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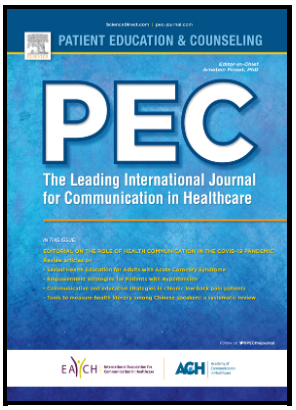

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A systematic review of the health literacy of adults with lifelong communication disability: looking beyond accessing and understanding information

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Abstract

Objective: To determine the a) extent to which people with lifelong communication disability are included in health literacy research, b) level of health literacy of people with lifelong communication disability, c) methods applied to measure the health literacy of people with lifelong communication disability, d) barriers and facilitators mediating the health literacy of people with lifelong communication disability, and e) outcomes of health literacy interventions for people with lifelong communication disability.

Methods: We searched for studies relating to health literacy, people with lifelong communication disability, and key areas of the Sørensen et al. (2012) health literacy model (i.e., accessing, understanding, appraising, applying health information, personal/environmental/systemic barriers and facilitators).

Results: Analysis of 60 studies demonstrated that this population is not well represented. Insufficient research exists to inform statements on level of health literacy or methods used to measure health literacy of this population. Barriers and facilitators appear consistent with those applicable to the general population. Health literacy intervention outcomes were variable.

Conclusion: Significant gaps exist in the research which has primarily focused on people with intellectual disability accessing and understanding health information.

Practice Implications: Findings can inform policies, practice, and future research on health literacy and people with lifelong communication disability.

Key words:

Health literacy, communication disability, lifelong disability, health promotion, information access

1. Introduction

Health literacy involves accessing, understanding and using health information, participating in health decisions, and achieving better health [1]. The term health literacy was introduced during the 1970's [2] and ongoing research encompasses a variety of populations and settings reflecting its importance to health care practices [3,4]. It is estimated that more than 7,000 research papers had been published on health literacy, including at least 26 papers defining health literacy [5]. Sørensen and colleagues (2012) synthesised 17 definitions of health literacy into a conceptual model which defined health literacy as a multidimensional concept incorporating a) individual competence, skills, and abilities; intended or necessary actions; b) formats of information and resources; c) health related objectives or goals; d) individual and service contexts; and e) healthcare timeframes (e.g., lifespan) [6]. This integrated health literacy model brings together critical concepts, conceptualising health literacy as individual strengths and weaknesses moderated by facilitators and barriers within society and health systems. The model incorporates four individual competencies of health literacy being the ability to *access, understand, appraise,* and *apply* health information across the three health domains being *health care, disease prevention,* and *health promotion*. This combination of competencies and domains within a matrix, results in 12 dimensions of health literacy. In addition, factors acting as barriers or facilitators are incorporated to account for environmental, personal, or situational antecedents and consequences that can act as health literacy moderators.

Health literacy enables individuals to work towards health goals across the lifespan. Reduced health literacy is correlated with inadequate health care interactions and poor

outcomes in healthcare settings [7]. Barriers presented by healthcare providers and environments may also challenge individual health literacy [8].

Individual health literacy competencies are particularly important to consider in relation to people with lifelong communication disability [9], due to the likely impact on the person's ability to communicate and interact. A lifelong communication disability results from a condition occurring before or at birth or before the age of 21, remains for life (e.g., cerebral palsy, intellectual disability, autism spectrum disorder), and relates to the "impairments, activity limitations and participation restrictions that affect an individual's ability to interact and engage with the world in ways that are meaningful to them and those they communicate with" [10]. People with lifelong communication disability are often excluded from healthcare interactions [11] and can experience higher health service utilisation rates, more frequent hospitalisation, higher risk of adverse events in hospital, problems with hospital discharge, and early readmission to hospital [12,13]. This means that people with lifelong communication disability are at a greater risk of experiencing reduced health literacy and service providers supporting people with lifelong communication disability should consider the multidimensional concepts of health literacy in order to facilitate engagement with health and disability services [14].

Health literacy can be evaluated through the application of an assessment tool designed and validated for general or specific populations. Evaluating the health literacy of a person with lifelong communication disability could be problematic due to a lack of health literacy assessment tools designed, standardized, and validated with diverse populations [15]. Representation of cultural diversity in health literacy assessment tools has improved over recent years [16], however similar tools have not been developed for people with disabilities. Additionally, there is little evidence that health literacy assessment tools designed for a general population are appropriate for use with people with communication disability.

As a group of people at risk of having lifelong communication disability, people with intellectual disability have been represented to some extent in health literacy research [17,18]. However, a recent review of health literacy interventions found only a limited number of published studies (n = 12) focused on or including people with intellectual disability [19]. Literature about the health literacy of people with intellectual disability often takes the form of commentary; and prioritises consultation with carers or service providers over people with intellectual disability [17]. To date, there is no review of the health literacy of people with a range of disabilities who are at risk of lifelong communication disability (e.g., cerebral palsy, intellectual disability, autism spectrum disorder) which could yield more insights into the health literacy of people with lifelong communication disability.

Therefore, the aims of this study are to systematically review the literature on health literacy to understand more about the a) extent to which people with lifelong communication disability are included in health literacy research, b) individual level of health literacy of people with lifelong communication disability, c) methods applied to measure the health literacy of people with lifelong communication disability, d) barriers and facilitators influencing the health literacy of people with lifelong communication disability, and e) outcomes of health literacy interventions for people with lifelong communication disability.

2. Methods

2.1 Inclusion criteria

To meet inclusion, studies were a) written in English, b) original, peer-reviewed research, or literature review of any design c) relate to adults with lifelong communication disability, and d) address one or more key areas of the Sørensen et al. (2012) model. This model was incorporated into the inclusion criteria as it provides a multidimensional definition that was developed from the synthesis of 17 published definitions and aligns well with the

aims of this review. No limits on date of publication or study design were applied. Excluded papers were a) in languages other than English, b) not original research, c) relating people with acquired communication disability, d) exclusively participants under 18 years of age, or e) addressing no key areas of the Sørensen et al. (2012) model.

2.2 Search strategy

Six scientific databases (Medline, EMBASE, Psychinfo, CINAHL via Ebsco, Web of Science, and SCOPUS) were searched in December 2019 using relevant key words and MeSH terms (see Table 1). The first author imported search results into Zotero reference management software [20] and removed duplicates before importing into Covidence online systematic review tool [21] for screening. The first author completed title and abstract screening, with decisions reviewed by the second author. Two raters independently screened full text articles for inclusion and any differences resolved through consensus discussion. At the full-text stage of screening, exclusion criteria was reviewed and confirmed after the first 20 papers and conflicts resolved by consensus.

To reduce the impact of the limitation of time passing since the initial search, in March 2022 the first author conducted a search in Scopus to locate any studies since December 2019 that had cited the included studies, applying the same inclusion/exclusion criteria and data extraction, with any new data incorporated into analysis.

[INSERT TABLE 1 AROUND HERE]

2.3 Data extraction

Data was extracted from final included papers by the first author to a spreadsheet and checked by the second author. Extracted data included year of publication, country of origin, study setting, lead discipline, aims, methods, outcomes, participant numbers, participant disability, level of communication disability, study inclusion and exclusion criteria,

application of a health literacy definition, application of health literacy assessment tools, areas of health literacy addressed in the research, and research findings.

2.4 Quality assessment

Included original research studies were evaluated using Quality Assessment Tool for Studies with Diverse Designs (QATSDD) which has been validated for use in evaluating studies of diverse designs [22]. The QATSDD provides a percentage score resulting from ratings across 14 items or quantitative and quantitative studies, and 16 items for mixed-method studies. A higher percentage score relates to a higher level of quality. QATSDD ratings were conducted by the first author and checked by a checked by a research assistant, with any differences of opinion resolved by consensus.

2.5 Data analysis

Extracted data was synthesised according to the review aims and across the key areas of health literacy, being the ability to access, understand, appraise, and apply health information, and barriers and facilitators at individual, environmental, systemic levels. A health literacy lens was applied during data analysis utilising the Sørensen et al., (2012) integrated conceptual model of health literacy. Results and discussion are presented in consideration of this multidimensional view of health literacy in relation to a population of people with lifelong communication disability.

3. Results

The initial search yielded 7566 titles after removing duplicates. Screening was conducted as described above with full-text assessment on 284 titles, with exclusion reasons aligning with exclusion criteria, such as studies only relating people with acquired communication disability or addressing no key areas of the Sørensen et al. (2012) model. The

subsequent forward citation search yielded 215 titles after removing duplicates, and four additional papers located in March 2022 which also met inclusion criteria. This resulted in the final inclusion of 60 papers in this review. See Figure 1 for the PRISMA chart [23]. Characteristics of the included studies are presented in Table 2.

[INSERT FIGURE 1 AROUND HERE]

[INSERT TABLE 2 AROUND HERE]

3.1 Locations, topics, and research aims

Studies published between 2001 and 2019 consisted of intervention studies (*n* = 30), literature reviews (*n* = 13), assessment studies (*n* = 3), and other studies (e.g., exploratory studies investigating novel areas of health literacy research, *n* = 15). Research studies were conducted in United Kingdom (*n* = 20), United States of America (*n* = 16), Canada (*n* = 4), Netherlands (*n* = 2), Australia (*n* = 1), Germany (*n* = 1), Ireland (*n* = 1), Spain (*n* = 1), and Sweden (*n* = 1). Topics covered were health behaviours (*n* = 26), health conditions (*n* = 11), medication (*n* = 8), food (*n* = 10), and communication (*n* = 8). Research setting types were community (*n* = 24), residential (e.g., group homes, *n* = 22), private residences (e.g., family residences, *n* = 18), outpatient (*n* = 7), and inpatient (*n* = 3). Research aims were diverse and therefore grouped into categories that were intervention effectiveness (*n* = 28), participant experiences (*n* = 14), intervention processes (*n* = 9) and evidence-based practice (*n* = 8). Details about topics, settings, and aim categories are presented in Table 3.

3.2 Study designs and research quality

The research methodologies used across the original research studies encompassed quantitative (*n* = 24), qualitative (*n* = 14) and mixed-methods (*n* = 8) designs. Methods for data collection in original research were questionnaires or surveys (*n* = 28), interviews (*n* = 19), focus groups (*n* = 8), and other (*n* = 9, e.g., audit, observation, journaling). Nineteen

studies used multiple methods. The research quality ratings obtained using QATSDD provide a percentage score where lower numbers equate to lower quality. Overall, scores averaged 49.0% for the 47 original research studies (range 19.0 – 83.3%). Qualitative research scores averaged 49.0% (range 23.8 – 83.3%), quantitative research scores averaged 42.9% (ranged 19.0 – 76.2%), and mixed-methods research scores averaged 40.0% (range 27.1 – 52.1%). These results demonstrate high variability in the quality of studies on the health literacy of people with lifelong communication disability with qualitative studies rating somewhat higher than other designs. Overall, studies rated poorly in categories of evidence of user involvement in design, justification for analytic method selected, evidence of sample size considered in terms of analysis, and rationale for choice of data collection tools.

3.3 Literature reviews

Thirteen review papers were included in this review. Reviews were systematic (*n* = 3) [24–26] and non-systematic (*n* = 10) [e.g., 19,27] with the number of included papers totalling 246 and ranging from four to 52. The focus of the reviews included health communication (*n* = 3) [19,28,29], health behaviour (*n* = 3) [24,30,31], health condition (*n* = 2) [26,32], health promotion (*n* = 1) [33], health literacy (*n* = 1) [17], medication (*n* = 1) [27], parenting (*n* = 1) [25], and safety (*n* = 1) [34]. Review aims included identifying research gaps (*n* = 5) [e.g., 17,33], intervention effectiveness (*n* = 5) [e.g., 26], participant experiences (*n* = 3) [27,29,34], behaviour change (*n* = 1) [24], or processes used in interventions (*n* = 1) [19]. The health literacy competencies addressed were access to health information (*n* = 9) [e.g., 25,31], understanding health information (*n* = 11) [e.g., 27,33], and applying health information (*n* = 2) [e.g., 24,25]. The health domains addressed were health care (*n* = 5) [e.g., 17,28], disease prevention (*n* = 7) [e.g., 24,26], and health promotion (*n* = 9) [e.g., 30,32].

Reviews citing original research studies, and the cited studies, are presented in table 2. Reviews citing studies that are included in this review are marked with a single asterix.

Individual studies included in the review papers are marked with a double asterix. Eighteen of the 47 (38%) original research studies were cited in one or more review papers, resulting in 23 citations in eight of the 13 reviews (61%). One review [33] cited six of the included studies, one review [27] cited five of the included studies, one review [28] cited three of the included studies, four [17,19,30,32] reviews cited two of the included studies, and one review [31] cited one included study.

3.4 Participants in original research studies

A total of 2310 participants aged 18 years and older were included in the original research studies ranging from four to 361 participants in an individual study. All participants with communication disability had intellectual disability, and none were reported to have other lifelong conditions (e.g., cerebral palsy, autism spectrum disorder). In total, 43 (91%) of the 47 included studies did not describe participants' communication skills or impairments. Where communication skills were described, broad terms were used (e.g., "difficulty with literacy", "ability to talk about their experiences") or were partially assessed using the standardized tools such as British Picture Vocabulary age score and Stanford–Binet Communication Domain age equivalent. British Picture Vocabulary age scores ranged from 2;0 to 13;0 and Stanford–Binet Communication domain age equivalents ranged from 5;1 to 7;4.

Thirty-eight of the 47 studies (81%) described participant inclusion criteria. Of these, 10 studies excluded people with communication disability through restrictive inclusion criteria or explicit exclusion criteria such as inability to answer comprehension questions [35], inability to provide informed self-consent [36–38], severe-profound intellectual disability [39,40], vision/hearing impairment [41], a diagnosed disability involving cognitive impairment (e.g. autism) [41], or being non-verbal [42].

3.5 Participant health literacy

Eight studies [17,19,29,33,43–46] explicitly stated or referenced a health literacy definition or model, from either Berkman et al. [47], Sørensen et. al. [6], Marks et al. [48], Nutbeam [14], or Nielsen-Bohlman et al. [49]. The health literacy competencies addressed were 'access to health information' (n = 53), 'understanding health information' (n = 48), and 'applying health information' (n = 18). None of the included studies evaluated participants' competency in appraising health information (i.e., the ability to evaluate the quality of health information). One study addressed 'communicative health literacy' which relates to competencies needed for interactions and exchanges of health information [19]. Health domains addressed were 'health promotion' (n = 30), 'disease prevention' (n = 21), and 'health care' (n = 24). Figure 2 provides a graphic representation of the number of included papers that address each individual health literacy competency and the moderators of health literacy across the health domains of health care, disease prevention, and health promotion.

[INSERT FIGURE 2 AROUND HERE]

Three studies included assessment of at least one aspect of participant health literacy [44,50,51]. One study involved use of a qualitative methodology to investigate knowledge of medication and barriers to self-management with 17 participants with intellectual disability to explore health knowledge and experiences of accessing and using health information to self-manage health conditions. Results indicated participants has awareness of their asthma diagnosis, and purpose of medication, however self-management abilities were variable [50]. Another study involved use of a survey developed in line with UK health guidelines to investigate health related skills of 45 participants with intellectual disability in relation to medication knowledge and ability to provide informed consent for the prescription of these medications. Results indicated that knowledge of medications is poor in relation to the proposed duration, disadvantages, name of treatments, calling into question their ability to

provide informed consent [51]. Finally, one study involved use of validated health literacy assessment tools (Adapted FCCHL [52]; Health LiTT [53]) with 18 participants with intellectual disability who were part of a larger cohort of people with neurofibromatosis (n = 86). Results of this study indicated participants with learning disabilities had lower scores on the Health LiTT assessment. However, in a multivariate analysis, education level *and* learning disability were significant predictors of Health LiTT scores while lower education alone was associated with lower adapted FCCHL scores [44].

3.6 Health literacy barriers and facilitators

Thirteen studies described individual or environmental barriers and facilitators impacting on the health literacy of people with lifelong disability, three of which were literature reviews [17,32,34]. Overall, factors acting as either barriers or facilitators included receptive communication abilities (poor or good), support of family/carers/disability organisations (withheld or provided), attitudes of support people (negative or positive), quality of interactions with health providers (poor or good), and evidence-based practice (withheld or applied). Factors forming barriers related to poor structure and organisation of an intervention [43] and insufficient consideration for needs of people with intellectual disability such as comprehension supports [17,34]. Factors forming facilitators related to appropriate modification of written and/or verbal information [54] and opportunities to apply new knowledge with support [55].

3.7 Health literacy interventions

A total of 30 studies were classed as intervention studies. The aims of the studies targeted individual health literacy competencies, or a change made within a service, such as the way letters were written. Interventions were either designed for a specific group of participants (e.g., residents in an intellectual disability inpatient forensic service) or modified

from mainstream programs to accommodate the perceived needs of people with intellectual disability. Three studies involved some form of co-design or consultation with stakeholders to develop the program [56–58]. None of the intervention studies utilised a health literacy definition or model.

The intervention studies investigated behaviour-change outcomes relating to physical activity (e.g., step count), body mass index (BMI), and other health behaviours (e.g., attempts to stop smoking), as well as pre- and post-intervention knowledge, self-efficacy, or quality of life. Intervention delivery models were a face-to-face (n = 25) [e.g., 59,60], group education (n = 24) [e.g., 57,61], brochures (n = 4) [40,58,62,63], videos (n = 2) [41,56], accessible written information (n = 2) [64,65], and environmental modification (n = 1) [66].

The health literacy competencies addressed were *access* to health information (n = 25) [e.g., 67,68], *understanding* health information (n = 23) [e.g., 69,70], *applying* health information (n = 10) [e.g., 66,71]. Health domains addressed were health care (n = 9) [e.g., 41,62], disease prevention (n = 13) [e.g., 56,72], and health promotion (n = 14) [e.g., 73,74]. Authors reported positive outcomes (n = 18) [e.g, 75,76], mixed results (n = 8) (i.e., positive change on some measures but not all measures) [e.g., 72,77], non-significant or no change (n = 3) [40,58,78], and acceptability of the program (n = 1) (i.e., what participants liked about the program) [57].

4. Discussion and Conclusion

The aims of this study were to systematically review the literature on health literacy to understand more about the health literacy of people with lifelong communication disability and the barriers and facilitators influencing their health literacy. The Sørensen et al., (2012) model guided analysis, providing an analytic lens through which the results will be discussed. Our analysis synthesised findings relating to individual health literacy competencies (i.e., ability to access, understand, appraise, and apply health information) as well as

environmental, personal, or situational barriers and facilitators; across the three health domains of health care, disease prevention, and health promotion. This supports conceptualisation of health literacy as a complex interaction of individual and social concepts becoming an "asset for improving people's empowerment within the domains of healthcare, disease prevention and health promotion" [6].

4.1 Discussion

4.1.1 The inclusion or exclusion of people with lifelong disability in health literacy research

Adults with intellectual disability were the only population of adults with lifelong communication disability in the health literacy research reviewed. This is despite the inclusion criteria and search terms being designed to locate literature including any adults who are at risk of lifelong communication disability associated with a range of disabilities (e.g., cerebral palsy, intellectual disability, autism spectrum disorder). Considering the large and growing broader body of research into health literacy, results of this review indicate people with lifelong communication disability have not been adequately included in health literacy research and are often actively excluded. Furthermore, research on the health literacy of people with lifelong communication disability has applied either no definition, or simplistic conceptualisations of health literacy, and relates primarily to the domains of disease prevention and health promotion. This indicates that health literacy research with this population does not incorporate or reflect the complexities of the Sørensen et al. (2012) multidimensional model of health literacy.

4.1.2 The health literacy and methods used to determine this with people with lifelong communication disability

To date, insufficient high-quality research is available to inform evidence-based statements about a) the health literacy of people with lifelong communication disability, or b) appropriate methods that should be used to assess the health literacy of people with lifelong communication disability. Few studies appear to have assessed the health literacy of people with lifelong communication disability and there is no indication that assessment methods applied in the included studies were appropriate for use with people with lifelong communication disability. Although reasons for this absence of evidence about health literacy in people with lifelong communication disability are not known, it is possible that there is an unfounded assumption that communication competency is the most significant predictor of health literacy for people with communication disability. However, the findings of Merker et. al. [44] indicate that the health literacy of people with intellectual disability may be linked to education level rather than factors relating to communication disability. Further research into this finding is needed in order to fully understand the impact of lifelong communication disability on individual ability to access, understand, appraise, and apply health information, and on ways to include this population in health literacy research.

4.1.3 Barriers and facilitators impacting on health literacy of people with lifelong communication disability

Results of this review indicate that barriers and facilitators impacting on the health literacy of people with lifelong communication disability are consistent with those applicable to the general population [79] such as family or social supports, features of health care settings and health care providers, and attitudes and motivation. These factors can be conceptualised as mediating factors between health literacy and health outcomes in that they influence the outcomes of any given health literacy intervention or health behaviour.

An important but limited collection of studies applied a focus to challenging environments in the health care domain where health care professionals can influence health literacy barriers and facilitators for people with intellectual disability. Expanding this body of evidence would provide valuable evidence on practical ways that health care providers can support the health literacy of this population. However, the results of this review indicate that there is limited evidence about any barriers and facilitators acting as mediators on the health literacy of people with lifelong communication disability. This limits any statement about how to strengthen the facilitators and overcome the barriers for this particular population.

4.1.4 Outcomes of health literacy interventions for people with lifelong communication disability

The majority of included intervention studies related to the domain of health promotion. Health promotion has been described as a processes that increase a person's ability to control and improve health [80] whereby health literacy can have a role in enhancing the outcomes of health promotion activities [81]. Studies aimed to educate people with intellectual disability with the purpose of increasing their ability to avoid illness and decrease risk factors for ill health. Outcomes reported predominantly related to *accessing* health information and supports for *understanding* health information.

Some intervention studies focused on *accessing* and *understanding* information also touched on concepts of *applying* information to make decisions. However, this was measured through hypothetical scenarios. Few studies evaluated how participants put information into practice in functional, everyday contexts. For example, Dukes & McGuire [82] evaluated participant ability to use sexual health information to make decisions using the Sexual Consent and Education Assessment (SCEA) to evaluate how participants might apply their new knowledge. Such an assessment gives some indication of capacity to make decisions

based on existing or new knowledge, however it does not allow for the multidimensional nature of health literacy in relation to the application of knowledge in everyday contexts.

The competency of *appraising* health information has been neglected in research to date, and this has implications for supporting people with communication disability to evaluate the quality of the health information. Although reasons for the neglect of the *appraising* and *applying* competencies are not well understood, it may be linked to an unfounded assumption that gaining access and understanding information automatically leads to applying information.

4.1.5 Limitations

As a period of over two years had passed since the initial search in December 2019, a checking procedure was implemented in March 2022 to locate any relevant research citing and of the included studies. The forward citation search, outlined in the methods section, yielded an additional four studies meeting the inclusion criteria [45,46,83,84]. Data was extracted with the relevant findings integrated into the results, discussion, and conclusion sections of the manuscript. These four studies did not change the findings of the review. Consistent with the analysis of the already included studies, the four additional studies a) did not include adults with lifelong disability apart from intellectual disability and used qualitative research methods with small numbers of participants b) effectively excluded people with more severe intellectual disability or communication disability [46,83,84], c) referenced a health literacy definition from either Berkman et al. [47], Sørensen et. al. [6], and c) a focused on the health literacy competencies of *accessing* and *understanding* health information [46,83,84]. Thus, relevant literature published since the initial search did not change the findings of this review and confirmed the analysis.

4.2 Conclusion

Despite a comprehensive and systematic search, this review revealed that there are a relatively small number of studies including people with lifelong communication disability in an extant body of health literacy research. All participants in the included studies had intellectual disability, indicating the need for health literacy research focussed on people with lifelong communication disability. As such, the findings reflect entrenched and pervasive patterns of exclusion of people with lifelong communication disability from health literacy research.

Research predominantly related to accessing and understanding health information. Few studies evaluated how participants put information into practice in functional, everyday contexts. Additional health literacy research is needed which focuses specifically on the needs of people with lifelong communication disability and comprehensively addresses all key areas of the Sørensen et al., (2012), or other model of health literacy.

4.3 Practice Implications

Evidence-based information about the health literacy of people with lifelong communication disability would support health professionals regularly providing written reports, brochures, or other health information to people with lifelong communication disability, to implement tailored strategies to support individuals to understand and use good quality health information. This in turn would enhance health outcomes, safety, and quality of life of individuals with lifelong communication disability, many of whom also have multiple health conditions. In the absence of such research, clinicians are potentially applying the findings of health literacy research without considering whether it can also apply to individuals with lifelong communication disability. Applying an appropriate health literacy model and specific health literacy definition to research with people with lifelong

communication disability will improve research evidence and better inform the inclusive intervention practices of health practitioners.

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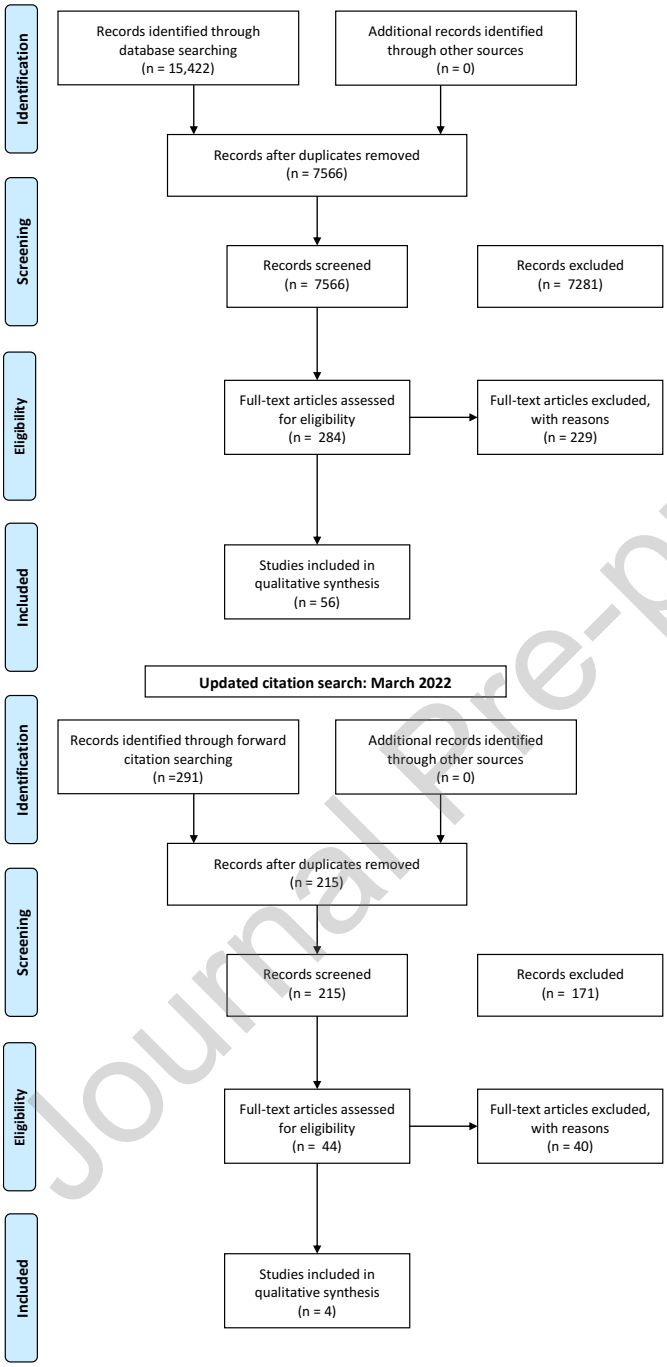
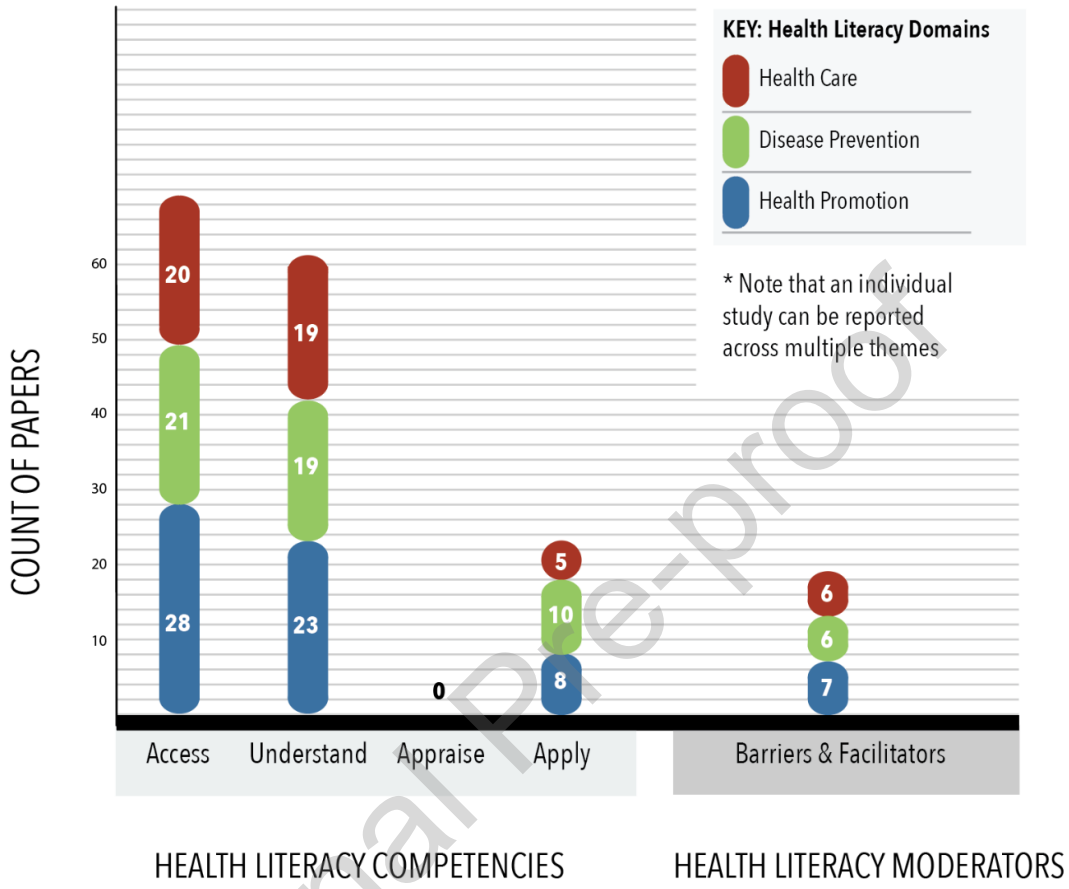
Figure 1: PRISMA Flow Diagram



(Note to editor: colour not needed for figure in print)

Figure 2: Health literacy dimensions addressed in included studies



Title: Health Literacy Dimensions Addressed in Included Studies

Description: Diagram showing how included papers are categorised across the health literacy framework (across competencies, moderators and domains). Adapted from Sørensen et al. (2012)

(Note to editor: colour not needed for figure in print)

Figure Captions

Figure 2: Diagram showing the number of included studies which have addressed a) the health dimensions (individual competencies across health literacy domains) as described by Sørensen et al. (2012) , and b) the barriers and facilitators to health literacy for populations with lifelong communication disability.

Table 1: Example of electronic search strategy

(TITLE-ABS-KEY (((communication OR speech OR language OR learning OR developmental OR intellectual OR lifelong OR "life long") W/1 (disabilit* OR disorder* OR delay OR impairment*)) OR ("cerebral palsy" OR "down syndrome" OR autism)) AND TITLE-ABS-KEY ((health W/1 (litera* OR educat*)) OR (patient W/1 (litera* OR educat*))))

Table 2: Characteristics of included studies

First Author	Year of publication	Location (country)	Type	Topic category	Setting Type	Aims category	Participants with disability	Description of Communication disability	Areas of HL addressed	QATSDD rating (%)
Bradbury-Jones	2013	N/A	Review (non-systematic)	Safety	N/A	Experiences	N/A	"Communication difficulties" and "AAC" mentioned but not described	Understand; environmental barriers/facilitators	N/A
Byrne	2016	N/A	Review (systematic)	Health behaviour	N/A	Intervention effectiveness; Behaviour change	N/A	None reported	Apply	N/A
Chinn*	2017	N/A	Review (non-systematic)	Communication	N/A	Intervention process	N/A	"Communication difficulties" mentioned	Communicative Health Literacy	N/A
Chinn & Homeyard*	2017	N/A	Review (non-systematic)	Communication	N/A	Intervention effectiveness	N/A	None reported	Access; understand	N/A
Coren	2018	N/A	Review (systematic)	Parenting	N/A	Intervention effectiveness	N/A	None reported	Access; understand; apply	N/A
Geukes*	2018	N/A	Review (non-systematic)	HL	N/A	EBP	N/A	None reported	Access; understand; environmental barriers/fac	N/A

									ilitators	
Heller*	2013	N/A	Review (non-systematic)	Health behaviour	N/A	EBP	N/A	None reported	Access; understand	N/A
Kerr*	2013	N/A	Review (non-systematic)	Health behaviour	N/A	Intervention effectiveness	N/A	None reported	Access; understand	N/A
Maine	2019	N/A	Review (systematic)	Health condition	N/A	Intervention effectiveness	N/A	None reported	Access; understand	N/A
Masteb roek	2014	N/A	Review (non-systematic)	Communication	N/A	Experiences	N/A	All included articles referred to communication skills of either persons with ID or GPs	Access; understand	N/A
Redquest*	2019	N/A	Review (non-systematic)	Health condition	N/A	EBP	N/A	None reported	Access; understand; environmental (policy) barriers/facilitators	N/A
Roll*	2018	N/A	Review (non-systematic)	Health promotion	N/A	EBP	N/A	None reported	Access; understand	N/A
Smith*	2019	N/A	Review (non-systematic)	Medication	N/A	Experiences; EBP	N/A	None reported	Understand	N/A
Aman**	2007	USA	Quant, Int	Medication	Pharmacy	Intervention effectiv	361	None reported	Access; understand	19

						eness				
Bodde	2012	USA	Quant, Int	Health behaviour	Community	Behaviour change	42	None reported	Access; Apply	40.5
Chester**	2011	UK	Quant, Int	Health behaviour	Inpatient	Behaviour change	79	None reported	Access; Apply	42.9
Clark	2001	UK	Quant, Int	Health condition	Education; Residential	Intervention effectiveness	18	British Picture Vocabulary age score: 2;6–9;10 (treatment group), 2;0–13;0 (deferred treatment group)	Access; Understand	40.5
Crowley	2008	UK	Quant, Int	Medication; Health condition	Outpatient; community	Behaviour change	8	British Picture Vocabulary Scale - Short Form raw scores rage 14-24	Access; understand	26.2
Dixon-Ibarra	2017	USA	Quant, Int	Health behaviour; Food	Residential	Intervention effectiveness; Intervention acceptability	18	None reported	Access; understand; apply	42.9
Dukes	2009	Ireland	Quant, Int	Sexual health	Residential	Intervention effectiveness	4	Stanford–Binet Communication domain age equivalent (years-months): 5;1, 6;2, 6;11, 7;4	Access; Understand	54.8
Feldman**	2012	Canada	Quant, Int	Rights	Community; Residential	Intervention process	31	VABS Adaptive Behavior Scale – Communication	Apply	35.7

								Standard Score		
Feldman**	2016	Canada	Quant, Int	Rights	Community; Residential	Intervention process	22	Vineland II Adaptive Behaviour Scale – Communication Standard Score; able to verbally communicate	Understand	50
Ferguson**	2014	UK	Quant, Int	Medication	Community; Residential	Intervention effectiveness	28	British Picture Vocabulary Scale-II (BPVS-II)	Access; Understand	42.9
Fish**	2017	UK	Quant	Medication	Conference	Experiences	58	None reported	Access; understand; environmental barriers/facilitators	42.9
Gove	2019	UK	Quant, Int	Communication	Outpatient	Experiences	16	None reported	Understand	40.5
Graff	2018	USA	Quant, Int	Sexual health	Education	Intervention effectiveness; Intervention acceptability	53	None reported	Access; understand	28.6
Greenwood	2014	USA	Quant, Int	Health behaviour	Community; Residential	Intervention effectiveness; Intervention acceptability	46	All women but two were at least minimally verbal; one woman communicated through vocalization and hand signals and another used a communication board	Access; understand	52.4

Heller**	2004	USA	Quant, Int	Health behaviour	Community; Residential	Intervention effectiveness	53	None reported	Access; understand	50
Horner-Johnson	2011	USA	Quant, Int	Health behaviour; Food	Community	Intervention effectiveness	6	None reported	Access; apply	50
Huneke**	2012	UK	Quant, Ax	Medication; Communication	Residential	EBP	45	None reported	Access; understand; apply	28.6
Johnson	2014	Canada	Quant, Int	Health behaviour; Food	Residential; Outpatient	Intervention process; Intervention effectiveness	9	None reported	Access; understand	31
Mann**	2006	USA	Quant, Int	Health behaviour; Food	Community	Intervention effectiveness; Intervention process	192	As per inclusion criteria ("communicative")	Access; apply	47.6
Marks**	2013	USA	Quant, Int	Health behaviour; Food	Community	Intervention effectiveness	67	As per inclusion criteria ("able to respond verbally to questionnaires")	Access; understand	76.2
Marks	2019	USA	Quant, Int	Health behaviour	Community; Residential	Intervention effectiveness	344	None reported	Access; understand	73.8
Merker	2018	USA	Quant, Ax	HL	Outpatient	Assessment	18	None reported	Areas assessed by these HL tools	57.1
Strydom**	2001	UK	Quant, Int	Medication	Outpatient; Inpatient	Intervention effectiveness	54	Reading ability reported	Understand	33.3
Swaine**	2014	USA	Quant, Int	Health behaviour	Education	Intervention effectiveness	198	None reported	Access; understand	42.9

Bains***	2020	UK	Qual	Health behaviour	Community; Residential	Experiences	12	able to give informed consent and possess sufficient verbal communication skills, using pictorial aids if appropriate, to participate in interviews	Access; understand; environmental barriers/facilitators	59.5
Baumbusch	2014	USA	Qual	Communication	GP	Experiences	11	None reported	Understand	38.1
Bergstrom**	2014	Sweden	Qual	Health behaviour	Residential	Intervention process	83	None reported	Access; understand; apply; environmental barriers/facilitators	59.5
Collins	2014	UK	Qual	Health condition	Community	EBP	3	Difficulty with literacy; needed help with understanding a referral letter	Access; understand	40.5
Davis**	2016	Aus	Qual, Ax	Medication; Health condition	Community; Residential	Assessment	17	None reported	Understand; apply; environmental barriers/facilitators	35.7
Dixon-Ibarra	2018	USA	Qual	Health behaviour; Food	Residential	Intervention process	5	None reported	Understand; environmental barriers/facilitators	50

Dunkley**	2018	UK	Qual, Int	Health behaviour; Health condition	Community	Intervention process	7	Communication supports' mentioned	Access; understand; apply	33.3
Johnson	2011	Canada	Qual	Health behaviour; Food	Residential	Experiences	28	None reported	Access; understand	40.5
Latteck***	2020	Germany	Qual	Health literacy	Community; Residential	EBP	33	None reported	Access; understand; environmental barriers/facilitators	42.9
Masteboroek	2016	Netherlands	Qual	Communication	GP; Residential; Community	Experiences	35	None reported	Access; understand; environmental barriers/facilitators	83.3
McCarthy	2010	UK	Qual	Health behaviour	GP	Experiences	23	Able to talk about their experiences	Access; Understand	27.1
Ninnoni	2019	UK (Scotland)	Qual	Health condition	Outpatient	Experiences	15	None reported	Access; apply	42.9
Oosterveld-Vlug***	2021	Netherlands	Qual	Health behaviour; communication	Community	Experiences	12	None reported	Access; understand; environmental barriers/facilitators	71.4
Porter*	2012	UK	Qual, Int	Health condition	Outpatient	Intervention process; Intervention effectiveness	5	None reported	Access; understand	23.8
Skelly***	2021	UK	Qual	Food	Community; Residential	Experiences	12	None reported	Understand	57.1

Willis	2016	UK	Qual	Health behaviour	Community	Experiences	12	None reported	Apply; environmental barriers/facilitators	57.1
Barnhart	2019	USA	Mixed, Int	Food	Residential	Intervention effectiveness; Intervention acceptability	8	None reported	Access; understand	35.4
Codling	2011	UK	Mixed, Int	Health behaviour	Community; Residential	Intervention effectiveness	38	None reported	Access; Apply	39.6
Fernández-Solano	2019	Spain	Mixed, Int	Health behaviour	Community	Intervention effectiveness	25	None reported	Access; understand	39.6
Rose	2014	UK	Mixed, Int	Health behaviour; Food	Inpatient	Intervention effectiveness	7	None reported	Access; understand	37.5
Taggart**	2018	UK	Mixed, Int	Health condition	Community	Intervention effectiveness	39	None reported	Access; apply	43.8
Wells**	2014	USA	Mixed, Int	Health condition	Residential	Intervention effectiveness; Intervention acceptability	37	None reported	Access; understand	45.2
Wilson	2018	UK	Mixed, Int	Health behaviour	Community	Intervention effectiveness	73	None reported	Understand; apply	52.1

Note: Ax = assessment, Qual = qualitative study, Quant = quantitative study, Int = Intervention study, UK = United Kingdom, USA = United States of America, Aus = Australia. * = reviews citing included original research studies. ** = original research studies cited in review papers. *** = studies included from March 2022 citation search.

Table 3: Description of topic categories, setting types, study aims categories, and number of studies in each

Topic category	Number of studies	Description
Health behaviour	26	Targeting any behaviour that relates to health outcomes (e.g., mammography, physical activity, smoking)
Health condition	11	Relating to a particular health condition (e.g., epilepsy, asthma, diabetes)
Food	10	Major focus on the consumption, knowledge, and/or preparation of food for health outcomes
Medication	8	Knowledge about medications is taught or assessed
Communication	8	Relating to oral or written communication in health environments or consultations
Health literacy	3	Studies that stated focus on assessment or reviewing health literacy
Rights	2	Relating to education or assessment of knowledge on rights in healthcare settings
Sexual health	2	Involving assessment or education on maintaining or increasing sexual health
Health promotion	1	A focus on the examination of a health promotion strategy
Parenting	1	Studies involving education on parenting
Safety	1	Relating to increasing knowledge and behaviours that promote being safe
Setting type	**Number of studies**	**Description**
Residential	22	Participants living in or receiving services from residential service providers (e.g., group home)
Community	22	Participants living in private locations (e.g., family home, independently)
Outpatient	7	Participants currently or previously receiving outpatient services
Education	3	Participants recruited from educational settings (e.g., University, training centre)
Inpatient	3	Participants currently or previously receiving inpatient services
GP	2	Participants in or linked to a general practice context

Conference	1	Attendees at a conference
Pharmacy	1	Research conducted with people attending a pharmacy

Study aims categories	Number of studies	Description
Intervention effectiveness	28	Studies that identify the degree to which an intervention provides a positive outcome
Experiences	14	Studies that aim to explore and describe participant experiences of health service practices
Intervention process	9	Aims that focus on the process of developing and/or implementing an intervention
Evidence Based Practice	8	Aim of the study is to identify or evaluate the implementation or development of evidence or to identify evidence gaps
Intervention acceptability	5	Aims that explore the degree to which and intervention is/might be acceptable to participants
Behaviour change	4	Aims that focus on behaviour change of participants
Assessment	2	Studies that aim to test knowledge or ability

CRediT author statement

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Highlights

- Only people with intellectual disability are included in health literacy research
- Health literacy research excludes people with other lifelong disabilities
- The research focus has been on accessing and understanding health information
- The research doesn't include appraising health information
- There is an emphasis on health promotion research rather than health literacy