

Children's health-related experiences in India: A scoping review

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ABSTRACT

Background & Objectives: The perspectives of children have become increasingly emphasized in healthcare research and practice in order to facilitate children's inclusion, participation, and decision-making in matters related to their health. In India, however, little is known about children's views regarding their health despite the various health challenges and ethical concerns they may face, such as poverty, malnutrition, and gender inequalities. The aim of this scoping review is to explore children's health-related experiences from their own perspectives in India from 2000 to 2020.

Methods: Five online databases were searched. Three independent reviewers screened articles for inclusion. Included texts were analyzed using thematic synthesis, which involved extracting and descriptively coding data, categorizing/grouping codes by similar topics, and comparing and contrasting topics to generate descriptive themes. The scoping review was reported using the PRISMA-ScR checklist.

Results: Fifty-two articles were included, and five descriptive themes were identified. The articles typically overlapped in themes, which related to children's health-related experiences (n=38), emotions (n=19), and knowledge (n=15); the impact of illness on children's lives (n=41); and children's ability to communicate their needs (n=12).

Interpretation & Conclusions: We identified the need to tailor research designs to better elicit children's perspectives and provide comprehensive health education for children and families in India. This scoping review helped to highlight gaps in healthcare policy, practice, and research, providing a starting point for more focused investigation into children's health-related experiences in India.



KEYWORDS

India, Children's healthcare, Scoping review, Child ethics, Lived experience

1 | INTRODUCTION

Childhood ethics is an emerging field of inquiry with a paucity of research examining health-related experiences from the child's perspective. (1) A child's perspective is defined as a direct view on "conditions, experiences, perceptions and actions, based on what he or she finds important". (2) Children's perspectives are being increasingly utilized to promote their participation, inclusion, and agency within fields such as education, health, and law. (3) According to the World Health Organization, (3) health extends beyond the simple absence of disease and encompasses physical, mental, and social well-being. The concept of whole person well-being involves various domains of one's life, including physiological and psychological processes, as well as physical, sociocultural, and spiritual environments. (4) Therefore, an individual's well-being can be deeply affected by their interpretation of day-to-day events, which may align with or go against personal values and beliefs. (5)

Ethics play an integral role in health care and services as healthcare providers must make decisions in patients' best interests by seeking to reduce harm and maximize benefit. The act of genuinely hearing, acknowledging, and addressing a patient's voice is therefore critical toward understanding a child's particular experiences, aspirations, and concerns. This helps to inform an individualized determination of their best interests, which should orient treatment decision-making and is particularly relevant for children who are vulnerable given their development, status as minors and limited legal decision-making capacities within healthcare contexts. (6) However, children with chronic illness have reported being excluded from decisions, discussions, and actions related to their care. This compromises clinicians' and parents'/caregivers' abilities to understand children's perspectives and in turn, their best interests, while leading to feelings of frustration, anger, and fear in children. (7) Nonetheless, young people have clear ideas regarding how their treatment can be improved (8) and have expressed desires for their voices to be heard in healthcare settings. (9) Given that self-management capacities and self-efficacy are positively

correlated with health-related quality of life for children with chronic illness, (10) eliciting children's perspectives during care may support a sense of control over their health, improve their care, and enhance their quality of life. For these reasons, seeking to understand and render children's perspectives visible in health-related literature is an important step towards advancing the field of childhood ethics. Despite increasing recognition of the children's voices in healthcare research and practice, research related to this topic has been geographically limited. In turn, children's perspectives regarding their health are still unclear in many low- and middle-income countries such as India. India has the largest child population (0 to 18 years) in the world but is also disproportionately affected by poverty, malnutrition, poor access to healthcare, gender inequalities, and other health and ethical concerns. (11–13)

This study presents a scoping review of health-related literature from the child's perspective in India. This review was conducted by VOICE (Views on Interdisciplinary Childhood Ethics), a group of researchers and community partners committed to advancing the field of childhood ethics and global child health. The goals of this scoping review are to: a) improve our understanding of children's health-related experiences by exploring the perspectives of children in India with illness, disability, and/or physical symptoms within empirical studies; and b) identify areas for further empirical research and examination of ethical concerns.

2 | METHODS

2.1 | Study design

We conducted a scoping review, also known as a knowledge synthesis design, allowing us to summarize a range of evidence and identify the key concepts underpinning a complex, new, or unfamiliar research topic. (14) The approach of a scoping review is broad and uses purposive sampling to identify evidence and gaps in the literature without a quality appraisal step. (15) The six steps of the scoping review framework are: (a) identifying the research question; (b) identifying relevant stud-

ies; (c) study selection; (d) charting the data; (e) collating, summarizing, and reporting the results; and (f) consultation. (14) Our results were reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; 16) checklist which can be found as a Supplemental Material (File S1).

2.2 | Identifying the research question

The objective of this scoping review was to explore the existing knowledge about children's health-related experiences from their own perspectives in India. We aimed to answer the research question: What do we know about children's health-related experiences in India?

2.3 | Identifying relevant studies and study selection

For this review, the term 'children' referred to individuals between 3 and 17 years of age. Seventeen years was selected as the upper limit for the age range as the age of majority in India is 18 years (i.e., when an individual ceases being a minor). (17) Only empirical studies examining children's health-related experiences from their own perspective were included (e.g., outlining findings in the child's own words). No language restrictions were implemented, but the studies were limited to those entirely conducted or at least partly conducted in India and by publication date from 2000 to June 2020. This time period was selected because the interdisciplinary interest in childhood studies emerged recently around the year 2000 (1), yielding an increase in literature exploring children's voices, agency, and perspectives. Thus, the current literature was seen as providing a synopsis of the state of knowledge on the topic.

Studies that were excluded were opinion papers or studies that were normative in focus (i.e., recognized norms defined by legal, ethical and/or professional practice standards). Moreover, data from infants (0-12 months), toddlers (12-36 months), and children giving opinions on health topics, illnesses, or conditions for

which they were not afflicted with were excluded. However, studies with some participants over 18 years of age but which fulfilled the rest of the inclusion criteria were included if most participants in the respective study were under 18 years of age, as these articles still contained valuable knowledge regarding children's perspectives.

2.4 | Search strategy

The search strategy paralleled the three-step process outlined by Peters et al. (18) whereby (a) an initial search was run in CINAHL and MEDLINE, (b) a second, comprehensive search was run using keywords derived from the initial search, consultation with a research librarian, and a target article. Then five online databases were searched: CINAHL (1937-2020), Global Health (1973-2020), MEDLINE (1949-2020), PsycINFO (1597-2020), and Web of Science (1900-2020); and (c) reference and citation searching was used to supplement the results from the reference lists in the included studies. (18) Keywords such as "child*", "India", "perception*", and "experience*" were searched within titles and abstracts, reducing the number of irrelevant retrieved articles. The detailed search strategy for MEDLINE can be found in File S2. Endnote X7 software was used to store, organize, and retrieve the search results. Additionally, interlibrary loans were used to locate articles not retrievable in the university collection. Following article retrieval, three independent reviewers screened titles, abstracts, and full-text articles to determine study inclusion.

2.5 | Charting the data then collating, summarizing, and reporting results

Selected articles were read in full and summarized in a data extraction sheet outlining the: year; study setting; study design and methodology (research type, sample size, data collection methods and tools); population demographics (age range, illnesses/symptoms, health-care context); qualitative and/or quantitative findings and outcome measures related to children's perspectives, reports, or understandings of their health-related

experiences; and any additional comments or discussion points (e.g., key takeaways, article discussion summary, recommendations and research implications, reviewer questions). The data extraction sheet was created by the first authors (YWW and JB) and tested by charting data from sample articles. The sheet was then reviewed by co-authors and refined in collaboration with the research team to ensure that the contents permitted standardized charting and aligned with our research question. Three authors (YWW, JW, SJ) charted the data. They met regularly with our research team to share their data extraction sheets; discuss and address questions, uncertainties, and concerns; and ensure the charting process remained consistent between the three authors.

The framework for collating and summarizing the results was based on recommendations for enhancing the consistency of scoping review methodologies (19), which includes conducting a descriptive numerical analysis and qualitative thematic analysis guided by our review question. Data analysis was led by the first authors (YWW and JB) in close collaboration with the research team who permitted for member checking and debriefing (i.e., obtaining feedback on data interpretations and analysis); provided input during quantitative and qualitative analysis; and vetted, gave feedback, and provided consensus on generated themes and findings. The descriptive numerical analysis for this scoping review consisted of numerically summarizing the characteristics of the included studies, such as the number of included studies, population demographics, and study designs. (14,19)

A thematic synthesis was conducted whereby the research question guided categorization of the codes and generation of descriptive themes. (20) Data analysis was iterative, inductive, continuous, (1) and conducted in three phases. The first phase included initial open coding, in which data relevant to the review question were extracted from the data extraction sheet and descriptively coded, generating units of analysis or codes. (21) In the second phase, we looked for similarities and differences between codes and grouped similar codes together to form topics, which captured the meaning

of the initial code groups. Examples of topics include “impacts of illness on children’s lives”, “children’s physical sensations and symptoms”, and “children’s understanding of their health and illness”. The third phase included relating topics to each other (axial coding), organizing individual topics into themes (thematic analysis), and drawing connections between themes (comparative analysis). (22) This allowed us to generate an understanding of children’s health-related experiences in India and identify areas for further empirical research and ethical examination.

3 | RESULTS

3.1 | Sample and Study Characteristics

The initial search yielded 11,304 articles. Once duplicates were removed, 10,547 articles were screened based on the inclusion criteria, after which 134 articles remained and were read and assessed in full for eligibility. Finally, 52 studies were included for analysis and summarized in a PRISMA flow diagram (Figure 1). This review synthesized the perspectives of 15,996 children between 3 and 21 years old (inclusive), and was comprised of 37 quantitative studies, 9 qualitative studies, and 6 mixed-methods studies, which were conducted in schools, communities, hospitals, rehabilitation centers, and clinics in both rural and urban settings. Seven studies included some participants above the age of majority (18 to 21 years). Participants had various illnesses and symptoms including asthma, cancer, renal disease, thalassemia, visual impairments, dental issues, leprosy, HIV/AIDS, menstrual symptoms, somatic symptoms, substance-use, depression, musculoskeletal pain, cleft-lip, pregnancy, and mobility impairments/disability.

3.2 | Thematic Analysis

The 52 studies in this review are summarized in Table 1. Five main themes were identified along with 11 sub-themes from the extracted codes (Table 2). Each theme was salient to the understanding of children’s health-

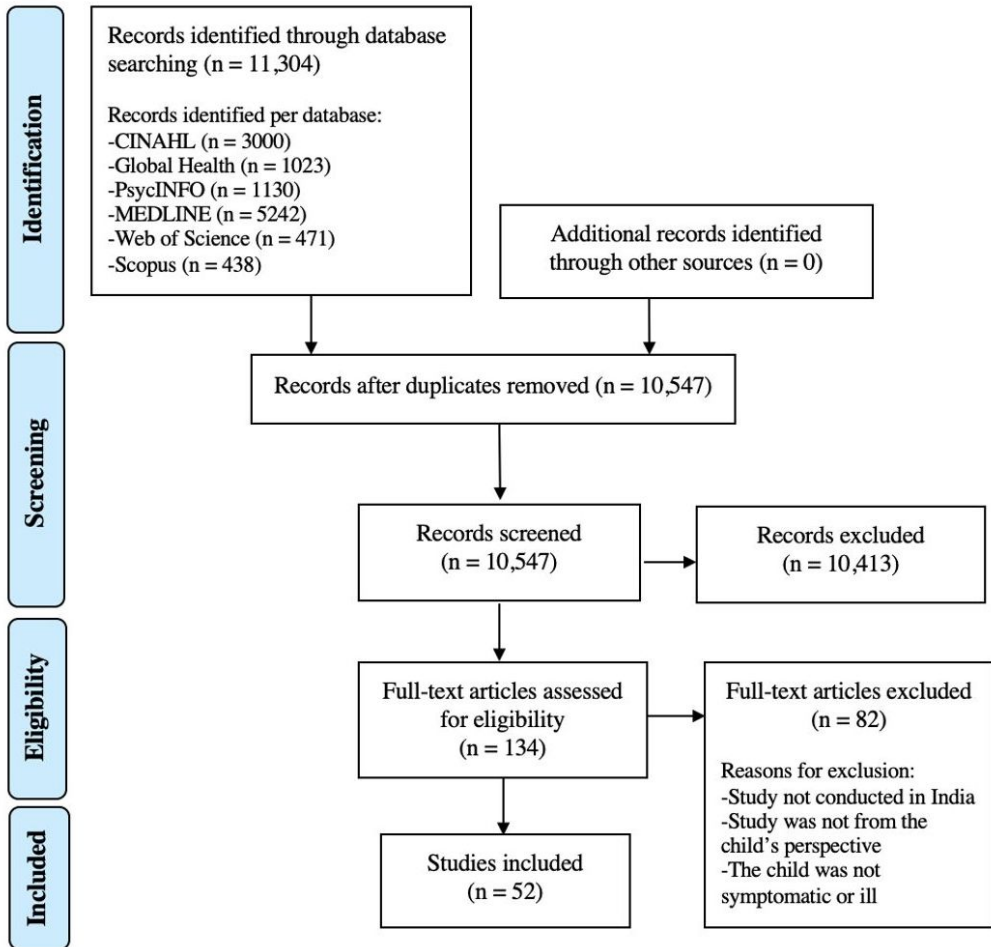


FIGURE 1 PRISMA (*preferred reporting items for systematic reviews and meta-analyses*) Flow Diagram

related experiences and are presented below.

3.3 | Children recalled detailed health-related experiences in healthcare facilities and communities.

Thirty-eight studies showcased children's abilities to recall and reflect on their health-related experiences. A key similarity between studies was that children were able to describe detailed memories of favourable and

unfavourable events related to their medical care, interactions with healthcare staff, and within healthcare facilities. For example, youth living with HIV recounted how discourteous service from healthcare staff left negative impressions of the clinic (23) while adolescents with cancer talked about the debilitating effects of treatment (e.g., oral ulcers, nausea, pain). (24) Conversely, children in PICU recounted comforting actions of nurses and doctors such as speaking nicely and painless injections. (25) Children's recollections also extended be-

yond themselves as they described witnessing the experiences of other ill children in the PICU undergoing invasive procedures, injections, and even death. (25)

Within the community, however, children mostly recounted negative experiences related to health barriers and social exclusion. Post-menarche girls, for example, reported having limited access to hygienic facilities at school (e.g., soap, clean water, toilets), prompting them to miss classes during menstruation. (26–29) Children living with HIV/AIDS reported experiencing discriminatory actions from family members including refusals to share food, avoidance, and propagation of misgivings. (23) Finally, children also reported experiencing bullying, teasing, and/or negative judgement from peers due to their symptoms and illness, contributing to absenteeism and treatment non-compliance. (29,30)

3.4 | Children expressed both positive and negative emotions related to their health.

Nineteen studies highlighted children's expression of positive and negative emotions related to their health. Using interviews, questionnaires, and focus groups, researchers showed that children experienced emotions such as fear, hope, anxiety, hopelessness, insecurity, appreciation, guilt, and sadness towards their health. In general, children's negative emotions—particularly fear and anxiety—stemmed from unpleasant physical symptoms (e.g., pain, discomfort, nausea), uncertainty about their health and future, and limitations due to dependence on caregivers, activity restrictions, and socioeconomic status. (31–33) Despite the psychological impacts of illness, pediatric PICU patients (25) and children with HIV/AIDS, (34) leprosy, (35) and asthma (36) also reported positive feelings, such as hope and contentment. Examples of when primarily positive emotions arose were when children had a positive outlook on life, (34,36) were knowledgeable about their illness, (35) and felt supported by healthcare providers. (25) While children's emotions varied with the severity and nature of their illness, their interpersonal experiences, access to resources in healthcare facilities, and communities also

contributed to their positive and negative emotions. For example, social exclusion and discrimination led to negative emotions, (29,30) while support and comfort from healthcare providers and family helped to attenuate the negative effects of illness (25, 34-36).

3.5 | Children had varying levels of knowledge regarding their health, treatment, and the consequences of illness.

Fifteen studies showed that children had varying levels of knowledge regarding their health. Children's beliefs and understanding of their illness and symptoms were shaped by their sociocultural backgrounds. Differences in health-related knowledge were particularly evident in children with thalassemia (37) and post-menarche girls. (32) For example, educated Hindu youth with thalassemia attributed their illness to medical causes, such as lack of prenatal screening. (37) Conversely, Muslim respondents (regardless of education level) believed that their illness was caused by a "sinful past". (37) For post-menarche girls, perceptions of menstruation varied by maternal education, such that adolescents from rural areas, where women's educational attainment was typically low, had significantly worse attitudes towards menstruation than their urban counterparts. (32) In particular, rural adolescents were less inclined to ask questions about and discuss menstruation, contributing to a poor understanding of menstrual symptoms, inability to identify organs involved in menstruation, and negative emotions such as feeling "ugly" or "gross". (32) Regarding other illnesses, such as those with HIV/AIDS or sickle cell hemoglobinopathy, most youth had some knowledge related to medication, treatment, and/or prevention. (34,38,39)

Overall, family, teachers, and friends played the greatest role in children's health-related knowledge and attitudes. Post-menarche girls, for example, often learned about menstruation from their mothers, (26–28,40). Youth who used tobacco, areca nut (a type of nut with similar properties as nicotine which is usually chewed and can be harmful to one's health), and other drugs were influenced by friends and/or by wit-

nessing family members use substances. (41–43) These different sources of knowledge influenced the accuracy and scope of children's health knowledge, as well as their understanding of the importance of treatment and consequences of untreated illness. Although most children understood the severity and impact of their various illnesses, most had incomplete knowledge regarding their symptoms and treatment, which negatively affected treatment seeking, medication compliance, and quality of life. For example, children with asthma commonly reported poor understanding of their disease, contributing to medication resistance. (44) Similarly, children with poor spectacle compliance reported that their parents did not understand their vision problems and that they themselves did not know what "normal" vision was (30) Although post-menarche girls commonly reported experiencing abnormal menstrual symptoms such as UTIs, infections, and lacerations, the vast majority did not seek medical treatment. (45,46)

3.6 | The impacts of health and illness extended beyond children's physical well-being.

Forty-one studies showcased how the impacts of health and illness extended beyond children's physical well-being. Children's various health statuses impacted their physical, emotional, and developmental well-being regardless of illness type and severity. Moreover, children's well-being varied with age, gender, and socioeconomic status (SES) such that girls, youth 12 years and older, and children with low SES tended to report greater physical and emotional burden and lower quality of life. (32,33,47,48) Although all children reported negative physical sensations such as discomfort, pain, or weakness, they tended to speak more about the impacts of health on their daily activities. Thus, children with health problems (e.g., vision deficits, dental issues, thalassemia, HIV/AIDS) generally reported lower quality of life than their healthy counterparts. (23,42,48,49)

One of the most common issues reported by children was the negative effect of illness on their schooling and relationships with peers. This was particularly salient

for children with dental problems, (47) vision impairments, (30) thalassemia, (37) sickle cell hemoglobinopathy, (38) HIV/AIDS, (34) musculoskeletal pain, (50) and unpleasant menstrual symptoms. (29) Children often complained of school absences due to physical symptoms, lack of support, and inadequate facilities to accommodate their health needs. (29,34,50,51) For example, children with sickle cell hemoglobinopathy and thalassemia expressed a lack of support from teachers. (37,38) Children with spectacles reported being teased by school peers (30) and post-menarchal adolescent girls reported having to cope with unhygienic, poorly equipped bathroom facilities that lacked privacy. (29)

Children's health also impacted their self-perceptions, such that youth with thalassemia, (37) cancer, (24) and sickle cell hemoglobinopathy (38) perceived their diagnosis as a psychological and economic burden for their family and society. Negative self-perceptions usually arose due to feelings of dependence, (24,37) disablement, and guilt. (38) Children's concerns also revolved around their self-image and desires to be like their "healthy" peers. (44,52–54) While some children with dental fluorosis reported that they liked the appearance of their teeth, others were worried about their appearance. (52) For children with vision impairments, appearance was an important contributing factor towards spectacle non-compliance, particularly amongst girls. (30,55)

3.7 | Children had the capacity to identify and communicate their health-related needs.

Twelve studies highlighted children's capacity to identify and communicate their health-related needs. Despite the physical and psychosocial challenges associated with ill-health, children were able to identify and communicate their health-related needs when their voices were elicited during interviews, focus groups, or self-report questionnaires. For example, adolescents with thalassemia, (37) cancer, (24) and leprosy (53) demonstrated understanding of their coping needs by expressing their desires for better access to counselling and

psychological support. Children's desires also extended beyond their personal needs: when asked what can be done to improve the intensive care unit, PICU patients suggested implementing "more beds so that more sick children can be in intensive care". (25)

Although few studies examined children's communication with healthcare providers, Tiwari et al. (56) found that children with end-stage renal disease were able to ask questions and talk to doctors, nurses, and other staff about their health. Children also revealed the most insight towards their health in group settings with other youth having similar health conditions. For example, results from a focus group study by Narayanan et al. (30) showed that youth with vision deficits had several ideas to encourage spectacle-compliance such as implementing science clubs to deliver education, emphasizing teachers' roles in the education and encouragement of spectacle-use, and providing trendy frames. Similarly, adolescents with various disabilities (e.g. hearing and vision impairments, and poliovirus) who participated in a community-based rehabilitation programme with other youth, with and without disabilities, provided several insights toward their experiences, desires, and needs. (57) The adolescents reported wanting more education, freedom to engage in day-to-day activities (e.g. social interactions, play, and going outside), and having someone to talk to about their emotions. (57) Despite their restrictions, the youth with disabilities viewed the group setting as a fun and effective way to engage with their community, assume control over their rehabilitation, and take charge of their lives. (57)

4 | DISCUSSION

The purpose of this scoping review was to examine children's health-related experiences in India, including children's participation, perceptions, knowledge, and decision-making capacities in matters concerning their health, as well as to identify gaps in the current literature. Despite children's various health statuses and India's pluralistic society, (58) children often reported similar health-related experiences, some of which paral-

leled circumstances in Western societies. (7-10) Overall, the studies were diverse in scope, topic, and focus, consisting of various methodologies and study tools such as self-report questionnaires, focus groups, interviews, participant observations, and children's drawings. In turn, this scoping review revealed a range of topics related to children's perspectives such as their recollections, feelings and emotions, and knowledge about their illnesses/symptoms. These aspects shed light on children's unique perspectives of their health in India, which can serve to enrich our understanding of their best interests. Rendering children's perspectives visible can influence how healthcare providers and other adults understand and address children's best interests in the provision of care, which is rooted in childhood ethics.

Most children had clear recollections of their health experiences regardless of illness, symptoms, and surroundings (school, hospital, community). Children and youth were particularly attuned to healthcare providers' actions, contributing to positive and negative attitudes towards health. For example, children recounted receiving discourteous service from healthcare staff, (23) but also being treated nicely by PICU nurses and doctors. (25) Researchers examining nurse-patient interactions with hospitalized children in Spain reported similar findings, such that children evaluated their treatment based on their perceptions of nurses' affect, interest, and sympathy towards them. (59) Youth used nurses' behavioural signals to distinguish between their preferred healthcare providers, contributing towards their treatment compliance and adaptation to hospitalization. (59) Additionally, Ullán et al. (60) found that unlike adults, children appeared to be more sensitive to the "symbolic" aspects of hospitalization, such as the emotional processes, needs, preferences, and behaviours of hospital users. Similarly, the studies in this scoping review highlighted that: a) children were observant of healthcare staff's behaviours towards themselves and others; and b) their observations directly impacted their emotions and perceptions regarding their health-related experiences.

In the Indian context, parents and peers influenced children's health-related attitudes, knowledge, and prac-

tices. Common challenges including medical non-compliance, poor psychosocial well-being, and lack of health knowledge were often exacerbated by low SES and inadequate support from family, teachers, and friends. These findings align with recent research by Olsen et al., (61) who found that European adolescents who had undergone ulcerative colitis surgery reported feeling “deserted, misunderstood, and ignored” by family and friends due to personal physical changes and school absences. In addition, researchers from Canada and the United States explained that children with a low SES are less likely to have access to medical care, nutrition, and environmental stimuli, increasing the likelihood of injury, mental and physical illness, and developmental delay. (62– 64) Despite some similarities, there were notable differences between children’s health experiences in India and Western countries, particularly related to menstruation and areca nut chewing. For example, American girls/females appeared to be more knowledgeable and accepting of menstruation, (65,66) had greater access to menstrual products (e.g., pads, tampons), (67) and adhered to less strict social restrictions (e.g., being able to attend school and family/religious events) (67) compared to girls from low and middle-income countries. In addition, research on areca nut chewing was limited to South Asia likely due to where it is grown, with only one study conducted in Europe that showed that children who used areca nut were exclusively South Asian. (68)

Finally, although only 16 out of 52 studies elicited children’s health-related opinions via interviews or focus groups, the qualitative and mixed-methods studies showed that children recognized their needs and desires, were insightful when suggesting healthcare changes, and appeared to be more engaged in health discussions in groups settings with other youth. Similarly, Livesley and Long (69) found that hospitalized children in England actively resisted passive roles in healthcare settings and worked hard to assert their competence, knowledge, and capabilities. The notion that peer groups are effective in promoting well-being, knowledge-acquisition and exchange, and collaboration is well supported in research. (70,71) In an overview

of loneliness across the lifespan, Qualter et al. (72) described how children increasingly value peer acceptance, intimacy, and social standing as they age. Consequently, disruptions in social functioning by poor health can contribute to feelings of rejection, negative attitudes towards health, and low self-esteem, which were all common issues in this scoping review. The utilization of focus groups to elicit children’s voices therefore supported young people’s psychosocial well-being by providing an safe environment to communicate health concerns and interact with peers. (72–74)

4.1 | Gaps and limitations

Although we have identified research examining children’s health-related experiences from their perspectives in India, we limited the evidence to empirical studies. Thus, further research into normative standards is required to examine the how notions of participation, inclusion, agency, consent, and assent are viewed in the Indian context, what practices are recommended based upon these views, and if the evidence summarized in this review reflects the adoption of practices. Next, studies were excluded from the review if they examined the health-related knowledge, attitudes, and beliefs of children who were not symptomatic or diagnosed with an illness (e.g., perception of boys towards menstruation). Given the importance of peer relations towards children’s health-related experiences, we recommend an extensive examination of the public health literature. This would provide a more comprehensive understanding of how children perceive their health in India. In terms of methodology, 36 out of 52 studies included in this review used only quantitative methods (e.g., questionnaires, objective medical examinations) to explore children’s health-related experiences, mostly related to quality of life. Although questionnaires are a quick, economic, and effective way to determine individuals’ perceptions regarding a specific topic, questionnaire-use may also lead to bias or reflect the preconceptions of the researcher instead, thus failing to truly capture the participants views, experiences, and voice. (75) Finally, the studies featured in this scoping

review were heterogeneous in terms of participant sociodemographic background, illnesses, methodologies, and findings, which precluded our ability to showcase potential relationships between children's sociodemographic characteristics and contexts (e.g., religion, socioeconomic background, gender/sex) and their health experiences. However, delving into these potential relationships through further empirical studies may help researchers and healthcare providers better understand the unique healthcare needs of children in India.

4.2 | Future directions and implications for practice

Through this scoping review, we have identified a need for more qualitative, interview-based, and child-centric methodologies (e.g., art, play) in conducting research with children. This will help to fully capture their health-related experiences, promote their inclusion in care, and support the provision of ethical care by healthcare providers. In terms of practice, this review highlighted the clear need for family-centred interventions that focus on providing health education to parents of children with health conditions, as well as enhancing health education in school settings. Furthermore, young people expressed insightful suggestions to improve care, showcasing the need for healthcare providers to elicit young people's voices and recognize the impact that clinicians may unconsciously have on children's health experiences. Future researchers may consider conducting a more focused review of the literature pertaining to specific ethical concerns or consequences impacting children. In all, this review provides a foundational body of evidence to serve as a starting point for continued research in the area of children's perspectives towards their health in India.

5 | CONCLUSIONS

The themes identified from this review demonstrated that ill and symptomatic children in India often expressed similar health-related experiences, views, and

needs across several domains of life despite their various health statuses, experiences, and backgrounds. These domains were not restricted to their immediate medical milieu, but rather extended to children's relationships, schooling, and activities of daily living. This scoping review identified key areas for improvement in children's healthcare including the need to elicit children's voices during care, provision of adequate psychosocial support, enhancing health education, and training healthcare providers to recognize the impact of their behaviours on children's health experiences while taking actions to provide appropriate, sensitive care. Given the widespread impacts of health services on other areas of children's lives, research in healthcare and childhood ethics play an integral part in insuring that these impacts are known and considered by those who make healthcare decisions in children's best interests. By highlighting this link, our scoping review contributes to children's healthcare and childhood ethics research. Although more research is needed to fully understand children's health-related experiences in India, the development of an ongoing dialogue between researchers, healthcare providers, as well as children and families can promote the inclusion of children in their own care and lead to improved health research and practices that are suitable for young people in India.

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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Author	Setting	Age (years)	Sample Size	Study Design	Data Collection Tools	Illness/Symptom	Main Findings	Relevant Theme(s)*
(Christy et al., 2002)	Rehabilitation center	3-10	n=50	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions)	Visual impairment	<ul style="list-style-type: none"> Children with visual impairment expressed their emotions and needs, but had difficulty expressing sympathy due to visual conditions, backgrounds, experiences, and age 	5
(Karande et al., 2005)	Pediatric intensive care unit (PICU) in tertiary care public hospitals	5-12	n=50	Qualitative, Phenomenological	Semi-structured interviews	Various severe illnesses (e.g., dengue shock syndrome, malaria, etc.)	<ul style="list-style-type: none"> Positive recollections of PICU stay related to aspects of medical care, personal factors, environmental factors Negative recollections of PICU stay were personal, such as being restrained in bed or seeing a dead body 	1, 2, 5
(John et al., 2005)	Hospital in Kolkata	10-20	n=258	Qualitative, Phenomenological	Focus group discussions, interviews	Leprosy	<ul style="list-style-type: none"> Adolescents were dependent on parents to seek care for their symptoms Children felt ashamed of their disabilities, despair, helplessness, and insecurity Expressed desire for support to cope 	1, 2, 5
(Patel & Pathan, 2005)	Regional Hemoglobinopathy Center (Urban)	8-14	n=52	Quantitative, Quasi-experimental, Cross-sectional	Self-report questionnaire (quality of life [QOL])	Sickle cell anemia (SCA) and sickle cell anemia trait	<ul style="list-style-type: none"> Children with SCA had greater restriction of physical activities Expressed feelings of sadness or disinterest, lack of support, intensity of weakness and pain, and realization of being affected by a major illness 	1, 2, 4
(Roy & Chatterje, 2007)	Various community locations	9-17	n=36	Qualitative, Phenomenological	Interviews	Thalassemia	<ul style="list-style-type: none"> Culture and education important in the construction of meanings Consequences of illness has been stressful, tedious, painful and causing psychological distress 	1, 2, 3, 4, 5
(Kumar et al., 2008)	Health clinic	Mean=15.7	n=360	Quantitative, Cross-sectional	Self-report questionnaire (perceptions, experiences)	General health problems	<ul style="list-style-type: none"> For health problems boys consulted their friends/peers (48%) while girls consulted their mothers (63%) 	3
(Singh & Ghai, 2009)	School providing integrated education	11-16	N=14	Qualitative, Participatory action research	Semi-structured interviews, focus groups, drawings made by participants	Mobility impairment/disabilities	<ul style="list-style-type: none"> Findings illuminated immense variation and fluidity in children's understanding of 'disability' Children desired to appear similar to 'non-disabled' children Most attributed 'disability' to existential causes 	1, 2, 3, 4

(Raval et al., 2010)	Suburbs of Ahmedabad	6-8	n=120	Mixed methods, Embedded, Cross-sectional	Child emotion vignettes, interview questions, questionnaire for mothers to complete (child behaviour)	Children with internalizing, externalizing, and somatic symptoms, and children with no symptoms	<ul style="list-style-type: none"> The internalizing and externalizing groups considered their expressions of anger and sadness uncontrollable and reported crying and utilizing aggressive behaviors, respectively, more than the control group The somatic complaints group considered emotions trivial and reported withdrawing more than the control group 	1, 2
(Gulati et al., 2011)	A community based rehabilitation program in the urban slums	12-18	n=42 (21 youth with disability, 10 youth without, 10 staff)	Qualitative, Critical ethnography	Participant observations focus group discussion, audio-visual data, field notes	Various disabilities (e.g., polio, hearing impairments, vision impairments)	<ul style="list-style-type: none"> Adolescents viewed the group setting as the most fun and effective way of getting involved Four central themes informed the framework: group participation, group demonstration, group recognition and the socio-cultural environment's interaction with disability Adolescents with disabilities expressed desires to negotiate and engage in meaningful age-appropriate occupations with their peers 	1, 2, 4, 5
(Dandi et al., 2011)	School in both urban and rural communities	12	n=2250	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (experiences)	Dental pain	<ul style="list-style-type: none"> Children expressed higher need for dental care when pain was severe, continuous, and/or aggravated on thermal stimuli Daily living was affected by dental pain Not all children with dental pain expressed their need to seek dental care 	1, 4, 5
(Khan et al., 2012)	Urban in-patient oncology unit	Mean =16.7	n=7	Qualitative, Phenomenological	Semi-structured interviews	Cancer	<ul style="list-style-type: none"> Children expressed mixed perception about cancer, reported uncertain and bleak future, and physical and psychological distress Children reported that their parents were the strongest source of support There is still stigma attached to cancer despite awareness programs 	1, 2, 4, 5
(Bansal et al., 2013)	Dr. B.R.A Institute Rotary Cancer Hospital	5-18	n=120 (40 youth with cancer, 40 siblings, 40 healthy youth)	Quantitative, Descriptive, Cross-sectional, Comparative	Self-report questionnaire (QOL)	Acute lymphoblastic leukemia (ALL)	<ul style="list-style-type: none"> The quality of life (QOL) of children with ALL was significantly poorer than that of their siblings and the healthy children in physical, emotional, social, and school health domains There was no significant difference in the QOL of siblings and healthy children in all domains of health 	1, 4
(Grover et al., 2013)	Two hospitals in New Delhi	7-12	n=20	Qualitative, Grounded theory	Semi-structured interviews	Asthma	<ul style="list-style-type: none"> Major reported issues included poor child understanding of disease and medication Child self-image, resistance to medication use and lack of responsibility in medication taking 	1, 3, 4

(Jodali et al., 2013)	Schools in rural areas	12-15	n=316	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, knowledge, concerns), teeth assessment	Dental fluorosis	<ul style="list-style-type: none"> Negative perceptions regarding dental fluorosis increased with the severity of fluorosis Children expressed feelings of distress, worry, embarrassment and hindrance from smiling Children were aware of the presence of fluoride and the health effects of fluorosis 	1, 2, 4
(Verma & Verma., 2013)	Schools	12-16	n=200	Quantitative, Correlational, Cross-Sectional	Self-report questionnaire (QoL, coping, symptoms)	Asthma	<ul style="list-style-type: none"> Symptom severity affected overall and positive QoL, both directly and indirectly via coping Positive reappraisal, and information seeking was related to increased QoL, whereas hiding asthma and worrying was related to lower QoL 	1, 4
(Siluwei et al., 2015)	Urban community clinic	13-19	n=900	Quantitative, Descriptive, Cross-sectional	Screening tool, self-report questionnaire (QoL, practices/habits)	Dental malocclusion	<ul style="list-style-type: none"> There was a positive association between malocclusion and impact on children's quality of life 	4
(Tiwari et al., 2015)	In-patient and out-patient unit of pediatric hospital	5-18	n=55	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL), parent proxy report	End stage renal disease	<ul style="list-style-type: none"> Kidney transplant group had better health related quality of life in comparison to maintenance dialysis group Kidney transplant group did not have difficulty in telling their parents and health care providers how they felt or to ask questions 	1, 4, 5
(Batra et al., 2016)	Dr. B. R. A. Institute Rotary Cancer Hospital	5-21	n=122	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL)	Retinoblastoma	<ul style="list-style-type: none"> Overall QOL was significantly poorer in retinoblastoma survivors as compared with controls Difficulties in maintaining friendships and competing were reported in the social health domain and the school health domain showed significantly higher absenteeism 	1, 4
(Govind-haraj et al., 2016)	Leprosy Mission Hospital	8-18	n=65	Mixed methods, Explanatory sequential, Cross-sectional	Self-report questionnaire (attitude towards health), interview	Leprosy	<ul style="list-style-type: none"> The results indicate that the children and adolescents had a positive attitude towards having leprosy. However, one-third of the participants experience internalised stigma 	1, 2, 4
(Sanjeeva et al., 2016)	HIV clinic	10-18	n=362	Mixed methods, Cross-sectional	Structured questionnaire (perceptions)	HIV/AIDS	<ul style="list-style-type: none"> Although about 60% of children were disclosed about their HIV, only one-third 	1, 2, 3

(Mehta et al., 2016)	HIV clinic	10-18	n=24	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (knowledge, perceptions, experiences), social desirability questionnaire	HIV/AIDS	<ul style="list-style-type: none"> were fully disclosed (know the name and treatments associated with HIV/AIDS) 62% of children were disclosed via an informal process (e.g., non-parental, peers, self-disclosure) Children experienced a range of emotions and actions upon disclosure (e.g., silence, asking questions) Most participants reported that they still had good relationships with family and friends, could overcome challenges in school, and had a positive outlook on their future; school absenteeism was common reported problem Disclosure was met with acceptance by one-third of the children, but 67% reported that they felt upset Despite disclosure, some children had incomplete knowledge about HIV 	1, 2, 3, 4
(Rani et al., 2016)	Urban, rural, and slum communities of Chandigarh	11-18	n=300	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences, practices, beliefs, symptoms)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Most girls reported pain and unhappiness during menstruation, but only 11.3% consulted a physician for dysmenorrhea Most of the girls in urban areas gained information about it through the teachers, whereas girls in rural and slum areas gained information from their mother Lack of accommodations and physical symptoms were major reasons for absenteeism 	1, 2, 3, 4
(Bhad et al., 2016)	Tertiary de-addiction centre	13-18	n=23	Quantitative, Descriptive, Cross-sectional	Semi-structured questionnaire (perceptions, experiences)	Adolescent males seeking treatment for inhalation drug use	<ul style="list-style-type: none"> Reasons for inhalant drug use were: curiosity and experimentation (39.13%), peer pressure (26.08%), anger toward family members (17.4%), boredom (8.69%), just for fun (4.34%), and to impress their friends (4.34%) 	1
(Dhilar et al., 2016)	Thalassemia Day Care Centre	2-18	n=241	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL), medical records	Thalassemia	<ul style="list-style-type: none"> Factors improving the quality of life were control of iron overload and adverse effects of ICTs, management of comorbidities and fewer hospital visits 	1, 2
(Chauhan & Kodhani, 2016)	Community	14-19	n=100	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Post-menarche girls with dysmenorrhea	<ul style="list-style-type: none"> There was significant association between dysmenorrhea and school absenteeism, school performance, daily activities, and social relations Girls experienced unpleasant physical and psychological symptoms, but only 5% consulted a doctor 	1, 3, 4

(Prem Kumar et al., 2016)	Orphanages in Hyderabad	12-16	n=400	Quantitative, Descriptive, Comparative	Self-report questionnaire (anxiety, strengths and difficulties)	HIV/AIDS	<ul style="list-style-type: none"> Children orphaned due to HIV/AIDS experience the highest average levels of anxiety, conduct problems, and peer relationship issues; girls also experienced worse symptoms Being an AIDS orphan and being a girl had the strongest effect on generalized anxiety 	2, 4
(Malhotra et al., 2016)	Three Uttar Pradesh districts	10-19	n=1800	Quantitative, Descriptive, Cross-sectional	Self-report questionnaires (perceptions and experiences)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Girls with more media exposure had greater knowledge about menstruation They commonly reported challenges with finding a place to dispose menstruation pads and washing cloths 	1, 4, 5
(Dhawan et al., 2016)	Community	< 18	n=509	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Injection drug using (IDU) children	<ul style="list-style-type: none"> IDU children reported regular contact with drug-using peers, familial conflict, and abuse Most IDU children reported experiencing sadness and anxiety and 66% felt that life was stressful and difficult 	1, 2, 4
(Seemivasan et al., 2016)	Schools	12-17	n=500	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Most of the girls felt scared on first menstruation (59%) 	1, 2, 3, 4
(Das, Detels, Javanbakht et al., 2017)	Community	8-15	n=34 (20 caregivers, 14 children)	Qualitative, Phenomenological	Interviews, focus group discussions	HIV/AIDS	<ul style="list-style-type: none"> Common issues shared by caregiver and children include concerns about illnesses, medications, HIV-related discrimination, health as a state of mind, available health services and satisfaction and grievances about them. Many participants reported poor accessibility due to distance, unpleasant experiences (discourteous service, and negative side-effects of drugs) 	1, 4
(Das, Detels, Afifi, et al., 2017)	Community	8-15	n=393 (199 caregivers, 194 children)	Quantitative, Correlational	Self-report questionnaire (QoL)	Children diagnosed with HIV or affected by HIV	<ul style="list-style-type: none"> HIV infection was associated with poorer scores in all QoL domains except 'discrimination.' Being on ART was not associated with any QoL domains but was found to be associated with poorer scores in the 'discrimination'. 	4
(Shama et al., 2017)	Pediatric day care centre & out-patient depart-	2-18	n=155	Quantitative, Cross-sectional, Comparative	Self-report questionnaire (QoL), parent proxy survey	Thalassemia	<ul style="list-style-type: none"> Children with thalassemia had worse QoL than their healthy counterparts 	4

(Sharma et al., 2017)	Schools	14-19	n=816	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Children who use tobacco	<ul style="list-style-type: none"> Peer influence was the major reason for initiation of smoking. Parental smoking was the second most important influencing factor in this research Majority of the students thought that teachers (70.6%) and parents (65.2%) were the most important source of information about the hazards of tobacco use 	1, 3
(Gopakumar et al., 2017)	Anti-retroviral therapy (ART) center	5-18	n=144	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL)	Children with HIV	<ul style="list-style-type: none"> Children with HIV reported good QOL and better physical QOL than their psychosocial QOL 	4
(Kumar et al., 2017)	Schools	5-16	n=165	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (sleep, perceptions, physical assessment)	Chronic, idiopathic musculoskeletal pain	<ul style="list-style-type: none"> Children with IMSP had pain at multiple body sites and psychosocial difficulties such as sleep disturbances, absenteeism, and sadness IMSP significantly occurred more in lower socio-economic class in comparison to upper and middle and was more prevalent in children with lower maternal education 	1, 4
(Mathiyalagen et al., 2017)	School	12-18	n=242	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (knowledge, attitude, practices)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Most girls reported experiencing abdominal pain, reproductive tract problems (but few sought medical care), and were restricted from attending religious events, going to school, and/or had to sleep separately Although most girls knew that menstruation was a natural process, few could identify the correct/relevant physiological features involved 	1, 3, 4
(Singh et al., 2017)	Districts of Uttarakhand	9-15	n=423	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (impact on life), physical assessment	Visually impaired children and dental problems	<ul style="list-style-type: none"> Participants >12 years of age had severe impact of poor oral health on their day-to-day activities as compared to those <12 years of age Children who presented with dentofacial deformities, dental caries, and traumatic injuries reported greater impact on daily life Visually impaired individuals showed a higher prevalence of dental caries, traumatic dental injuries, and dentofacial anomalies 	1, 4
(Rajagopal &	Community and schools	10-20	n=270	Mixed methods, Triangulation, Cross-	Focus groups, interviews, and self-report questionnaires	Post-menarche girls with menstruation	<ul style="list-style-type: none"> Common perceptions include "menstrual blood is the accumulated dirt that flows out of the body every month" 	1, 3, 4, 5

Author (Year)	Setting	Age	n	Methodology	Sectional	(perceptions and experiences)	related symptoms	Findings	Limitations
(Narayanan, Kumar, & Ramani, 2017)	Schools	13-17	n=64 (32 parents, 32 children)	Qualitative, Phenomenological	Focus groups	Adolescents who need vision correction	<ul style="list-style-type: none"> Girls stated that there was a lack of clean washrooms in homes/schools Girls using cloths also stated that usage of cloth led to laceration and discomfort. Most girls did not take any medication for these problems or consult a doctor Adolescents generally did not like wearing their spectacles and reported judgements and teasing from peers They reported poor understanding of normal vision, preventing them from enjoying the benefits of their spectacles Adolescents wanted fun/interesting spectacle education sessions (e.g., cartoons, famous personalities, other adolescents wearing spectacles, science clubs) 	1, 2, 3, 4, 5	
(Chordia et al., 2018)	Hospital	8-18	n=93	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL)	Transfusion-dependent thalassemic children	<ul style="list-style-type: none"> Mean PedsQL score was higher in 8-12 y age group as compared to 13-18 y Lowest mean score was observed in School functioning Children with one transfusion per month had better QoL compared to children visiting 3-4 times a month for transfusion 	4	
(Singhal et al., 2018)	Schools	13-18	n=120	Quantitative, Quasi-experimental, Non-randomised controlled trial	Self-report questionnaires (symptoms, stress, coping, etc.)	Subclinical depression	<ul style="list-style-type: none"> The intervention group evidenced clinically significant reductions in depressive symptoms, negative cognitions, and academic stress, and increased social problem solving and coping skills, at both post-intervention and follow-up 	4	
(Dudeja et al., 2018)	Urban slums	6th-12th grade	n=250	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (knowledge, practices)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Only 56.4% of girls had knowledge about menarche pre-menarche; most reported gaining knowledge from their mothers 90% of the girls faced health complaints (e.g., dysmenorrhea) and had restrictions in place due to menstruation including religious, physical and social restrictions All reported dissatisfaction with toilets and handwashing facilities on the school premises 	1, 3, 4, 5	
(Vashisht et al., 2018)	Schools	8th-12th grade	n=600	Mixed methods, Triangulation, Cross-sectional	Focus groups, self-report questionnaires (perceptions, practices)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Most students (65.5%) reported that menstruation affected their school functioning as they were not allowed to attend school during their periods and lacked accommodations 	1, 4	

(Gupta et al., 2019)	Urban and rural Delhi communities	13-18	n=200	Quantitative, Descriptive, Comparative	Self-report questionnaire (attitudes)	Post-menarche girls with menstruation related symptoms	<ul style="list-style-type: none"> Girls in rural areas experienced worse negative feelings and experiences related to menstruation than urban adolescents Mother's educational and occupation status significantly affected adolescents' menstrual attitudes 	3, 4
(Verma et al., 2019)	Schools	8-14	n=500	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (practices), health examination	Tobacco use	<ul style="list-style-type: none"> Friends (78.04%) were most common influencing factor for tobacco use, followed by family members (12.2%) and media (9.7%) 	1
(T. K. Singh et al., 2019)	Dental clinics/hospitals	12-15	n=520	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Adolescents with orthodontic treatment	<ul style="list-style-type: none"> Females felt more self-conscious, less fit to work/function, and more worried due to their teeth in comparison to males Both genders felt embarrassed due to their teeth 	1, 2, 4
(A. Singh et al., 2019)	Districts of Uttarakhand	9-15	n=250	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences)	Hearing impairments	<ul style="list-style-type: none"> Hearing-impaired children with dental problems reported higher impact scores Children >12 years had higher impact scores and lower QOL than younger children Hearing-impaired children had maximum difficulty in maintaining personal hygiene due to oral health problems 	4
(Nagapan et al., 2019)	Hospital	8-16	n=160	Quantitative, Descriptive, Comparative	Self-report questionnaire (perceptions, experiences), health examination	Cleft-lip	<ul style="list-style-type: none"> Children with orofacial clefts had statistically significantly lower QOL than control for Functional Well-being, Social/Emotional Well-being, and School Environment subscales 	4
(Morjaria et al., 2019)	Schools	11-15	n=460	Noninferiority randomized clinical trial, Mixed methods, Explanatory sequential	Interviews, observations, health examination	Vision impairments	<ul style="list-style-type: none"> The two most frequent reasons for spectacle non-compliance in this cohort were teasing or bullying by peers and lost, forgotten, or stolen spectacles Girls reported parental disapproval as a reason for non-wear more frequently than boys 	1, 4
(Deepa Lakshmi et al., 2020)	Schools	8-15	n=628	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (QOL, perceptions, experiences), health examination	Permanent anterior teeth fractures	<ul style="list-style-type: none"> All children with tooth fractures reported negative oral health related quality of life 54% reported negative QOL; this was higher amongst children > 13 years 	4

(Gupte et al., 2020)	Schools	11-18	n=166	Qualitative, Phenomenological	Focus groups	Areca-nut chewing, tobacco use	<ul style="list-style-type: none"> Adolescents reported witnessing family members and adults using the substances and felt that it was not fair when they were told not to use it; they perceived tobacco to be stress-relieving and expressed curiosity towards cannabis and alcohol Key influencing factors in initiation include normalization, curiosity, attraction, critical situations (e.g., pressure from an adult), easy access and affordability 	1
(Gothwal et al., 2020)	LV Prasad Eye Institute	8-18	n=309	Quantitative, Descriptive, Cross-sectional	Self-report questionnaire (perceptions, experiences, functioning)	Children with glaucoma	<ul style="list-style-type: none"> School-aged children treated for Primary Congenital Glaucoma during early childhood experience significantly better vision function and QOL than those treated for secondary glaucoma 	4

*Theme 1: Children were able to recall and reflect on their health-related experiences
 Theme 2: Children expressed both positive and negative emotions related to their health
 Theme 3: Children had varying levels of knowledge regarding their health
 Theme 4: The impacts of health and illness extended beyond children's physical well-being
 Theme 5: Children had the capacity to identify and communicate their health-related needs

TABLE 1 Brief summary of articles included in the scoping review.

Major Themes	Sub-themes
Children recalled detailed health-related experiences in healthcare facilities and communities	Children had vivid memories of favourable and unfavourable events in the healthcare setting and community
Children expressed both positive and negative emotions related to their health	<p>Negative emotions primarily arose when children experienced uncomfortable symptoms, uncertainty, and health-related limitations</p> <p>Positive emotions primarily arose when children were knowledgeable about their health, felt supported, and/or maintained a positive outlook</p>
Children had varying levels of knowledge regarding their health, treatment, and the consequences of illness	<p>Children's health-related knowledge and attitudes were influenced by their sociocultural backgrounds</p> <p>Family and peers were the most commonly reported sources of health-related information which influenced the accuracy and scope of children's health-related knowledge</p> <p>Most children had incomplete knowledge regarding their illness/symptoms, contributing to distress, confusion, and poor treatment compliance</p>
The impacts of health and illness extended beyond children's physical well-being	<p>Illness significantly disrupted children's schooling, social relationships, and day-to-day activities such that children reported unwanted school absences, exclusion from peers and family, difficulties with activities of daily living, and other social and physical limitations and restrictions</p> <p>Illness impacted children differently depending on gender, age, and background</p>
Children had the capacity to identify and communicate their health-related needs to clinicians and researchers	<p>Children understood the additional stressors associated with illness, expressed their need for more psychosocial support, and took into consideration the needs of other ill children when making suggestions to improve care</p> <p>Children spoke openly about their health-related needs and desires when their voices were elicited</p> <p>Children were most empowered in collaborative group settings with healthy peers and youth who have similar conditions</p>

TABLE 2 Summary of main themes and subthemes