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Health Literacy in Occupational Therapy Research: A Scoping Review

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Health Literacy in Occupational Therapy Research: A Scoping Review

Abstract

Background: Low health literacy is a significant problem in the United States. Patient education is a key component of occupational therapy intervention. Occupational therapists have the skills to develop patient education materials (PEMs) all patients can understand. Few studies on health literacy exist in occupational therapy research. The purpose of this scoping review was to summarize the breadth of literature on health literacy in occupational therapy research and to identify knowledge gaps.

Method: A scoping review methodological framework (Arksey and O'Malley, 2005; Levac et al., 2010) was used to search five databases. A descriptive numerical summary and qualitative thematic analysis were used to summarize the results.

Results: Eighteen articles met the inclusion criteria. Quantitative results describe variation in research design, outcome measures, intervention focus, and setting. Qualitative themes include exploring health literacy knowledge, practices and perceptions of occupational therapists, and assessment of consumer needs and understanding related to health literacy. Gaps in the literature include the impact of low health literacy on patient outcomes, guidelines for appraising and modifying PEMs, and the effectiveness of modified PEMs.

Conclusion: There is a need to establish evidence-based guidelines and a standard of care for patients with low health literacy.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

health literacy, occupational therapy, patient education materials, scoping review

Cover Page Footnote

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Erratum

Order of authors corrected. Andraya Musallam as second author and Kirsten Vaas as third.

Credentials Display

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Health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzen & Parker, 2000, p. vi). Low health literacy is a significant problem in the United States. The National Assessment of Adult Literacy survey evaluated the health literacy skills of American adults using four levels: below basic, basic, intermediate, and proficient (Kutner et al., 2006). Results of the survey found only 12%–14% of adults have proficient health literacy skills. Proficiency is associated with having the ability to perform the complex and challenging literacy activities necessary to participate fully in one’s own health care. For example, the ability to draw abstract inferences, compare, contrast, and apply complicated information from health-related texts and to locate and use quantitative information to solve multistep problems (Kutner et al., 2006).

The U.S. Department of Education identifies literacy and numeracy as skills that help people accomplish tasks and realize their purposes (Centers for Disease Control and Prevention [CDC], 2021a). Basic literacy skills include the ability to understand, evaluate, use, and engage with written text to participate in society (PIAAC Literacy Expert Group, 2009a). Skills in literacy are necessary to search for and comprehend written patient education materials (PEMs). Numeracy is the ability to access, use, interpret, and communicate mathematical information and ideas to engage in the demands of a range of life situations (PIAAC Literacy Expert Group, 2009b). Skills in numeracy are needed to perform tasks such as understanding nutrition labels and determining the dosage of a medication. Low health literacy makes it difficult for consumers of health care services to effectively take part in health-related decision-making.

Health literacy is influenced by the match between one’s reading ability and the readability (e.g., grade level required to read and comprehend text) of PEMs (Kutner et al., 2006). Research has shown that the average American adult reads between the eighth and ninth-grade level, yet most PEMs are written at or above the tenth-grade reading level (Doak & Doak, 2006). The Pfizer Principles for Clear Health Communication reports that health outcomes are impacted by low health literacy in two ways: (a) a mismatch between reading abilities and the reading level of written health information and (b) lack of health-related information that is easy to understand (Doak & Doak, 2006). Patient education plays a central role in occupational therapy service delivery. Occupational therapists who provide written PEMs must recognize how low health literacy can make it challenging for consumers to access, process, and understand health information (Parker, 2000; Warren, 2013).

The American Occupational Therapy Association’s (AOTA’s) *Societal Statement on Health Literacy* advocates for the role of occupational therapy in creating a health-literate society (AOTA, 2017). This includes developing, promoting, and implementing health education techniques and materials that are readable and understandable to all patients (AOTA, 2020; Grajo & Gutman, 2019). Using a collaborative approach, occupational therapists can empower their patients to become active members of the health care team. This may lead to increased consumer confidence in the health care system (Raynor, 2012).

Purpose

Low health literacy is a significant problem in American adults. Occupational therapists can assist in the creation of a more health-literate society through the development of approaches and materials that are easy to access and understand (AOTA, 2017). For example, occupational therapists have the skills to facilitate a match between the consumer’s reading ability and the readability of PEMs. Few studies have examined health literacy in occupational therapy research. The purpose of this scoping review is to: (a)

summarize the extent and scope of existing research on health literacy in occupational therapy practice and (b) identify knowledge gaps in the literature. This information is needed to advance knowledge in occupational therapy practice and inform future research. To the authors' knowledge, this is the first scoping review of research related to health literacy in occupational therapy practice.

Method

Procedures

A scoping review design was chosen for this study because the authors sought to identify key concepts in the published literature and identify knowledge gaps, rather than assess quality. In general, the reasons for conducting a scoping review are to examine the extent and nature of research activity, disseminate research findings, identify gaps in the literature, and inform future research (Arksey & O'Malley, 2005; Levac et al., 2010; Tricco et al., 2016b). For this study, the scoping review methodological framework developed by Arksey and O'Malley (2005) and expanded by Levac et al. (2010) was carried out in five stages: (a) identifying the research question; (b) identifying relevant studies; (c) study selection; (d) charting the data; and (e) collating, summarizing, and reporting the results. Additional guidance on data synthesis was obtained from the Joanna Briggs Institute (Aromataris & Munn, 2020; Peters et al., 2020).

In addition, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018) was used as a guide. The PRISMA-ScR Checklist was developed to increase understanding of relevant terminology, core concepts, and key reporting items for all readers, including researchers, policymakers, health care providers, and consumers (Tricco et al., 2018). For this study, the checklist was used to demonstrate rigor, enhance the quality of reporting, and develop a visual representation of the search results.

Stage 1: Identifying the Research Question

Research questions for scoping review studies are broad in nature to summarize the breadth of evidence (Arksey & O'Malley, 2005; Levac et al., 2010). This scoping review aims to answer the following research question: What is the existing research on health literacy in occupational therapy practice? Findings from this study will be used to summarize the extent and scope of existing research and identify knowledge gaps in the literature. Linking a broad research question to a more specific purpose assisted the authors in establishing an effective search strategy (Levac et al., 2010).

Stage 2: Identifying Relevant Studies

Levac et al. (2010) recommends that scoping review teams include members who provide expertise on information synthesis. For this study, the authors collaborated with a research librarian to develop a comprehensive search strategy. The final search terms included: consumer health information, literacy, health information, self-management, and occupational therapy. In June of 2020, the authors conducted a systematic search of five databases: PubMed, CINAHL Complete, Web of Science Core Collection, OTSeeker, and ERIC. Databases were chosen in order to retrieve research articles related to medical sciences, occupational therapy, and education. The full search strategy is available in Appendix A. The initial search results were compiled into a spreadsheet using Zotero software (<https://www.zotero.org>).

Stage 3: Study Selection

A broad approach to study selection was used to generate the breadth of existing literature. After the initial search results were generated, one author manually removed the duplicate articles. All authors worked together to identify criteria for eliminating articles that did not address the research question. This

helped to alleviate ambiguity created by a broad research question (Levac et al., 2010). The inclusion criteria for this study were peer-reviewed research studies, published in English, focused on health literacy, and in the context of occupational therapy practice. Exclusion criteria consisted of reports, editorials, opinion pieces, dissertations, theses, and conference abstracts. Articles written by occupational therapists that did not indicate direct application to occupational therapy practice were also excluded. Because of the lack of existing research on this topic, articles were not excluded based on publication year or study type; therefore, quantitative, qualitative, mixed methods, and reviews were eligible to be included. Article titles, abstracts, and full copies of articles that met all criteria were reviewed independently by two authors. The reference lists were scanned manually to identify additional articles. Discrepancies in the study selection process resulted in all authors coming to a consensus on whether the articles in question should be included in the review.

The initial search produced 1,667 articles. After 609 duplicates were removed, the authors screened the titles and abstracts of 1,058 articles. This resulted in the exclusion of 997 articles. The remaining 61 articles were read in full. Forty-four articles did not meet the inclusion criteria. Several articles were excluded for lacking direct application to occupational therapy practice. Seventeen articles met the full inclusion criteria. One additional study was identified in the reference lists of the included articles. In total, 18 articles were included in this scoping review. A flow diagram depicting the article selection process is presented in Figure 1.

Stage 4: Data Charting

According to Nyanchoka et al. (2019), the purpose of charting data is to identify, characterize, and summarize evidence and identify gaps in the literature. At the beginning of the process, a data charting form was developed collectively (see Appendix B). The form was designed to apply to all included studies. A descriptive analytical method was used to extract information from the literature to summarize the participants and populations, assessments and outcome measures, focus, and setting of the research (Arksey & O'Malley, 2005). Together, these data items formed the basis for the scoping review analysis. As recommended by Levac et al. (2010), two authors read each study and charted their findings independently. All authors continually updated the form throughout the data charting process.

Stage 5: Collating, Summarizing, and Reporting the Results

The fifth stage of the scoping review framework consisted of three distinct steps: (a) analyzing the data, (b) reporting the results, and (c) applying meaning (Levac et al., 2010). Descriptive statistics and qualitative thematic analysis were used to analyze the data set (Arksey & O'Malley, 2005; Levac et al., 2010). Qualitative analysis was descriptive in nature. Because of the small sample of articles, qualitative software was not needed to facilitate the process. Basic coding was completed by hand to identify common themes in the literature (Aromataris & Munn, 2020; Peters et al., 2020). Two authors completed the coding process. Any discrepancies were brought to the attention of all authors for resolution. The results identified common themes and gaps in the literature to inform future research. Findings will provide insight into clinical implications in the broader context of occupational therapy practice.

Figure 1
PRISMA Flow Diagram of Article Selection Process

Note. From “Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement,” by Moher et al. (2009).
<https://doi.org/10.1371/journal.pmed.1000097>

Results

After the study selection process, $N = 18$ articles met the inclusion criteria for this scoping review. These articles were published across 15 journals. The studies varied in publication date, origin, and study design. Year of publication ranged from 2001 to 2020 (Leslie et al., 2020; Sharry & McKenna, 2001). Approximately half (55%) of the articles were published in the past 5 years. The countries of publication include the United States $n = 8$ (44%), Australia $n = 6$ (33%), Canada $n = 3$ (16%), and the United Kingdom $n = 1$ (11%). Research designs include survey $n = 6$ (33%), case study $n = 3$ (16%), scoping review $n = 2$ (11%), literature review $n = 2$ (11%), quasi-experimental $n = 2$ (11%), narrative $n = 1$ (.05%),

phenomenological $n = 1$ (.05%), and grounded theory $n = 1$ (.05%). Data were quantitative $n = 11$ (61%), qualitative $n = 4$ (22%), and mixed $n = 3$ (16%).

Study Participants and Sample Sizes

Study participants in the included studies consisted of occupational therapists $n = 8$ (44%) and health care consumers $n = 6$ (33%). The remaining study designs were described as literature reviews $n = 2$ (11%) and scoping reviews $n = 2$ (11%). The life stages of consumer participants included older adults $n = 4$ (66%) and adults $n = 2$ (33%). The diagnoses of consumers included chronic health conditions $n = 4$ (22%), spinal cord injury $n = 1$ (.05%), and developmental delay $n = 1$ (.05%). The sample size of included studies ranged from two to 214 participants (Griffin et al., 2006; Smith et al., 2010). The mean number of participants was 50.

Assessments and Outcome Measures

A variety of assessments and outcome measures were identified in the literature. Assessments included the International Patient Decision Aid Standards (IPDAS; Elwyn et al., 2006), the Test of Functional Health Literacy in Adults (TOFHLA; Nurss et al., 1995), the Rapid Estimate of Adult Literacy in Medicine (REALM; Murphy et al., 1993), the Health Literacy Questionnaire (HLQ; Osborne et al., 2013), the Health Literacy Advisor (HLA; Health Literacy Innovations, 2018), the Patient Education Materials Assessment Tool – Printable (PEMAT-P; Shoemaker et al., 2014), the Health Literacy Environment Review Instrument (Rudd & Anderson, 2006), and the Suitability Assessment of Materials (SAM; Doak et al., 1996). The readability formulas used to measure the grade level of written health information included the Flesch Reading Ease (Flesch, 1948), the Flesch-Kincaid Grade Level (FKGL; Kincaid, 1975), the Simple Measure of Gobbledygook (SMOG; McLaughlin, 1969), the Gunning-Fog Index (GFI; Gunning, 1968), the RIX (Anderson, 1983), and the Dale-Chall (Dale & Chall, 1948). Additional outcome measures included surveys $n = 4$ (22%), pre/post-intervention quizzes $n = 3$ (16%), semi-structured interviews $n = 3$ (16%), questionnaires $n = 1$ (.05%), and self-report $n = 1$ (.05%).

Intervention Focus and Setting

Trends related to the focus and setting of interventions were evident in the literature. Intervention focused on practices for promoting knowledge in occupational therapists $n = 8$ (44%), assessing consumer understanding $n = 6$ (33%), and evaluating the readability (i.e., grade level) of PEMs $n = 2$ (11%). The studies took place in a variety of settings, including hospitals $n = 8$ (44%), educational institutions $n = 5$ (27%), pediatric clinics $n = 2$ (11%), the community $n = 2$ (11%), and the participant's home $n = 1$ (.05%).

Thematic Analysis

Data were analyzed quantitatively and qualitatively. First, data were organized into major themes to summarize the extent and scope of existing research on health literacy in occupational therapy practice (see Table 1). The primary theme identified was related to the health literacy knowledge, practices, and perceptions of occupational therapists $n = 12$ (66%). For example, the ability to identify low health literacy and evaluate the quality of PEMs before providing them to specific patient populations (Atwal et al., 2011; Galati et al., 2018; Sharry et al., 2002). The secondary theme consisted of articles associated with assessment of consumer needs and understanding related to health literacy $n = 6$ (33%). This included how consumers locate, interpret, and apply health information (Armstrong-Heimsoth et al., 2019; Cheung et al., 2016).

Table 1*Major Themes in the Literature*

Theme	Citation
Health literacy knowledge, practices, and perceptions of occupational therapists.	Atwal et al. (2011) Brown et al. (2012) Flaherty et al. (2019) Galati et al. (2018) Griffin et al. (2003) Koenig & Provident (2019) Leslie et al. (2020) Levasseur & Carrier (2010) Levasseur & Carrier (2012) Sharry et al. (2002) Sharry & McKenna (2001) Smith et al. (2010)
Assessment of consumer needs and understanding related to health literacy.	Armstrong-Heimsoth et al. (2019) Cheung et al. (2016) Griffin et al. (2006) Kern et al. (2019) McKenna & Scott (2006) Warren et al. (2016)

Qualitative thematic analysis was used to group the charted data into the following categories: (a) definitions, (b) knowledge gaps, and (c) reported limitations. The full list of charted data categories and subcategories is reported in Table 2. Definitions of the term “health literacy” were identified in the articles for comparison (Arksey & O’Malley; Levac et al., 2010). Nine articles (50%) provided a clear definition of health literacy that was sourced from a major health organization, including the United States Department of Health and Human Services $n = 3$ (16%), the CDC $n = 2$ (11%), the Canadian Public Health Association $n = 2$ (11%), the World Health Organization $n = 1$ (.05%), and the United Kingdom Department of Health $n = 1$ (.05%). Koenig and Provident (2019) used a variation of the definition provided by the Institute of Medicine (2004). Warren (2013) created her own definition of functional health literacy. For the articles where no clear definition was provided $n = 7$ (38%), a definition was implied based on information provided and related references cited.

Sixteen articles (88%) identified one or more gaps in the literature. Significant knowledge gaps included the impact of low health literacy on patient outcomes $n = 3$ (16%), the effectiveness of population specific PEMs $n = 3$ (16%), and validation of population-specific assessments $n = 3$ (16%). Additional gaps included use of the internet as a resource for quality PEMs $n = 2$ (11%), measuring health literacy in caregivers $n = 2$ (11%), the development of population specific materials $n = 2$ (11%), longitudinal outcomes of home programs $n = 1$ (0.5%), barriers to implementing health literacy interventions $n = 1$ (0.5%), and establishing best practice for promoting health literacy in occupational therapy practice $n = 1$ (0.5%). Three articles called for larger sample sizes in future research (Leslie et al., 2020; McKenna & Scott, 2006; Warren et al., 2016). Two studies did not identify any gaps in the literature.

Fifteen articles (83%) reported one or more study limitations. Common limitations identified in the literature included a small sample size $n = 7$ (38%), selection bias $n = 6$ (33%), narrow study focus $n = 3$ (16%), limited generalizability $n = 3$ (16%), unreliable data $n = 3$ (16%), poor response rate $n = 2$

(11%), lack of empirical research $n = 1$ (.05%), a practice effect $n = 1$ (.05%), and time limits ($n = .05\%$). Three articles did not report study limitations.

Table 2*Charted Data Categories*

Category	Subcategory
Sources of Health Literacy Definitions	U.S. Department of Health and Human Services; CDC; World Health Organization; Canadian Public Health Association; United Kingdom Health Department; Institute of Medicine (variation); self-definition; no explicit definition
Gaps in the Literature	Impact on health outcomes; effectiveness of modified PEMs; quality of online PEMs; OT and patient perceptions; health literacy of caregivers; educating OT students; best practice; population-specific materials and assessments; longitudinal outcomes; barriers to implementation; validate assessments; evaluate interventions; larger samples
Reported Limitations	Small sample; poor response rate; length of survey; selection bias; narrow study focus; lack of empirical evidence; limited generalizability; questions unclear; practice effect; unreliable data; time limits

Discussion

This scoping review summarized the extent and scope of evidence on health literacy in occupational therapy research and identified gaps in the existing literature. Much of the existing research is focused on the current practice and perceptions of occupational therapists. Research has shown that despite the prevalence of American adults with low health literacy, health care professionals are using protocols and strategies at a suboptimal rate (Coleman et al., 2013; Flaherty et al., 2019). Health literacy is a complex concept and the existing literature in occupational therapy research lacks clarity. For example, only nine articles (50%) provided a clear definition of the term health literacy. Occupational therapists who lack knowledge and understanding of health literacy terminology will be less likely to determine if the health information communicated to patients is accessible and comprehensible.

Barriers to promoting health literacy in occupational therapy practice were identified in the literature. Galati et al. (2018) surveyed occupational therapists to gain insight into current practice and perceptions related to health literacy. Over one third of respondents reported having no knowledge or education on health literacy. Limited resources and lack of training on health literacy were identified as barriers in practice. Engagement in continuing education has been shown to increase awareness of low health literacy in health care providers. Results from a 6-week workshop conducted by Koenig and Provident (2019) indicate training was beneficial for occupational therapists who implemented health literacy strategies in clinical practice. Although not widely known, opportunities for continuing education are available. For example, the Agency for Healthcare Research and Quality (AHRQ), the CDC, and the Medical Libraries Association (MLA) offer professional education and training programs to increase health literacy skills at no cost to health care professionals (AHRQ, 2021; CDC, 2021b; MLA, 2021).

Training opportunities such as these can help occupational therapists empower patients with low health literacy to take part in their own health-related decision-making.

Consumers of occupational therapy services are often provided PEMs at the point of care. Adherence is influenced by the match between the readability (i.e., grade level) of PEMs and the consumer's reading ability. According to Argent et al. (2018), inability to follow home programming can negatively impact the therapeutic relationship between patient and therapist. In general, PEMs are written at a grade level that is too complex for the average adult to understand (Atwal et al., 2011; Griffin et al., 2006; Levasseur & Carrier, 2012). This notion aligns with results from the National Assessment of Adult Literacy survey on health literacy skills in American adults (Kutner et al., 2006). Occupational therapists who provide appropriate PEMs can improve patient compliance and self-efficacy of treatment (Argent et al., 2018).

Providing PEMs that are readable and understandable is necessary to support informed health-related decision-making and health outcomes. Griffin et al. (2003) suggest assessing the readability level of frequently used PEMs. For patients with low health literacy, modifying PEMs written above the sixth grade reading level is also recommended. Levasseur and Carrier (2012) suggest simplifying written materials with short sentences of 10 words or less and as few syllables as possible and eliminating unnecessary words, active verbs, and words that can be illustrated. In addition, Griffin et al. (2003) suggest evaluating the design characteristics (i.e., literacy demand, graphics, layout, and typography) of PEMs with the Suitability Assessment of Materials (SAM) instrument (Doak et al., 1996). Piloting modified PEMs with a small sample of patients from the target population is also recommended. These strategies are consistent with existing research that encourages occupational therapists to modify PEMs to ensure they are accessible to all patients (AOTA, 2020; Grajo & Gutman, 2019; Raynor, 2012).

Patient education is a key component of occupational therapy intervention. AOTA strives to ensure that occupational therapists have the professional communication and education skills necessary to help their patients access and understand health information (AOTA, 2017). Flaherty et al. (2019) recommend occupational therapy educational programs place greater emphasis on health literacy in the curricula. More specifically, programs should focus on the use of plain language to develop written PEMs that are easy to read and understand. This perspective is important, especially at a time when students are learning to integrate medical terminology into written communications. Educating occupational therapy students will result in newly trained therapists who are health literate before they enter the workforce (Flaherty et al., 2019).

AOTA's Accreditation Council for Occupational Therapy Education (ACOTE) is the accrediting agency for occupational therapy education in the United States (ACOTE, 2021). In 2018, the most recent educational standards for occupational therapy programs were published (ACOTE, 2018). Standard *B.4.21. Teaching-Learning Process and Health Literacy* requires occupational therapy programs to "demonstrate, evaluate, and utilize the principles of the teaching-learning process using educational methods and health literacy education approaches" (ACOTE, 2018, p. 32). ACOTE's educational standards for all degree levels include designing activities, clinical training, and instruction at the level of the audience (i.e., persons, groups, and populations). Additional research is needed to identify strategies for achieving this standard, as well as the degree to which existing programs are meeting ACOTE's standard for health literacy.

The body of literature on health literacy in occupational therapy practice was also compared to other health professions. The field of nursing has notably more research, as well as published guidelines

for promoting health literacy in clinical practice. For example, the Health Literacy Tapestry model provides a holistic framework that fosters a partnership between the patient, nurse, and health care system (Barton et al., 2018; Parnell, 2015). This model can be combined with the health literacy competencies and practices identified by Coleman et al. (2013). The American Speech-Language-Hearing Association (ASHA) provides a comprehensive list of resources and guidelines to promote understanding of health literacy in speech-language pathologists and audiologists (ASHA, 2021). In 2019, the American Physical Therapy Association (APTA) published a position statement on health literacy (APTA, 2019). Research on health literacy appears to be the most limited in physical therapy practice. The application of guidelines from interprofessional disciplines, such as nursing, may assist in developing a standard of care for occupational therapy practice.

Strengths and Limitations

One key strength of this study was use of a team approach to study selection that was transparent and replicable (Anderson et al., 2008; Levac et al., 2010). In addition, a rigorous method was used for mapping the research (Levac et al., 2010). The authors acknowledge the potential for publication bias because of excluding non-peer reviewed research and research published in languages other than English. The authors also chose to exclude theses and dissertations because of a lack of timely access caused by library closures related to the COVID-19 pandemic. Database searching was limited to resources that were accessible by their academic institution. Relevant articles may have been missed by not including additional databases such as Embase. The search strategy was designed to include articles that specifically mentioned direct application to occupational therapy practice. Therefore, the authors may have excluded articles of interest to occupational therapists.

Implications for Practice

The findings of this study provided implications for occupational therapy practice. Health outcomes are negatively impacted by a mismatch between patient reading ability and the readability (i.e., grade level) of PEMs. The readability and suitability of PEMs should be assessed based on the needs of a specific target patient population. PEMs written above the sixth grade reading level should be modified for patients with low health literacy. Occupational therapists identify a lack of resources and training as barriers to promoting health literacy. The occupational therapy profession would benefit from establishing a standard of care for patients with low health literacy.

Conclusion

Low health literacy is a significant problem in the United States. Occupational therapists can play an important role in promoting health literacy to support informed health-related decision-making in the patients they serve. Limited research exists to guide the development and implementation of health literacy strategies in occupational therapy practice. This scoping review explored the extent and scope of existing research on health literacy in occupational therapy practice. Based on the findings of this study, key implications for occupational therapy practice include: the impact of low health literacy on patient outcomes, awareness of the need to assess and modify PEMs for patients with low health literacy, and lack of training and professional development opportunities for occupational therapists. Additional research is needed to investigate the impact of low health literacy on patient outcomes, develop guidelines for appraising and modifying PEMs, and determine the effectiveness of modified PEMs. The results of this study highlight the need to establish a standard of care for health literacy in occupational therapy practice.

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Appendix A

Search Strategy: Available Evidence on Health Literacy in Occupational Therapy Research

Database	Search Terms
PubMed	("Consumer Health Information"[Mesh] OR "literacy"[tw] OR "health information"[tw] OR "self-management"[tw] OR "self management"[tw]) AND ("Occupational Therapy"[Mesh] OR "occupational therapy"[All Fields] OR "occupational therapies"[All Fields] OR "occupational therapist"[All Fields] OR "occupational therapists"[All Fields])
CINAHL Complete	(MH "Consumer Health Information+") OR "literacy" OR "health information" OR "self-management" OR "self management" AND (MH "Occupational Therapy+") OR "occupational therapy" OR "occupational therapies" OR "occupational therapist" OR "occupational therapists" EXPANDERS turned off
Web of Science Core Collection	"literacy" OR "health information" OR "self-management" OR "self management" (Topic) AND "occupational therapy" OR "occupational therapies" OR "occupational therapist" OR "occupational therapists" (All Fields)
OTSeeker	literacy
ERIC	(MAINSUBJECT.EXACT.EXPLODE("Health Education") OR "health education" OR "literacy" OR "health information" OR "self-management" OR "self management") AND (MAINSUBJECT.EXACT("Occupational Therapy") OR "occupational therapy" OR "occupational therapies" OR "occupational therapist" OR "occupational therapists")

Appendix B Data Charting Form

Author, Year, and Country of Publication	Research Design	Definition of Health Literacy	Participants and Sample Sizes	Assessments and Outcome Measures	Intervention Focus and Settings	Reported Limitations	Gaps in the Literature
Armstrong-Heimsoth et al. (2019) United States	Survey (Quantitative)	U.S. Department of Health and Human Services	Adults with chronic health conditions ($n = 103$)	Pre/post survey used to assess changes in ability to find and discern quality health information online	Determine if educational workshops improve ability to find and discern trusted online PEMs in community-based settings	Use of pre/post survey as measurement tool instead of assessment for health literacy	Explore alternative and online approaches for dissemination of information to larger populations
Atwal et al. (2011) United Kingdom	Survey (Quantitative)	No explicit definition Two related citations	Occupational therapists who work with older adults ($n = 5$)	International Patient Decision Aid Standards (IPDAS); SMOG Readability Formula	Evaluate the readability of information leaflets in acute care settings	Poor survey response rate	
Brown et al. (2012) Canada	Survey (Mix of Qualitative/ Quantitative Responses)	United Kingdom Department of Health and Social Care	Occupational therapists who work with children who have sleep disorders and/or pain ($n = 141$)	Questionnaire with two sections: sleep disorders and pain. Common outcome measures were parent/caregiver, child, and teacher reports	Examine practices for promoting health literacy in occupational therapists working with children with chronic illness and sleep disorders and/or pain in pediatric clinical settings	Low response rate; length of survey and number of open-ended questions	
Cheung et al. (2016) Australia	Grounded Theory (Qualitative)	No explicit definition Two related citations	Mothers of young children with developmental delays ($n = 14$)	Semi-structured interviews	Explore how mothers interpret and use health information from OT, PT, and SLP during home therapy	Small sample size and selection bias	

Flaherty et al. (2019) United States	Case Study (Quantitative)	U.S. Department of Health and Human Services	Home programs designed by OT doctoral students (<i>n</i> = 16)	Health Literacy Advisor (HLA); and Patient Education Materials Assessment Tool – Printable (PEMAT-P)	Examine readability, understandability, and actionability of PEMs designed by OT doctoral students in an educational setting	Small sample size	Explore health literacy education within OT and OTA programs to improve teaching strategies and curricula. Explore longitudinal outcomes of home programs in different settings and populations
Galati et al. (2018) United States	Survey (Mix of Qualitative/ Quantitative Responses)	Centers for Disease Control and Prevention	Occupational therapists and certified occupational therapy assistants who work with older adults (<i>n</i> = 80)	Modified survey to explore current practice of occupational therapists using written communication in practice	Gather health literacy knowledge and practices of occupational therapists and certified occupational therapy assistants in SNF and subacute settings	Survey focused on OT practices for written communication only. Some definitions and questions unclear	Determine barriers occupational therapists face that hinder application of health literacy strategies
Griffin et al. (2003) Australia	Literature Review (Qualitative)	No explicit definition One related citation	Occupational therapists working with adult patients with various health conditions	Commonly used readability formulae: Flesch Reading Ease; Gunning-Fog Index; RIX; Dale-Chall Formula; SMOG Grading. Design elements assessed with the Suitability of Assessment Materials (SAM)	Overview of issues and guidelines to help occupational therapists develop and evaluate PEMs		Pilot studies to assess custom materials on a sample from the intended patient population
Griffin et al. (2006) Australia	Case Study (Quantitative)	No explicit definition One related citation	Older adults with various health conditions (<i>n</i> = 214)	Rapid Estimate of Adult Literacy in Medicine (REALM); Flesch Reading Ease	Compare the grade level of PEMs with the literacy skills of older adults in inpatient hospital settings	Selection bias and power limits generalizability	

Kern et al. (2019) United States	Phenomenological (Qualitative)	Centers for Disease Control and Prevention	Older adults with spinal cord injury (SCI) (<i>n</i> = 41) Caregivers (<i>n</i> = 8)	Semi-structured interviews	Explore changing needs of aging individuals with SCI and to identify supports and barriers to achieving health outcomes in a rehabilitation setting	Small sample size, selection bias, and caregivers interviewed with study participant present	
Koenig & Provident (2019) United States	Survey (Mix of Qualitative/ Quantitative Responses)	Institute of Medicine Modified variation	Occupational therapists participating in a series of workshops (<i>n</i> = 6)	Pre/post intervention survey and two pre/post intervention health literacy quizzes	Determine if a health literacy workshop series for occupational therapists could improve knowledge and ability	Small sample size, sample bias, practice effect associated with repeating similar assessments in a short amount of time	RCTs and larger studies to establish best practice for health literacy
Leslie et al. (2020) United States	Narrative (Qualitative)	World Health Organization	Early intervention (EI) providers including OT, PT, and SLP (<i>n</i> = 10)	Cognitive interviewing and verbal probing; Health Literacy Questionnaire (HLQ)	Determine if providers engage with HLQ items as intended by the developers in EI settings	Small sample size may not generalize to other EI providers due to diverse range of clinical backgrounds. Interviews limited by time and questions	
Levasseur & Carrier (2010) Canada	Scoping Review (Quantitative)	Canadian Public Health Association	Articles addressing health literacy and rehabilitation (<i>n</i> = 10)	Databases: MEDLINE, OTDBASE, CINAHL, AMED, and MANTIS. Keywords: rehabilitation, physical therapy, occupational therapy, health, and promotion. Published between 1980–2008	Gain understanding of health literacy, identify clinical implications, and find ways to improve it	Small sample size, author bias may have influenced the review. Search did target a specific specialty	Increase understanding of how health literacy influences health outcomes

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Levasseur & Carrier (2012) Canada	Scoping Review (Quantitative)	Canadian Public Health Association	Articles, reports, and textbooks addressing health literacy and rehabilitation (<i>n</i> = 44)	Databases: Medline, OTDBASE, CINAHL, AMED and MANTIS Keywords: health literacy, rehabilitation, occupational therapy, and health promotion. Published between 1980–2010	Identify how occupational therapists can adapt practice to incorporate health literacy into rehabilitation settings	Lack of empirical research on health literacy	
McKenna & Scott (2006) Australia	Quasi-Experimental (Quantitative)	No explicit definition One related citation	Older adults with various health conditions (<i>n</i> = 14)	Four leaflets on: role of OT, arthritis, energy conservation, and stress management. True/false tests were used to measure knowledge pre/post reading	Examined whether knowledge acquisition improved after reading revised PEMs in hospital settings	Small sample size, selection bias, 13 of 14 participants scored above 9th grade reading level, results reflect knowledge, not attitudes or behavior	
Sharry et al. (2002) Australia	Survey (Quantitative)	No explicit definition No related citations	Occupational therapists who work with older adults with physical disabilities (<i>n</i> = 50)	Survey questionnaire designed to be self-administered, completed by phone, or during a face-to-face interview	Examine occupational therapists use and perceptions of PEMs and the factors they consider before distributing them to patients in physical disabilities settings	Small sample size, selection bias, and lack of reliability data for questionnaire	Explore patient perceptions of PEMs distributed by occupational therapists; whether provision of PEMs improves health outcomes; and, if simplifying improves patient satisfaction
Sharry & McKenna (2001) Australia	Literature Review (Quantitative)	No explicit definition No related citations	Articles pertaining to use of the internet for patient education (<i>n</i> = 58)	Databases: MEDLINE and CINAHL. Manual searches of online journals from allied health professions. Keywords: World Wide Web, Internet, patient education,	Increase awareness of benefits and pitfalls for occupational therapists using the internet as a resource for patient education and determine best		Future research is needed on occupational therapists use of the web as a patient education resource, as well as the quality and effectiveness of the

				health information, consumer, and informatics	practice in this emerging field		information contained
Smith et al. (2010) United States	Case Study (Quantitative)	U.S. Department of Health and Human Services	One stroke unit located in a rehabilitation facility, and one senior independent living facility (<i>n</i> = 2)	Health Literacy Environment Review instrument. Areas evaluated: navigation, print communication, oral communication, technology, policies and protocols. Interviews of administrators and staff. Observation of patient-provider interactions	Evaluate health literacy from the providers perspective to determine strengths and barriers of the environment that impact a patient's ability to manage their own health		Determine whether changes made in health care facilities result in improved health outcomes
Warren et al. (2016) United States	Quasi-Experimental (Quantitative)	Self-defined No citation	Older adults with age-related macular degeneration (AMD) (<i>n</i> = 50) Older adults without AMD (<i>n</i> = 50)	Test of Functional Health Literacy in Adults (TOFHLA) with two-time conditions: standard and unlimited	Investigate whether older adults with AMD demonstrate lower functional health literacy than older adults without AMD	Studying only people with AMD limits generalization to larger population with low vision	Include other age-related eye diseases. Question efficacy of timed tests. Explore tests to accommodate readers with low vision