the evidence on constructs related to family health literacy in the articles that underwent a full text review but ultimately were not determined eligible, it was apparent that the bulk of past research in this area has focused most on psychosocial (e.g., attitudes, beliefs, knowledge) constructs versus behavioral constructs (e.g., application of a new skill). Because the articles included in this systematic review primarily focused on health outcomes that were psychosocial versus behavioral in nature, it may be important for future research to more clearly delineate the role of health literacy in relationship to similar and potentially related constructs influencing health outcomes. In addition, it would be helpful for future research to determine the relative influence and interplay (e.g., effect modification) of various factors including health

literacy on health outcomes for children with DDs. Evidence mapping results additionally suggest that examination of health literacy related constructs in children has been somewhat limited, and as findings from this study show the assessment of health literacy in children with DDs is focused on adolescents. Greater knowledge of family health literacy and its measurement from the perspective of children with DDs may, therefore, be beneficial and helpful to understanding its associations with health outcomes for children with DDs.

Limitations

Although we sought to be as inclusive as possible in conducting this systematic review, there are several limitations to consider. First, the results of this review were potentially affected by language bias due to the search being limited to English language articles. That is, some international studies published in languages other than English may not have been included in the search results. In addition, our search only found publications included in the databases searched. This means certain gray literature, such as white papers or technical reports, was not included. Similarly, publications included in journals that were not indexed in the databases searched may have been missed. A potential for publication bias also exists insofar as studies that yielded null findings are generally less likely to be published and, consequently, may be underrepresented in this review (Jooper, Schmitz, Annable, & Boksa, 2012). There is also a possibility that certain articles on relatively rare DDs (e.g., Prader-Willi Syndrome) that we did not specify with search terms or articles about children with DDs that were only characterized in terms of intellectual functioning and adaptive behavior but not explicitly referred to as DDs or neurodevelopmental disabilities were missed. Furthermore, our findings are limited in that we cannot know if the outcomes examined in the included articles (e.g., accuracy of reporting on child's ADHD) directly affect the health outcomes of children with DDs.

Conclusions

This systematic review provides new knowledge regarding the evidence on health literacy and health outcomes among children with DDs. Importantly, only 4 published studies were found with highly variable quality and mixed results on associations of family health literacy with health outcomes for this child subpopulation that is prone to experience health disparities. Additional work in this area is, therefore, needed with more diverse samples of children with DDs, a greater array of health outcomes, and increased methodological rigor including the use of longitudinal designs and valid, reliable health literacy assessments.

Figure 2a & b. Caption

In the bubble plot, bubble size indicates the number of times each construct was assessed across the 43 articles, which underwent full-text review, but were excluded. Larger bubbles signify that the construct was examined in a greater number of studies. Some studies assessed more than one construct, so the numbers shown do not sum to 43. In the bubble color gradient, lighter bubble color indicates constructs were more psychosocial in nature, while darker bubble color signifies the constructs were more behavioral in nature.

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Figure 1. PRISMA Search Strategy

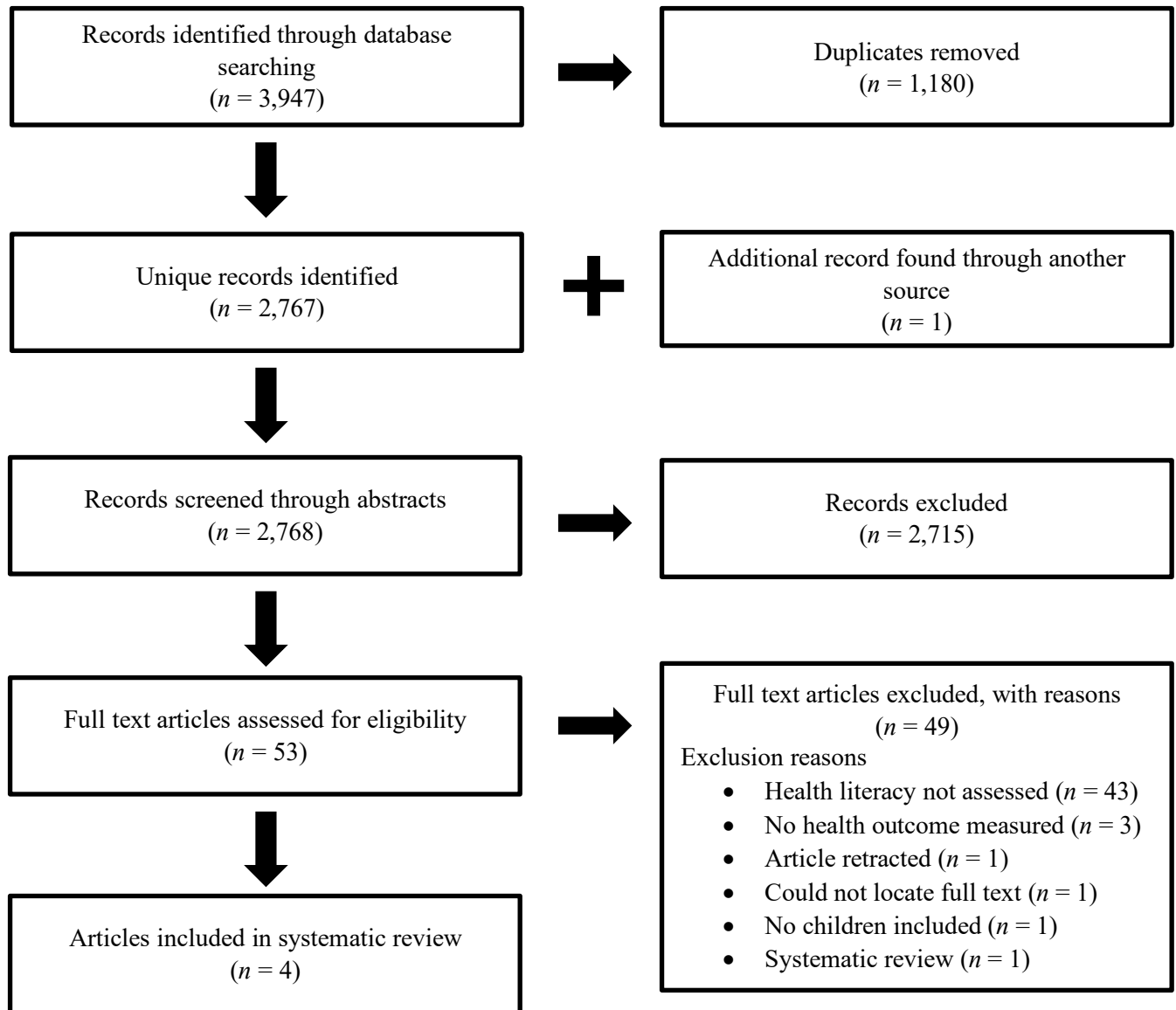


Figure 2a. Map of Parent-Based Health Literacy-Related Constructs from 41 Excluded Full Text Articles

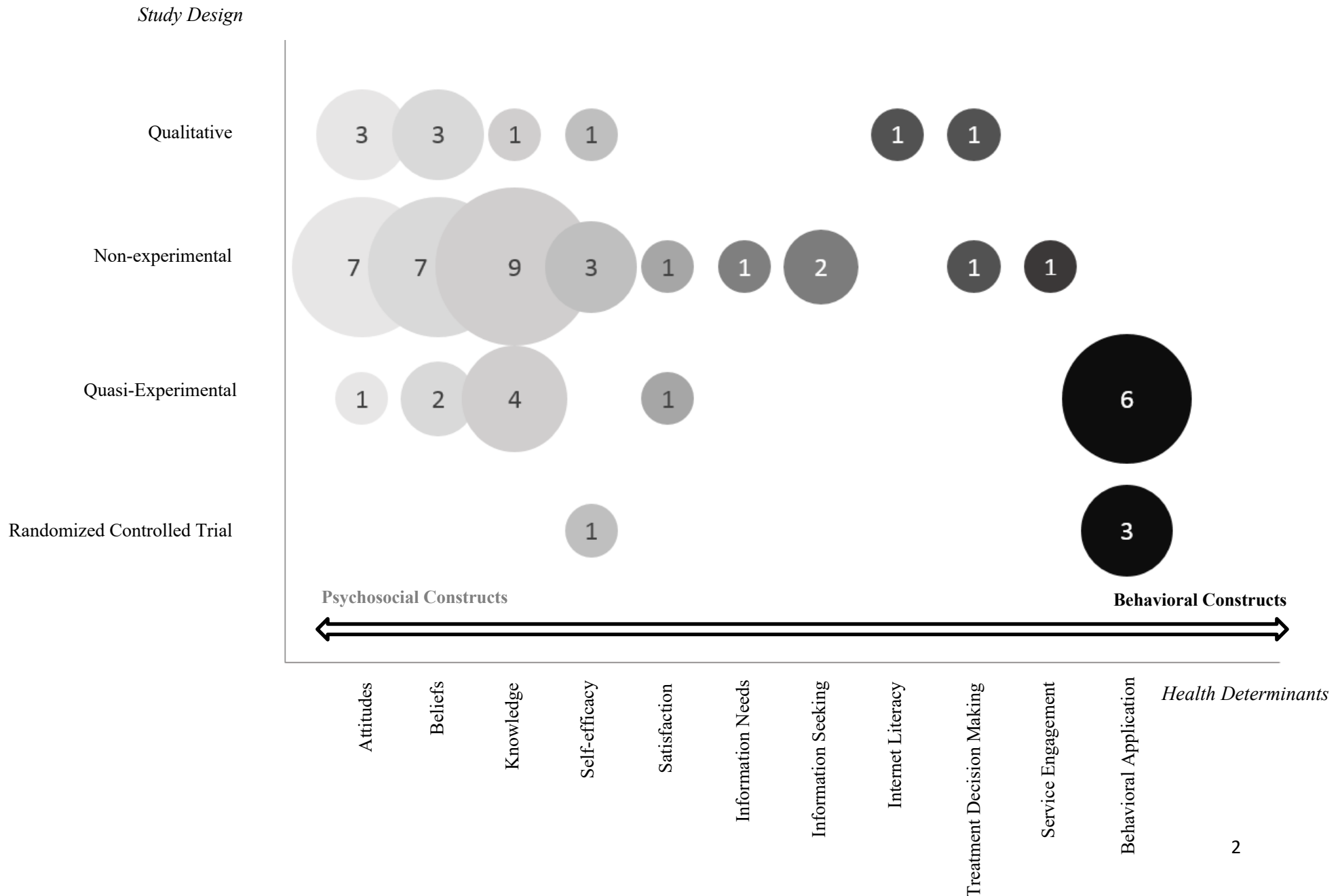


Figure 2b. Map of Child-Based Health Literacy-Related Constructs from 6 Excluded Full Text Articles

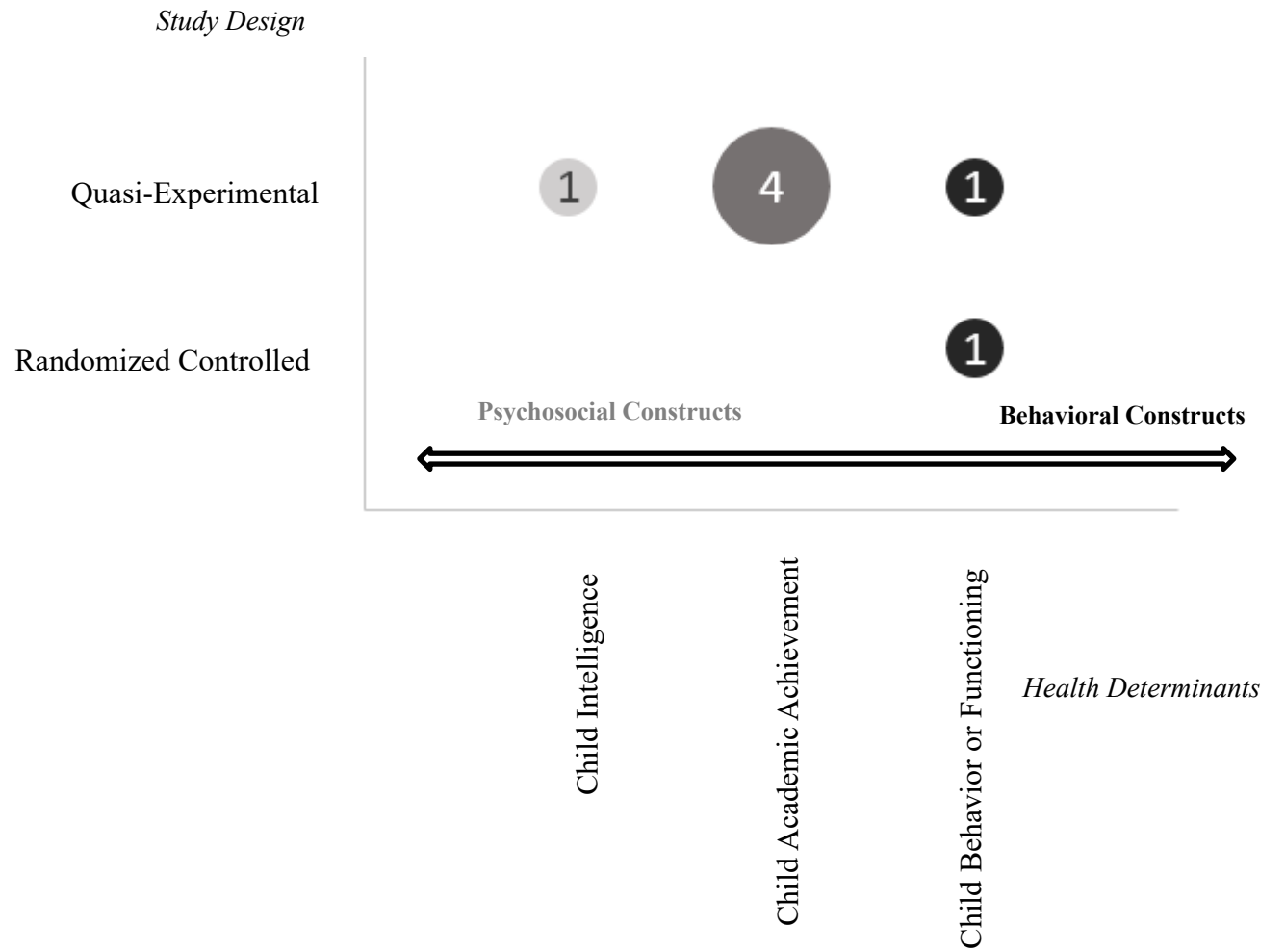


Table 1. Keywords used in Database Searching

Concept	Keywords
Children	child*, pediatric*, paediatric*, adolescen*, infan*
Caregivers	caregiver*, parent*, guardian*
Literacy	Literacy, REALM, "educational status", "newest vital sign", NVS, TOFHLA, "wide range achievement test", WRAT, numeracy, "reading ability", "reading level*", "reading skill*", "parent health activities test", PHAT, "reading comprehension"
Developmental Disorders	"developmental disorder*", "neurodevelopmental disorder*", "developmental disabilit*", "neurodevelopmental disabilit*", "development disorder*", "intellectual disabilit*", "learning disorder*", "learning disability*", "tic disorder*", "down syndrome", "downs syndrome", "cerebral palsy", "fetal alcohol", kernicterus, "fragile x", "muscular dystroph*", deaf*, blindness, autis*, "attention deficit disorder*", "hearing loss", "vision disorder*", "low vision"

Asterisk [*] indicates a wildcard character.

Table 2. Study Quality Review Criteria (adopted from Keim-Malpass et al., 2015)

LEVEL I – Randomized control trial (RCT) or experimental study

LEVEL II – Quasi-experimental study (no manipulation of independent variable, may have random assignment or control)

LEVEL III – Non-experimental study (no manipulation of independent variable, includes descriptive, comparative, correlational studies or uses secondary data)

LEVEL IV – Qualitative study (focus groups, starting point where no previous data exists).

A - HIGH

Consistent, generalizable results

Sufficient sample size

Adequate control

Definitive conclusions

Consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence

B - GOOD

Reasonably consistent results

Sufficient sample size for the study design

Some control

Fairly definitive conclusions

Reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence

C - LOW

Little evidence with inconsistent results

Insufficient sample size for the study design

Conclusions cannot be drawn

Table 3. Detailed Information and Quality Ratings for Included Studies about Health Literacy and Health Outcomes among Children with DDs

Authors, year	Objectives	Design	Setting	Condition(s)	Sample size	Child age	Health literacy assessment(s)	Health literacy relevant findings	Quality rating
Cheung et al., 2016	To explore mothers' information use in child development services where home therapy follow-up is part of intervention or the family's care plan.	Qualitative study with semi-structured interviews	Australia	Developmental delays including fine-motor, gross motor and/or speech and language delay; children born with prematurity; epilepsy; and global developmental delay	<i>n</i> = 14 mothers	1-6 years	Unstructured questions about mothers' experiences, thoughts, and views on information about therapy services and home therapy programs.	The results of the study supported the Maternal Decision-Making Model of information use, which describes a four-stage process. These stages are a conceptualization of how health literacy plays out in mothers' utilization of health information. The four stages identified included: <i>acquisition, appraisal, application, and review of health-related information</i> . Within each of the four stages, two unique processes were identified that described how mothers utilized and mastered each stage. The first stage, <i>acquisition</i> , was dependent upon <i>collaboration</i> between mother and therapist, as well as mothers' <i>learning preferences</i> . Mothers were found to <i>appraise</i> information related to home therapy programs per their <i>understanding</i> of the material and the material's <i>relevance</i> to their child's well-being and their own situation. <i>Application</i> of the information was based on mothers' <i>capacity</i> to apply information and <i>resourcefulness</i> in terms of personal (self-help) and social (help-seeking) behaviors. Finally, application of information was <i>reviewed</i> by mothers, who <i>evaluated</i> and assessed the need for <i>modifications</i> related to the applications. Contextual factors including information characteristics, personal characteristics, relationships, and environment were also identified as influencing each stage of the maternal decision-making process.	IV, C

Authors, year	Objectives	Design	Setting	Condition(s)	Sample size	Child age	Health literacy assessment(s)	Health literacy relevant findings	Quality rating
Dharmapuri et al., 2015	To assess the relationship between health literacy levels and medication adherence in adolescents.	Cross-sectional survey with self-administered questionnaire	United States, Southern Region	40 (36%) participants reported having a chronic illness, and 22 (20%) reported having a learning disability.	<i>n</i> = 112 youth	12-21 years	Rapid Estimate of Adult Health Literacy in Medicine-TEEN (REALM-TEEN)	The median REALM-TEEN score was 57 (range = 0-66), corresponding to a 6th-7th-grade literacy level. No statistically significant association was found between the REALM-TEEN scores and having a chronic illness (<i>P</i> = .081); however, poor medication adherence was significantly associated with having a chronic illness (<i>P</i> = .003) or having a learning disability (<i>P</i> = .041). Medication adherence and REALM-TEEN scores were not significantly correlated (<i>P</i> = .069).	III, C

Authors, year	Objectives	Design	Setting	Condition(s)	Sample size	Child age	Health literacy assessment(s)	Health literacy relevant findings	Quality rating
Porter et al., 2012	To determine (1) the extent to which paper-based and computer-based environments influence the sufficiency of parents' report of child behaviors and the accuracy of data on current medications, and (2) the impact of parents' health literacy on the quality of information produced.	Randomized controlled trial with computer assisted interview	United States, Northeast Region	Attention deficit/hyperactivity disorder	<i>n</i> = 180 mothers and fathers	5-12 years	Test of Functional Health Literacy in Adults (TOFHLA)	170 (94.4%) of 180 parents were literate. Of the lower literate group (<i>n</i> = 10), 0/3 parents with inadequate TOFHLA scores provided sufficient data to screen for ADHD, and 6/7 parents (85.7%) with marginal TOFHLA scores provided sufficient data. Of 170 literate parents, 157 (92.3%) provided sufficient data for ADHD screening. Literate parents, as compared to lower literate parents, had significantly increased odds of sufficient data (OR = 8.0, 95% CI: 2.0–32.1). With literacy modeled as a continuous score, a small but significantly increased odds of sufficient data reported was found for every single integer increase in the TOFHLA score (OR = 1.1, 95% CI: 1.0–1.1; <i>P</i> = .0004). Health literacy did not retain a statistically significant association with sufficiency of ADHD screening data when other factors were accounted for in a multivariable regression model. Among parents with low literacy, only 14.3% provided accurate data regarding their child's medication usage, while 42.2% of literate parents provided accurate information about their child's medication. Multivariable analysis results showed that literacy was not significantly associated with medication reporting accuracy; however, increased odds of accurate medication reporting were associated with literacy vs. low literacy.	I, B

Authors, year	Objectives	Design	Setting	Condition(s)	Sample size	Child age	Health literacy assessment(s)	Health literacy relevant findings	Quality rating
Smith & Samar, 2016	This study sought to (1) quantitatively test if disparities in health literacy and health knowledge exist based on deaf or hard-of-hearing status among adolescents; (2) compare interactive and critical health literacy skills and experiences between adolescents who are deaf or hard-of-hearing versus hearing; and (3) identify subgroups of deaf or hard-of-hearing adolescents who have stronger health literacy than others.	Cross-sectional survey with self-administered questionnaire	United States, Northeast Region	Deaf or hard-of-hearing (hearing comparison group)	<i>n</i> = 187 deaf and hard-of-hearing and 94 hearing college bound high school students	Mean age of hearing = 15.8 years Mean age of deaf or hard-of-hearing = 17.0 years	Health Literacy Skills Instrument Short Form (HLSI-SF), S-TOFHLA, and the Comprehensive Heart Disease Knowledge Questionnaire	After controlling for demographic factors (i.e., age, grade, gender, race/ethnicity, socioeconomic status), deaf or hard-of-hearing participants had significantly lower scores than hearing participants on the HLSI-SF, the S-TOFHLA, and the Comprehensive Heart Disease Knowledge Questionnaire. Deaf or hard-of-hearing participants were significantly more likely than hearing participants to rate the following specific interactive and critical health literacy skills and experiences as hard versus easy: creating a healthy environment for themselves (<i>P</i> = .0005), determining the accuracy of health information obtained from other people (<i>P</i> = .0048), deciding how much exercise is needed to stay healthy (<i>P</i> = .0762), and deciding when they need to go see a doctor (<i>P</i> = .0120). Among deaf or hard-of-hearing participants the HLSI-SF and S-TOFHLA were significantly associated with the frequency of discussions about family medical history after controlling for demographic factors. All three health literacy measures were significantly associated with the ease of deciding when to see a doctor, after controlling for demographic factors, among deaf or hard-of-hearing participants. Both the HLSI-SF and Comprehensive Heart Disease Knowledge Questionnaire were significantly associated with the ease of deciding truth of printed health information, and the ease of deciding which foods are healthy after controlling for demographic factors, among deaf or	III, B

Authors, year	Objectives	Design	Setting	Condition(s)	Sample size	Child age	Health literacy assessment(s)	Health literacy relevant findings	Quality rating
								<p>hard-of-hearing participants. The Comprehensive Heart Disease Knowledge Questionnaire alone was significantly associated with ease of deciding the truth of health information from other people and ease of deciding when to talk to a doctor about family medical history, after controlling for demographic factors, among deaf or hard-of-hearing participants.</p>	

Appendix A. Detailed Search Strategy for Medline (Ovid) Database

Search Number	Search Query
1	exp child/ or exp infant/ or adolescent/
2	(child* or pediatric* or paediatric* or adolescen* or infan*).ti,ab.
3	1 or 2
4	caregivers/ or exp parents/ or legal guardians/
5	(caregiver* or parent* or guardian*).ti,ab.
6	4 or 5
7	literacy/ or exp information literacy/ or exp educational status/
8	(literacy or REALM or "educational status" or "newest vital sign" or NVS or TOFHLA or "wide range achievement test" or WRAT or numeracy or "reading ability" or "reading level*" or "reading skill*" or "parent health activities test" or PHAT or "reading comprehension").ti,ab.
9	7 or 8
10	neurodevelopmental disorders/ or developmental disabilities/ or exp child development disorders, pervasive/ or communication disorders/ or intellectual disability/ or learning disorders/ or tic disorders/ or down syndrome/ or cerebral palsy/ or fetal alcohol spectrum disorders/ or kernicterus/ or fragile x syndrome/ or muscular dystrophies/ or exp hearing loss/ or exp vision disorders/ or Attention deficit disorder with hyperactivity/
11	("developmental disorder*" or "neurodevelopmental disorder*" or "developmental disabilit*" or "neurodevelopmental disabilit*" or "development disorder*" or "intellectual disabilit*" or "learning disorder*" or "learning disability*" or "tic disorder*" or "down syndrome" or "downs syndrome" or "cerebral palsy" or "fetal alcohol" or kernicterus or "fragile x" or "muscular dystroph*" or deaf* or blindness or autis* or "attention deficit disorder*" or "hearing loss" or "vision disorder*" or "low vision").ti,ab.
12	10 or 11
13	3 and 6 and 9 and 12
14	limit 13 to English language

Search commands utilized

Command	Action
Exp	Include Medical Subject Heading (MeSH) terms found below the given term in the MeSH hierarchy
/	MeSH term search
*	Wildcard character
Quotations	Phrase search
.ti,ab.	Title or abstract keyword search

