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Conceptualization of health literacy from the perspective of children and adolescents – a meta-ethnography

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Existing models of health literacy have included a limited perspective of children and adolescents. We conducted a meta-ethnography to develop a child- and adolescent-centered conceptualization of health literacy. We dually screened 3564 abstracts, 205 full texts, assessed the 40 included studies' methodological limitations, and considered 25 data-rich studies in our synthesis. We assessed our confidence in each finding using GRADE-CERQual. Our model shows that health literacy development involves active information seeking (moderate confidence), passive information receiving (very low confidence), processing information (moderate confidence), and (not) taking action (moderate confidence). This process is embedded in a socio-cultural environment, educational system, healthcare system, internet/media, and living environment (very low to moderate confidence). Our model shows that children's and adolescents' health literacy is influenced by cognitive psychological (moderate confidence) and sociodemographic factors (moderate confidence). Social relationships play a crucial role (moderate confidence). Our model supports the development of evidence-based interventions and policies that promote youth and child well-being, laying the foundation for lifelong health literacy. This approach also provides a basis for future research to explore health literacy concepts that are grounded in young people's real-life contexts.

Registration: Before writing this manuscript, we developed a study protocol and registered it on PROSPERO: CRD4202343090.

Keywords Health literacy, Adolescent health, Child health, Conceptual model, Meta-ethnography, Health literacy model

The multidisciplinary concept of health literacy has become an increasingly important research topic in health and medical sciences¹. Limited health literacy has been associated with a disproportionate impact on socioeconomically disadvantaged population groups, where it can act as a health moderator, mediator, and determinant^{2,3}. In children and adolescents, higher health literacy levels are linked to healthier behaviors and to overall better health outcomes⁴. Children with disadvantaged backgrounds often have more difficulty dealing with health information and achieve poorer scores on average in health literacy and knowledge than children from less disadvantaged backgrounds.

While theoretical concept development in health literacy research has focused primarily on adults¹, there is an absence of a conclusive theoretical framework regarding child and adolescent health literacy⁵. Sanders et al.⁶ propose a health literacy model encompassing prose/document literacy, oral literacy, numeracy, and systems-navigation skills, with age-appropriate activities suggested for children and adolescents. However, stage models can be criticized for their idealistic, one-size-fits-all approach, which assumes a normative perspective and neglects cultural differences, social interactions, and living environments⁷. Wharf Higgins et al.⁸ used in their case study a socio-ecological perspective to examine health literacy in their primary study, considering micro-level context (e.g., age, gender), meso-level context (e.g., family, school) and macro-level context (e.g., media, government policies). A systematic review of the health literacy definitions and models in childhood

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and adolescence was published in 2017⁹. The health literacy dimensions identified in this review are similar to those identified for adults in previous studies. They have an action-related focus where children and young people are viewed as actors that actively and deliberately participate in seeking, processing, and evaluating health information, neglecting the unique characteristics of children and adolescents and the context-specific nature of health literacy in this age group. Bröder et al.⁹ suggest that this might result from the fact that active participation in the conceptual development process of health literacy definitions and models was rarely realized in research.

Adolescents and children are dependent on their parents or caregivers for the provision of material, financial and social resources^{9,10}. They move through social, emotional, cognitive developmental processes and they are highly dependent on their socio-ecological context^{9,11}. We argue that the complex, socially constructed nature of health literacy in young age groups is best explored through the children's and adolescents' perspectives. Therefore, we aimed to develop a child- and adolescent-centered definition and conceptualization of health literacy using a qualitative evidence synthesis (QES). A QES enables the identification of different perspectives, captures contextual nuances and provides insights into the lived experiences of young people, which addresses the existing research gap in understanding the interpretation and application of health literacy concepts in young age groups.

Methodological approach

To meet the objectives, we conducted a QES using meta-ethnography, following the Cochrane Handbook¹² and Sattar et al.'s¹³ step-by-step guide. Meta-ethnography aims to guide the development of conceptual models and theories and is particularly suitable for synthesizing analytical findings, as the reviewer reinterprets the primary studies' conceptual findings, translating them into higher-order themes^{13,14}.

Materials and methods

We developed a study protocol, which we registered on PROSPERO: CRD42023430908 and uploaded it on open science framework (OSF) (https://osf.io/x7yvr/). Changes to the protocol are mentioned throughout the methods section. Within this manuscript, we adhered to the meta-ethnography reporting guidance (eMERGe)¹⁵.

Inclusion and exclusion criteria

We focused on studies exploring children's and adolescents' perceptions of health literacy. Eligible studies included those addressing health literacy in children aged 8–14 and adolescents aged 15–19. We included studies using qualitative methods. Studies in English and German from 2002 onwards—the year the first article on health literacy in children and adolescents was published ¹⁶—were considered. The full inclusion and exclusion criteria are detailed in the Appendix (Table S1).

Search methods for the identification of studies

We applied a stepwise approach to identify relevant studies (see Appendix Tables S2 – S7). Following recommendations ^{13,17}, this approach privileges specificity over sensitivity and aims to identify all relevant rather than all eligible studies. We conducted a first round of database and supplementary searching and then evaluated if further searches would be necessary. In a first step, an information specialist searched MEDLINE (Ovid) and CINAHL (Ebsco) from inception to April 6th, 2023. Preliminary searches had shown that these databases were highly relevant for this topic. According to Frandsen et al. ¹⁸, they are also highly relevant for retrieving qualitative health research in general. The information specialist developed search strategies using a combination of free text and controlled vocabulary (e.g., Medical Subject Headings). We limited the searches to English and German and used a methodological filter for qualitative studies ¹⁹. Another information specialist peer-reviewed the MEDLINE search strategy according to the Peer Review of Electronic Search Strategies (PRESS) Guidelines ²⁰.

The first step was followed by a first round of literature selection in November 2023. Based on a selection of relevant studies identified, we conducted supplementary citation-based searches. Citation-based searches included (1) manual reviewing the included studies' reference lists and key references, (2) forward citation searching of pertinent papers in Scopus and Citationchaser, and (3) conducting similar articles search on pertinent papers in Google Scholar. These supplementary search methods were expected to find studies that were not retrieved by the database searches and give us an indication of whether and which additional search steps should be undertaken to broaden the scope of the search. After analyzing the studies retrieved, we decided not to conduct any further searches, because in this step we only found one study that provided additional information to the data.

We updated the database and citation-based searches between October 31st and November 4th, 2024 to include evidence published since our initial search. The citation-based searches used all studies included until this point as seed articles.

Selection of studies

We developed abstract and full-text review forms based on our inclusion and exclusion criteria, which we pilottested with 50 abstracts and five full texts for clarity and consistency. Two trained reviewers independently screened titles, abstracts, and full-text articles, resolving discrepancies through discussion or a third reviewer. The screening process was assisted by Covidence²¹, with all results tracked in EndNote, Version 20²².

Sampling of studies

We sampled studies based on their data richness, using Ames et al.'s 1 to 5 scale²³. A score of 1 indicated thin data, while 5 indicated a large amount and depth of qualitative data. We sampled all articles scoring 3 or higher. After synthesizing this data, we reviewed the remaining studies to determine whether they added anything new to the findings (see Tables S8 – S9 in the Appendix).

Assessing the methodological limitations of the included studies

Two reviewers independently assessed the methodological limitations for each sampled study using an adapted version of the Critical Appraisal Skills Programme (CASP) tool^{23,24} (see Table S10 in the Appendix). Discrepancies were resolved through discussion with a third reviewer.

Data extraction

We designed and pilot-tested a data abstraction table to extract key study characteristics. Data were extracted by one reviewer and checked for completeness and accuracy by a second.

We extracted data from the included studies including information about the first author, publication year, study country, setting, participant characteristics, objectives, contextual information, any used theoretical or conceptual framework, and study research methods. We coded the outcomes and key findings using MAXQDA 2022²⁵.

Data analysis and synthesis

We analyzed and synthesized the data according to Sattar et al.'s steps 3 to 7 based on Noblit and Hare's original steps (see Table S11 in the Appendix). First, we familiarized ourselves with the key concepts of the included studies, and coded their raw data, focusing on participant quotations and authors' interpretations. We identified common and recurring concepts, comparing them across studies to highlight similarities and differences, which were organized into higher-order constructs. These were synthesized into a conceptual health literacy model, which we finalized with input from the project consortium.

Grading certainty of evidence

To assess our confidence in each finding, we used the GRADE-Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) approach²⁷, which evaluates confidence based on methodological limitations, coherence, data adequacy, and relevance of the included studies to the review question. Two reviewers independently assessed each finding; the final GRADE-CERQual assessments were based on consensus (see Table S12 in the Appendix).

Results

Literature search and selection

We identified 5415 records through the database searches and other methods; after removing duplicates, 3564 remained. After abstract screening, 205 records moved on to the full-text screening. Based on the full texts, we included 40 studies meeting our eligibility criteria (see Fig. 1). We sampled 25 studies for in-depth qualitative synthesis based on data richness²⁸.

Study characteristics

Table S8 (Appendix) presents the study design, research methods, research aim, country, setting, and key sample characteristics of all 25 sampled studies. Most sampled studies originated from the US (n=6), Australia (n=4), and Finland (n=2). Six studies²⁹⁻³³, focused exclusively on children (aged 8–14 years), while 15 ^{34–48} included adolescents (aged 15–19 years) or both. Three studies^{37,49,50} did not report specific age ranges. Nineteen studies^{29,31–41,43–46,49–51} provided information on sex, with a predominance of females in most studies. Three studies^{35,37,40} had more male than female participants, and two^{43,51} reported an equal distribution. One study⁵² had only male participants. Gender was explicitly addressed in one of the sampled studies⁴⁷. Twelve sampled studies^{29–32,35,36,39,42,43,45,49,50} were conducted studies with children or adolescents with diverse characteristics (e.g., ethnicity, socioeconomic status, disability, illness). Eleven of the included sampled studies^{29–32,35–37,39,41,45,48–50,52} utilized focus groups. Interviews were employed in six studies^{29,34,40,44}, eight^{30,33,42,43,45,46,50,51} adopted mixed-method approaches.

Synthesis of findings

We synthesized our analysis findings into a model (see Fig. 2). Following the model from the inside out, the findings are detailed in the following chapter (see Table 1 for findings description and Tables S12 – S13 in the Appendix for the GRADE-CERQual qualitative evidence profile).

Finding 1: active information seeking (moderate confidence)

Adolescents usually have a reason to actively seek health-related information 40,46,49. Adolescents mentioned that experiencing symptoms prompts them to seek information 40 to understand the symptom causes or treatments 46 or to learn strategies 46,53. They explained that they want to validate or reassure themselves about their symptoms 40,46. The following adolescents' quote illustrates: "I am looking at when to see a doctor to see if it's a serious thing 40 p. 4. Adolescents stated that they search for health information before or after a health appointment 46, or when they forgot to ask a question during a doctor's visit 49.

Adolescents mentioned that they utilize the internet 38,45,49 and traditional media (TV, radio) 38,42 but

Adolescents mentioned that they utilize the internet^{38,45,49} and traditional media (TV, radio)^{38,42} but also friends, family, and teachers^{38,42} as health information sources, and that when seeking sensitive health information, they prefer quick, accessible, and complete³⁰ information with personal relevance³², high quality, and privacy³².

Finding 2: passive information receiving (very low confidence)

In several studies, children and adolescents mentioned that they also receive health-related information passively (i.e., without searching)^{29,39,42,46}. Adolescents confirmed that they receive health information from

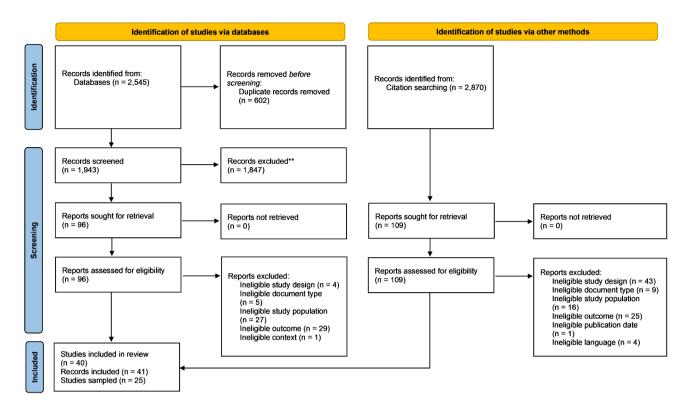


Fig. 1. Prisma Flow Diagram according to Page et al.²⁸. This diagram illustrates the process of selecting studies for inclusion in the review. It shows the number of records identified, screened, and included, along with the reasons for exclusions at each stage of the review process.

health practitioners^{39,42}, parents, peers, and schools⁴², and by learning from family health behavior and others' and personal experiences^{29,42}.

Finding 3: processing (moderate confidence)

The authors concluded that children and adolescents rely on existing mental frameworks that evolve as they gain new information or experiences. The complexity of their understanding varies based on how involved they are in their own health decisions^{29,30}. Several authors indicated that children and adolescents are conscious of mis- and disinformation and potential health risks^{39,40,44,46,49}. Adolescents reported an awareness of potential disinformation in online sources, and some experienced difficulties evaluating the relevance because of information overload⁴⁰.

Adolescents exhibited varying levels of trust in health information from celebrities, health professionals, parents, friends, intervention providers or manufacturers³⁴, and social media⁴⁶. Adolescents reported frustration after not finding needed health information, a reassured feeling when finding others on the internet with similar experiences⁴⁶, and confusion due to the diversity of statements⁴⁴. One adolescent reflected that, "*In one material, it is written that someone has to drink 8 glasses of water every day. In one other article that you have to drink as much as you want. In another article, that you can't drink a lot, because it's harmful. It is confusing"⁴⁴ p. ¹⁰. Adolescents revealed that uncertainty in their health knowledge led to self-doubt in their decision-making processes⁴⁹.*

The steps of processing health information include paying attention, thinking, reflecting, asking questions, and questioning the health information and its reliability^{44,48}. Some adolescents possessed a foundational understanding of health-related research and scientific principles³⁴. Authors revealed that only few actively compared data across multiple sources to verify its validity⁴⁵ or considered its reliability⁴⁴. Adolescents in another study mentioned that actively consulting others or finding additional sources to corroborate is a common practice in making health information judgments³⁴. Adolescents in a third study stated that they evaluate the reliability of health-related content using diverse criteria. For official websites, they check elements like URLs, logos, and professional appearance, while on social media, they consider factors as likes, dislikes, and user interactions⁴⁸.

The authors of one study³³ reported that children rated food as good or bad for their health, influenced by their individual experience or knowledge. Some participants in Subramaniam et al.'s⁴⁵. study described that they rely on others' appraisals (e.g., teachers, relatives). Adolescents in several studies considered the financial cost of a health product^{34,36,46} as a quality indicator, believing that a higher investment signified a more reputable product³⁶.

Finding 4: (not) taking action (moderate confidence)

Whether children and adolescents can make informed health decisions also depends on their knowledge and opportunities, including understanding and expressing health-related rights and responsibilities in the

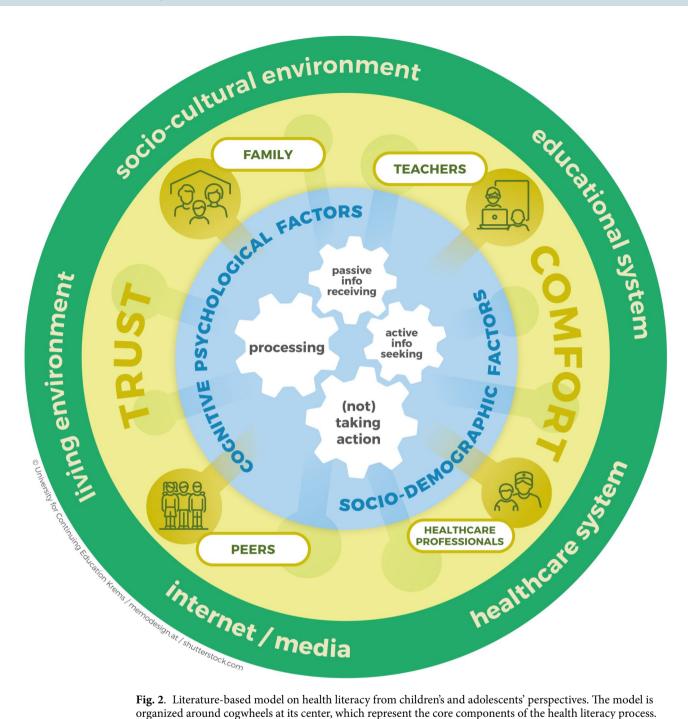


Fig. 2. Literature-based model on health literacy from children's and adolescents' perspectives. The model is organized around cogwheels at its center, which represent the core components of the health literacy process. The blue area encompasses various individual cognitive, psychological, and sociodemographic factors. Expanding outward, the yellow area illustrates how health literacy is embedded within social relationships. The green circle highlights the socio-cultural environment, including the educational system, healthcare system, internet/media, and living environment.

healthcare system, as adolescents³⁹ mentioned. According to Massey et al.'s³⁹ and Taba et al.'s studies⁴⁶, some adolescents considered parents as gatekeepers. Adolescents shared experiences of parents gradually entrusting them with more responsibilities, signaling a transition toward greater autonomy in managing their health³⁹.

Knowledge about health can affect children's⁵¹ and adolescents'^{44,50} responsibility level⁵¹ but is not a guarantee for engagement in behavior⁵⁰. Adolescents mentioned that, before making a health-related decision, they consult a healthcare provider³⁶ to compare arguments and pros and cons³⁶, and consider near-term consequences⁴¹.

In one study, boys described barriers to taking action for mental health issues, including stigma, privacy concerns, and the need to protect themselves or those close to them. Some avoid taking action for their mental health, believing such issues are not aligned with "boy culture," as illustrated by the following quote: "Yes, but it's not the coolest thing for a boy to say that I have thoughts or want to commit suicide." Furthermore, boys in this study cited a lack of knowledge about mental health and whom to approach as key reasons for not taking action.

Finding	Finding description
Finding 1 Active information seeking (moderate confidence)	Children and adolescents stated that they actively seek health information for various reasons, primarily driven by experiencing symptoms, to understand causes or treatments or to learn strategies, intending to validate or reassure themselves about their health, or when preparing for health appointments. They use their social relationships and the sociocultural environment, educational system, healthcare system, internet/media, and living environment as sources. Adolescents value quick, easy, accessible, complete, and personally relevant information, emphasizing quality and privacy when seeking sensitive health information.
Finding 2 Passive information receiving (very low confidence)	Children and adolescents reported accessing health information not only actively but also passively. Passive health information comprises information from parents, schools, health professionals, social media, or personal experiences without seeking it. Sources are booklets from healthcare providers, interactions with health practitioners, and family health behaviors and experiences, with younger children primarily influenced by their family members and older adolescents exposed to a wider range of sources.
Finding 3 Processing (moderate confidence)	Authors of different studies presumed that children and adolescents use preexisting frameworks when processing health information. These ideas evolve as they acquire new information from their experiences or through new knowledge. Children and adolescents reported that their processing of health information is influenced by several factors, such as their awareness of misinformation and evaluation of information source. The study authors observed that children and adolescents compare information and context and use their personal experience to appraise health information. Authors of one study stated that adolescents evaluate the reliability of health content on official websites by checking elements like URLs, logos and professional appearance, while on social media they consider factors as likes, dislikes, and user interactions. Besides that, adolescents mentioned that seeking and processing health information can evoke different emotions.
Finding 4 (Not) taking action (moderate confidence)	Adolescents and children reported different factors and reasons that influence their decision-making about their health behavior, including knowing their health-related rights, being able to navigate the health system, and overall taking responsibility for their health. Some adolescents mentioned that their parents are gatekeepers to the healthcare system. Some boys described that barriers to taking action for mental health issues were lack of knowledge, stigma, privacy concerns, and whom to approach.
Finding 5 Cognitive psychological factors (moderate confidence)	Children and adolescents believed that their health literacy was influenced by several cognitive-psychological factors. Some thought that having a future-oriented mindset, high personal motivation, strong self-control, and/or considering the long-term consequences of their health behavior led to better implementation of health-literate behavior. Others perceived themselves or their peers to have low risk perceptions and/or motivation for a generally healthy lifestyle and mentioned that this may hinder the effective use of health literacy skills. They argued that levels of self-efficacy, or confidence in one's ability to make independent health decisions, are crucial. They also mentioned that acquired skills (e.g., reading, spelling skills) and knowledge have a significant impact on their health literacy.
Finding 6 Sociodemographic factors (moderate confidence)	Children and adolescents identified physiological and demographic factors, such as gender, age, personal health status, migration background, religious beliefs, and socioeconomic status as influencing health literacy. Participants mentioned that girls may have body image concerns and may therefore restrict their eating behavior. Gender also influenced their interactions with healthcare providers and their perceptions of health responsibilities in their families, emphasizing maternal roles. Some boys described that gender roles shaped their engagement with mental health practices. Several authors noted age-related differences: when seeking health information, adolescents preferred online sources; children relied heavily on family discussion. Adolescents with chronic illnesses showed how their health status affects understanding of illnesses, developing coping mechanisms for pain management, and shaping health-related decisions and behaviors (e.g., attitudes toward tobacco use). Adolescents mentioned that being from a migrant background can lead to health literacy challenges due to language barriers and reliance on translators and social networks.
Finding 7 Family, teachers, healthcare professionals, and peers (moderate confidence)	Family is a significant source for obtaining, discussing, and counterchecking health information or clarifying symptoms. Teachers and healthcare professionals are reported as health information sources, but the extent of discussions about health information differs depending on, for example, whether they trust teachers or professionals. With increasing age, peers and friends play a role for children and adolescents in accessing, discussing, and communicating health information and in cheering them up when they have health concerns. Overall, trustful relationships across various social connections are key to effective health communication for children and adolescents.
Finding 8 Living environment (low confidence)	Children and adolescents noted limited healthy options in school canteens and the influence of food availability at home on their meal choices. Additionally, children and adolescents drew conclusions from their environment, tapping into various sources for health-related knowledge, while emphasizing the need for infrastructure (food, sports, offered activities) to promote healthy behavior. Children and adolescents highlighted the importance of their surroundings (e.g., neighborhood) and the negative effects of stressful environments (e.g., family, school issues) on whether they can make healthy decisions.
Finding 9 Socio-cultural environment (very low confidence)	Adolescents reported that stigma, taboos, and religious restrictions hinder open discussions about health and impacted their utilization of health literacy skills. Further, adolescents reported that embarrassment and discomfort influenced their information-seeking behaviors, underscoring the ongoing challenges adolescents face in discussing sensitive topics openly.
Finding 10 Educational system (low confidence)	Children and adolescents acknowledged the educational system's crucial role in shaping their health literacy, emphasizing disparities in health education effectiveness across schools. They relied on health classes and teachers for health information while also recognizing the importance of access to supportive environments within the school setting.
Finding 11 Healthcare system (very low confidence)	Children and adolescents recognized that competencies in health literacy empower them to navigate barriers, such as scheduling appointments and accessing information, emphasizing the essential role of primary care physicians as gateways to the healthcare system.
Finding 12 Internet/ Media (moderate confidence)	Adolescents relied on digital platforms such as the internet and social media for health-related information, with a preference for comprehensive, clear, interesting and simple content. Despite challenges, such as discerning trustworthy sources, understanding complex medical terms, navigating algorithms and monetary motivations, adolescents reported actively seeking information through search engines and online platforms.
	Social media was particularly valued as an accessible and anonymous tool for health information and support. Adolescents appreciated the lack of pressure to engage, the lived experiences and opinions shared by others, and the role of social media in validating and de-stigmatizing health challenges. These platforms fostered a sense of community and reassurance, especially for adolescents with chronic conditions, who used them to exchange information, share advice, and enhance their coping strategies.

Table 1. Findings descriptions.

They felt they needed a strong justification to see a school nurse and were unsure when symptoms became serious enough to seek help 52 .

Finding 5: cognitive psychological factors (moderate confidence)

Adolescents in four studies^{31,39,49,50} recognized the role of a future-oriented attitude, personal motivation, self-efficacy, and risk perception as psychological factors influencing the adoption of healthy behavior.

Adolescents mentioned that future-oriented attitudes influence health literacy. While many questioned the need for preventive health visits or the long-term consequences of their current health behaviors⁴⁹, others expressed positive attitudes toward preventive screenings³⁹. Adolescents' use of health literacy skills is influenced negatively by low personal motivation and positively by high personal motivation (e.g., because of sports goals)^{31,49}. Adolescents in Parisod et al's³¹ study discussed that individual motives and motivation

levels led them to engage or not engage in health-risk behavior. For example, while some smoke cigarettes to be socially accepted, others refrain because of smoking's negative effect on athletic performance. Chronic illness can also lead to high personal motivation levels, as explained by one adolescent who goes to body checks more often due to illness⁴⁹. Adolescents emphasized that individual self-efficacy plays an important role in resisting social pressure and making healthier choices^{31,32}. Furthermore, adolescents identified low risk perception as an important determinant, as some perceived certain health issues as not serious, which reduced the use of health literacy skills in decision-making⁴⁹.

Adolescents and children noted medical terminology as a barrier^{34,40,45,46}. Three studies^{36,42,45} found that knowledge and skills affect to which degree adolescents can seek health-related information or make informed health decisions. Some children and adolescents stated in these studies that their understanding of health information is significantly influenced by whether they can read and understand the given information or formulate relevant search strategies, as illustrated by one adolescent: "I don't really know how to spell it [endometriosis]. I saw something about this on television, and I did actually want to know more about it, but I didn't know how to spell it" ³⁶ p. ²⁴².

Finding 6: socio-demographic factors (moderate confidence)

Children and adolescents stated that their gender identity plays a role in the patient–provider relationship³⁷, the gender perceptions children develop relevant to health responsibilities³³, and in developing concerns about body image and lack of self-esteem³². Some adolescents in a study conducted in Mexico indicated that interacting with an opposite-gender provider could lead to feelings of embarrassment. The following quote illustrates: "You feel a lot of embarrassment because, they tell you 'raise your blouse a little bit so I can check your stomach,' and you say like, thinking 'oh, no, how embarrassing"³⁷ P. 8. The children in another study³³ showed that the gender-associated roles were clear, as they mainly discussed their mother's responsibility and role when it came to healthy eating. Adolescent girls in Smart et al.'s study³² expressed concerns about body image and self-esteem, as they faced pressure regarding their appearance, leading to unhealthy eating behaviors. In one study, boys described how assumed gender roles (e.g., that boys do not show emotions) shaped their engagement with mental health practices⁵².

Age determined whether children or adolescents searched for online information. Adolescents in Loers et al.'s³⁸ study stated that they prefer to search online, especially for relevant and applicable health information. Children, however, relied heavily on conversations with family members, as children in Fairbrother et al.'s study mentioned³⁰. Loers et al.³⁸ acknowledged that finding, understanding, and evaluating health information differed by age, and concluded that this may be because of cognitive development. In Smart et al.'s study (2012)³², older adolescents demonstrated more nuanced descriptions of their learning needs and knowledge, and health claims.

Adolescents with chronic sickle cell disease 43 described how their condition affects their understanding of health (e.g., they must closely consider health, illness, and treatment options), how they must develop coping mechanisms to manage pain (e.g., relying on family and peer support, finding distractions, seeking refuge in religion) and, more generally, how their health-related decisions and behaviors are affected (e.g., hiding the chronic disease because of fear of stigma).

Adolescents in Parisod et al.'s study³¹ mentioned that adolescents' own health status (e.g., having asthma) influences their attitudes about tobacco use.

Adolescents with migration background in two studies found that language constraints can be a barrier to decisions about health-related information^{42,45}. Adolescents in Richter et al.'s study⁴² mentioned that it was helpful to have translators at doctor's appointments and that language barriers influenced their ability to read nutrition labels. They acknowledged the important role of guidance from their social networks, leveraging the experiences and insights of others who shared migration experiences.

The impact that socioeconomic background has on health literacy is illustrated by the children's descriptions in Velardo and Drummonds study³³. Some reported limited access to fresh food options due to financial constraints. They understood that financial limitations made it difficult to maintain a healthy diet.

Finding 7: family, teachers, healthcare professionals, and peers (moderate confidence)

<u>Family</u> Family is a major health information source for children and adolescents and a help in processing it^{29,30,32,34,35,37,42}.

Adolescents stated that they discuss new information with family members and consult parents for help with search strategies, managing severe symptoms, scheduling doctor appointments, and discussing online health information before applying it^{42,46}. Some mentioned that they prefer consulting family first for health information instead of using the internet, doctors³⁷, or asking peers³².

One adolescent expressed: "I would definitely first ask my parents, if they have somehow already heard something about it." ^{38 p.7}.

Chronically ill adolescents⁴³ mentioned that they discuss symptoms with family, which the authors presumed created a sense of belonging and collective security. Conversely, the authors of this study concluded that adolescents do not discuss long-term consequences with their parents, and instead expressed concerns that their condition worries their parents.

Smart et al.³² concluded that trust, comfort, and respect are important. Early adolescents in Parisod's study³¹ mentioned that they make observations about their parents and have discussions with them.

<u>Teachers</u> Several studies reported that children and adolescents access health information from their teachers and consider them a health information source 29,31,32,34,35,41 .

When counterchecking new health information, many adolescents ask adults, including teachers, as mentioned in Smart et al.'s study³². Adolescents more precisely described needing a comfortable, trusting,

and respectful relationship with teachers to discuss health issues with them. Some adolescents in this study mentioned that they do not trust teachers with sensitive health information. Others said some teachers are trustworthy.

Children primarily depended on health classes and teachers among other important health information sources²⁹, despite limited use of the internet and print sources²⁹. For most adolescents, teachers and coaches play roles in disseminating valuable information³⁴.

<u>Healthcare professionals</u> In some studies, adolescents reported that healthcare professionals are a main health information source^{29,34,37}. Adolescents in Smart et al.'s³² and Taba et al.'s studies⁴⁶ reported asking doctors to countercheck new health information. Schönbächler-Marcar et al.'s study⁴³ showed that adolescents value expert consultations on medicine intake.

In two studies, adolescents expressed discomfort in gender-specific scenarios and preferred same-gender doctors^{37,39}. The participants in Hoffman et al.'s study³⁷ reported that a lack of doctors' professionalism and positive attitude was a barrier to a good patient–provider relationship.

Some adolescents appreciated health professionals' supportive role. Some acknowledged that making an appointment with a primary care physician is a crucial step and that primary care physicians are gateways to the healthcare system (e.g., to specialists)³⁹. Some faced difficulties scheduling appointments at convenient times, while others expressed frustration with long wait times.

Adolescents expressed a desire for continuity of care with the same healthcare provider to mitigate embarrassment, taking to confiding in a "doctor friend"³⁹. Boys in one study expressed that they would feel more comfortable seeking help if they saw their school nurse more frequently, allowing them to build a better relationship⁵².

Several studys^{32,34,37,40} showed that trust and comfort level is important for the patient–provider relationship. Adolescents in Taba et al.'s⁴⁶ study noted trusting health care professionals because "*They've studied for a lot longer and helped more people than Google*"⁴⁶ p. ⁹. Doctors' lack of professionalism has been identified by adolescents as a barrier³⁷.

<u>Peers</u> Children and adolescents reported obtaining health information from their peers and friends^{35,38}, engaging in discussions about chronic disease⁴³ and health information³², and observing their behaviors³¹. Children and adolescents reported obtaining health information from their peers and friends^{35,38}, engaging in discussions about chronic disease⁴³ and health information³², and observing their behaviors³¹.

However, in some studies, adolescents showed that when applying search strategies to access health information, they rarely seek help from peers and, instead, consult their parents^{32,46}. However, in some studies, adolescents showed that when applying search strategies to access health information, they rarely seek help from peers and, instead, consult their parents^{32,46}.

Finding 8: living environment (low confidence)

Eight studies illuminated the influence of living environments on health literacy^{29,31,33–35,45,46,51}. Children in Parisod et al.'s study³¹ emphasized their sensitivity to their surroundings, particularly expressing concerns about the environmental impact of snus litter, which is expressed in a negative attitude toward snus in general. Children in Velardo and Drummonds study³³ underscored the significant impact of school canteens on food choices, revealing a preference for unhealthy snacks due to limited healthy options. Children and adolescents drew conclusions from their surroundings, highlighting environments should offer sports equipment and engaging activities, access to valid information to enhance health literacy^{29,34,45,51}, and school interventions to support their practical application of health topics^{33,34,46,51}.

Finding 9: socio-cultural environment (very low confidence)

Adolescents' religion impact their health literacy skills use, leading some to avoid doing something against their religious moral. One adolescent stated: "They do something that is against their religion so they fear to open up about it" some adolescents prioritized discussions about mental health over physical, while highlighting the persistent stigma hindering open discussions around mental health topics³⁵.

Richter et al. 42 summarized that it is difficult to separate the effects of language barriers, limited social support networks, lack of time, different cultural food practices, and other related factors when it comes to the influence of migration background on health literacy.

Finding 10: educational system (low confidence)

Children and adolescents found that school discussions, materials, and lessons shaped their understanding of health-related matters $^{29,31-34,49,51}$. One quote highlights: "School, like when you're in health class and we learn more about like health stuff" 49 p. 8 .

Children appreciated programs such as school gardening initiatives that sparked conversations about health within their families, indicating the broader impact of such interventions on their health literacy learning experiences³³. Adolescents also recognized the influence of access to school health classes in facilitating their health literacy development⁴⁹. Furthermore, adolescents mentioned applying media or health literacy⁴⁹ in seeking online information, and search strategies learned from digital literacy in school or school assignments⁴⁶. The relationship to their teachers plays a pivotal role.

Finding 11: healthcare system (very low confidence)

Five studies \$2,37,39,46,49 reported information on the healthcare system and relationship as factors influencing health literacy.

Massey's research³⁹ revealed that adolescents faced barriers to accessing healthcare services due to discomfort, emphasizing the importance of trust in providers and continuity of care with the same healthcare provider to mitigate embarrassment. Competencies related to health literacy empowered adolescents to overcome barriers, such as difficulties scheduling appointments. Additionally, adolescents recognized the role of primary care physician as gateway to specialized care^{39,46}. Adolescents in one study described social media content as helpful after negative experiences of navigating the health care system or when they do not feel comfortable accessing health system support⁴⁷.

Adolescents mentioned the importance of access to healthcare providers and health information in health literacy acquisition. Positive experiences facilitated easy access, poor access hindered the ability to learn about health. One quote highlights: "Not enough clinics around to talk to people and teach them about health" 19 p. 8.

Finding 12: internet/media (moderate confidence)

Adolescents relied on digital platforms such as the internet and social media for health-related information^{32,35,36,38,39,43,46,49}. They tended to prefer searching online for relevant information, altering their seeking behavior based on challenges in finding information and situational accessibility³⁸. They actively sought information via search engines and in social media^{35,36,43,46,49}.

Children and adolescents reported that they received health-related information through social marketing campaigns and TV and internet advertisements^{30,31,49}. They considered appearance, quality, relevance, language, style, ranking, country of origin, and source in appraising health information^{34,38,44,46} and preferred comprehensive, clear, interesting (e.g., in a humorous way)⁴⁸, and simple information^{38,46}. They acknowledged the importance of structured, balanced health information, mentioning bullet points, keywords, short summaries, and clear and simple explanations with plain language as useful and age-appropriate⁴⁰. Some prefer information from well-known organizations, such as universities and governments^{40,45,46} and authors with professional expertise and degrees^{45,46}.

Adolescents understand social media such as TikTok as an easy and free way to access health information and to find support, even if they are aware of the challenges (e.g., algorithms, monetary motivations of content creators, censorship, self-diagnosis)^{47,53}. One adolescent acknowledged that in social media "there's not a whole lot of pressure to engage with. If you want to learn more or if you want to engage, you can."⁴⁷.

Adolescents asserted that one advantage of social media is that they are able to remain anonymous^{47,48}. Adolescents in three studies stated that they find other users lived experiences and opinions on social media platforms helpful, even if they question the reliability of the information provided^{47,48,53}.

Adolescents stated that they view social media platforms like TikTok as a tool to validate and de-stigmatize health challenges. Seeing others share their experiences reassures them they are not alone and offers a chance to connect with supportive online communities^{47,53}. Adolescents with a chronic condition further utilized digital resources to enhance their coping strategies, for example, by accessing social support and exchanging information with others who have been diagnosed with the same condition, sharing symptoms, and providing advice to one another.

Discussion

This QES presents the first health literacy model developed from children's and adolescents' perspectives. At its core is the health literacy process. Children and adolescents seek active information about health-related topics, often prompted by symptoms to understand their causes or treatments, validate concerns, or prepare for or follow up on medical appointments. Passive information receiving mainly occurs in the family, at school, on social media, or through their own or others' experiences. Children and adolescents depend on and work with preexisting mental frameworks, evolving them as they acquire new information (through knowledge or experiences). Processing health information can evoke a range of emotions. Knowing one's health rights, taking responsibility for one's health, and navigating the health system autonomously are factors that influence children and adolescents during the health decision-making process.

Health literacy is not an isolated process driven only by the conscious and purposeful engagement of children and adolescents in seeking, processing, and evaluating health information. Rather, it is influenced by a range of individual, social, and contextual factors, as other studies have also shown^{29–31}. Individual factors represent the child's cognitive and psychological development as well as their sociodemographic background. Children and adolescents are embedded in social relationships, during which they learn from, communicate with, and observe role models. This interplay of social relationships is embedded in a socio-cultural environment, educational system, healthcare system, internet/media, and living environment where children and adolescents live.

The concept of health literacy is closely aligned with developmental stages⁵⁴. This QES shows that children and adolescents develop mental frameworks as they encounter new information and experiences^{29–31}. Younger children use simpler frameworks³³, while adolescents display more detailed knowledge, evaluating sources and learning needs^{32,34}. Both children and adolescents rely on family to discuss health issues^{29–32,34,35,37,42}. Children are aware of their dependence on family for healthy choices³³, while adolescents see parents as gatekeepers in healthcare navigation, gaining autonomy with age^{39,46}. Adolescents access information from family but also from peers, doctors, search engines, and social media. Adolescents have more diverse motivations for accessing information than children do, including the desire for social acceptance, which influences health behaviors. They also express concerns about mental health³⁵, health risk behaviors³², and sexual health^{35,37}.

The QES predominantly included studies focusing on adolescents rather than children, reflecting a research gap identified by Rubio and Blay⁵⁵. This bias may stem from adolescents' greater cognitive and emotional maturity, enabling them to better articulate their experiences, motivations, and challenges making them more accessible for research⁵⁴. Future research should prioritize the inclusion of children, as done by Boxctel et al.,⁵⁶ and integrate developmental theory into research designs, as Fleary et al.⁵⁷ suggested.

Our meta-ethnography fills a gap concerning the recognition of contextual factors in children's and adolescents' health literacy. It demonstrates that relationships and interactions with family, teachers, health professionals, and peers strongly influence health literacy development in young age groups. The quality of these relationships, particularly building trust and creating comfort, is crucial^{8,9} and shaped by the socio-cultural environment, educational and healthcare systems, internet/media, and living conditions⁹.

Our model further enhances understanding of key social actors and environments affecting health literacy in young age groups. While some adolescents view parents as gatekeepers, both children and adolescents generally see their families as social learning environments for finding, discussing, and evaluating health-related information. Bröder et al.⁵ emphasizes that children and adolescents are highly dependent on their parents in terms of material, financial, and social resources and that parental health literacy impacts their children's health.

Our inductively developed model presents a socioecological perspective, similar to the model developed by Wharf Higgins et al.,⁸ which details the various environmental systems and relationships within which children and adolescents are embedded. While their model embeds trust and comfort within broader system levels, we explicitly highlight these aspects in relationships. Our review reinforces their case study's findings about the importance of contextual and relational factors in shaping health literacy.

The literature review revealed several research gaps. Few studies have examined the impact of environmental factors on children's and adolescents' health literacy. There is limited data on the actual decision-making process, including which factors influence health decisions, whom they consult for various health issues, and the role of emotions like shame and trust. Further research should explore social media's role in shaping health literacy, as it increasingly influences how adolescents access, interpret, and share health information. Given that children and adolescents are experts in their own living environments, participatory research offers a promising avenue for addressing these gaps.

Strengths, limitations, and reflexivity

Our meta-ethnography strengths include rigorous systematic analysis and wide-ranging data synthesis. We developed the first child- and adolescent-centered health literacy model based on the literature. We used the GRADE-CERQual approach to assess our confidence in each finding. Limitations include our focus on middle- and high-income countries, which limits generalizability to low-income regions. While we included queer identities, most studies used binary gender understanding, restricting gender difference analysis.

Methodological limitations include the subjective nature of qualitative synthesis and the potential omission of relevant studies. Our analysis quality depends on the available published research. Our interpretation of the findings was influenced by our team's experience in Austrian and German healthcare systems. As most team members identified as women, we considered gender-specific aspects of health literacy, including role models and social expectations.

Conclusion

We presented a literature-based, child- and adolescent-centered definition and conceptualization of health literacy. Including their perspectives is crucial for developing targeted interventions and informing policies that promote well-being and empower them to build strong health literacy from a young age.

Our model has potential applications in practice, research, education, and policymaking. Practitioners can use it to underpin community- and school-based programs. Researchers can develop new measurement tools and evidence-based interventions based on the model's dimensions. The model can inform curriculum development in education and guide national health literacy strategies. By promoting informed health choices, critical thinking, and equitable access to health education, our review contributes to the achievement of SDG 3 (Good Health and Well-being), SDG 4 (Quality Education), and SDG 10 (Reduced Inequality).

Data availability

This study is based on a synthesis of existing evidence. No new data were collected or generated. All data used in this work were obtained from previously published studies, which are cited within the manuscript. The analysis file generated during this study is available from the corresponding author upon reasonable request.

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Author contributions

K.S., as the first author, was primarily responsible for the conceptualization, investigation, formal analysis, validation, visualization, and the writing of both the original draft and the review and editing stages. L.S. and L.A. significantly contributed to the conceptualization, investigation, formal analysis, validation, and writing of the manuscript. I.S., the review lead, played a central role in the conceptualization, methodology, investigation, formal analysis, validation, and supervision, while actively participating in the writing and revision of the manuscript. A.W., D.R., L.G., and O.O. provided essential validation and supported the review and editing process. I.K. developed the database search strategy and contributed to the overall methodology. U.G., as the project lead, oversaw the conceptualization, validation, and supervision, and was instrumental in securing the necessary resources, as well as contributing to the writing and review of the manuscript. Throughout the study, K.S., I.S., L.S., L.A., A.W., D.R., L.G., O.O., and U.G. engaged in crucial team meetings where discussions were central to refining the research direction and ensuring the quality of the outcomes.

Declarations

Competing interests

The authors declare no competing interests.

Ethical statement

This research was conducted as a meta-ethnography, which involves the systematic synthesis of existing qualitative studies. As no new data were collected from human participants, ethical approval was not required. The analysis was based solely on previously published studies. The privacy and confidentiality of the original study participants were respected, as no identifiable information was used or disclosed in this metaethnography.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used DeepL Translate [DeepL.com], ChatGPT [chatgpt.com] and Claude Pro [claude.ai] in order to shorten and linguistically improve the original text. After using these tools, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Additional information

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