

Health Literacy and Empowerment in Oral Health among Visually Impaired Children: Insights from a Qualitative Study in Kerala

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ABSTRACT:

Oral disease is one of the most common yet preventable diseases among children globally and the visual impaired children are disproportionately affected by oral diseases. Although the oral hygiene status and caries experience in visually impaired children in India has been documented in various quantitative studies, there is little knowledge about how these children perceive, access and act on oral health information, nor what the conditions are like in which they feel confident to take control of their oral health. The present qualitative study aimed to examine the level of health literacy and empowerment related to oral health among visually impaired children attending both residential and integrated schools of Kerala, a state where the overall health literacy is very high and health promotion is an established tradition. The study was conducted in a semi-structured manner using 18 children aged 10-17 years who were interviewed, two focus group discussions, and interviews with teachers and caregivers. Reflexive thematic analysis was used for the analysis of the data. Five interconnected themes emerged: sensory-adapted learning, balance of dependence and autonomy,

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institutional setting, mediation by caregivers and peers, and challenges to access of dental care. The data indicate that although knowledge about oral health is often present and fragile, tactile and auditory learning styles are important elements of empowerment and supportive social mediation is critical, while critical health literacy, or questioning and advocating, is not developed. The research paper calls for an "oral health education for children that is sensory-inclusive and intentionally shifts children from receiving instruction to having autonomy and voice.

Keywords: health literacy, empowerment, oral health, visual impairment, children, qualitative research, Kerala

1. Introduction

Oral health is part of overall health and part of living a good life, but often oral health is not included in disability and child wellbeing discussions. Dental caries is one of the most prevalent childhood diseases and according to the World Health Organization (WHO, 2022), it affects nearly half of the world's population. Brushing is a feedback-dependent and visually-guided activity, and most oral hygiene instructions are given in a visual way, which makes the daily activity of maintaining a clean and healthy mouth more difficult for children with disabilities, and even more difficult for visually impaired children. There is sufficient Indian research to show sub-optimal oral health in visually impaired children. High caries prevalence and moderate to severe gingivitis prevalence was observed in south Indian sample, the majority of which was visually impaired children, and similarly, a study in Bangalore reported that the oral health knowledge and hygiene practices were poor in these children (Shetty et al., 2010; Prashanth et al., 2011). The deficit is not inherent but rather the results of making information accessible, as demonstrated by intervention studies with specially designed programmes that employ auditory and tactile stimuli (Sardana et al., 2019). The stories of the children behind the statistics are not part of what these largely quantitative studies examine: how the children make sense of messages about their oral health, what makes them feel capable or incapable of self-care, and how families, teachers and institutions enable or constrain children's agency.

This gap is significant because modern public health does not consider the transfer of knowledge enough. The focus of health literacy is shifted with the idea of developing the knowledge, skills and confidence to access, comprehend and apply health information to inform health decisions and action (Nutbeam, 2000; Sørensen et al., 2012). Importantly, health literacy is known to be a pathway to empowerment which involves people having more control over decisions and actions that impact their health (Nutbeam, 2000). Enhancing the oral health status of an VI child is not simply about everyone telling him or her to brush twice each day, but also about giving him or her the ability to brush on their own, to determine if the mouth is clean without looking, and to seek help or care when they need it. This is a unique context for such an inquiry that Kerala provides. The state has a long tradition of easily available public health services and a decentralised health planning process, and also has the highest literacy rate in India. The question is prompted: where general literacy and health infrastructure are relatively good, do visually impaired children have a corresponding increase in the levels of empowerment in their oral health or do sensory and institutional barriers remain? The current study is qualitative in nature and aims to answer this question. The study had three main objectives: (a) to understand how visually impaired children in Kerala learn and understand information about oral health; (b) to find out what factors help or hinder them in becoming more empowered and autonomous in their oral

care; and (c) to understand the challenges they face in accessing dental care. The study seeks to capture the children's perspectives to guide the design of empowering oral health education that is in tune with their senses.

2. Background and Conceptual Framework

2.1 Oral health of visually impaired children

Visual impairment does not only affect oral self-care; there are several ways. Children who cannot see plaque may not be brushing enough or may have unique brushing habits; they will also have less feedback on where they are brushing to ensure they are getting it all. South Asian literature has repeatedly emphasized that there is higher plaque scores, gingival inflammation and caries experience among visually impaired children as compared to the sighted children, and less exposure of professional dental care (Shetty et al., 2010; Prashanth et al., 2011). Comparative work in other settings comes to similar conclusions (Tagelsir et al., 2013). The literature also shows that adapted instruction works: tactile models, braille pamphlets and audio guidance have been proven to increase knowledge and clinical indices (Sardana et. al., 2019; Joybell et. al., 2015). These results suggest that it is not the impairment itself, but the means of communication, that is the key modifiable factor.

2.2 Health literacy and empowerment

According to Nutbeam (2000) there are three stages towards increasing health literacy. Functional health literacy is defined as "the

capacity to comprehend and take action when presented with simple health information. Interactive (or communicative) health literacy requires greater cognitive and social skills in that a person is able to extract information, understand the message and make use of the information in adapting to a changing situation. Critical health literacy refers to the highest level where individuals are able to critically evaluate information and to gain more control over health choices, and the processes that influence them. Every phase gives more independence and self-esteem (Nutbeam, 2000). In this tradition, empowerment is a process and a product. It is based on self-efficacy (Bandura, 1997) – the perception of one's own capacity to perform a behaviour successfully – and autonomy and voice – the capacity to act independently and to express needs. When applied to oral health care for visually impaired children, the framework suggests that education should go beyond mere factual information (functional literacy) to develop interactive skills for adapting techniques to the non-visual world, as well as the critical skills for questioning barriers, and for claiming care. International instruments (United Nations, 2006) also recognize children with disabilities' right to accessible health information and to participation in decisions about them. In this study, the conceptual framework is shown in Figure 1. It connects adapted inputs to the three levels of health literacy, on to dimensions of empowerment, then to dimensions of oral health outcomes, and, last, there's a reinforcing feedback loop such that successful, confident self-care encourages additional learning.

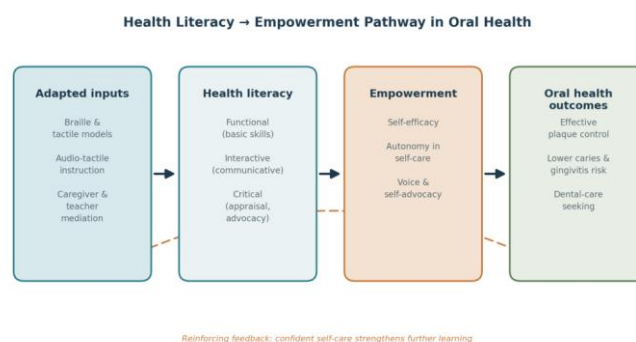


Figure 1. Conceptual framework linking adapted inputs, levels of health literacy, dimensions of empowerment, and oral health outcomes. Adapted from Nutbeam (2000) and Bandura (1997).

3. Methodology

3.1 Design and paradigm

The qualitative, constructivist design was used, based on the assumption that it is important to appreciate the meanings people give to their experience (Lincoln & Guba, 1985). This study aimed to explore the issue in depth instead of the extent, with an emphasis on rich descriptions of what visually impaired children learn about, do and feel about oral care.

3.2 Setting and participants

The study was conducted in three institutions in Kerala that educate the visually impaired

children, two residential schools for the blind and one integrated school where children with visual impairment and sighted students study together. Participants were purposefully sampled to maximize variability in age, level of impairment (congenital total blindness, acquired blindness, and low vision), and where they resided (a residential versus a day scholar program setting). 18 children between the ages of 10 and 17 were interviewed one-to-one and a sub-sample were involved in two focus group discussions. Six teachers and wardens and five parents/carers were also interviewed to provide background to the children's accounts. Table 1 summarises participant characteristics.

Table 1. Characteristics of child participants (N = 18)

Characteristic	Category	Number of children
Age group	10–13 years	8
	14–17 years	10
Sex	Girls	8
	Boys	10
Degree of impairment	Congenital total blindness	9
	Acquired blindness	4
	Low vision	5
Living arrangement	Residential (hostel)	12
	Day scholar	6

3.3 Data collection

Data were generated between three complementary sources. Semi-structured interviews with children followed an open, conversational approach to the topics of daily oral care, sources of oral health information, self-care attitudes, experiences of dental care visits and recommendations for improvement. The two focus group discussions were conducted with six to seven children each, to have the

children build on each other's experiences and to bring up norms they share. Interviews with teachers, wardens and the caregivers were conducted to find out the way oral health was taught and supervised. Interviews were held in Malayalam or English language depending on the preference of the participants and were audio recorded after obtaining consent and verbatim translated if necessary. The sources of the data are summarised in Table 2.

Table 2. Summary of data collection methods

Method	Participants	Focus
Individual interviews (children)	18	Routines, knowledge sources, autonomy, dental visits
Focus group discussions	2 groups	Shared norms, peer learning, collective barriers
Interviews (teachers/wardens)	6	Teaching methods, supervision, institutional routines
Interviews (parents/caregivers)	5	Home practices, expectations, access to care

3.4 Analysis

Transcripts were analysed reflexively using the 6 phases of reflexive thematic analysis described by Braun and Clarke (2006, 2021) which were familiarisation, initial coding, theme construction, theme review, theme definition and theme naming, and report production. Coding was original inductive and done manually, codes were grouped into candidate themes and were developed against the whole data set and the conceptual framework of the study. A reflexive journal was used by the lead analyst to challenge assumptions, while interpretations that were generated were discussed with a second researcher to enhance credibility.

3.5 Rigour and ethics

Trustworthiness was achieved by using the criteria of credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985) and by triangulating across the child's, teacher's and caregiver's accounts, describing the context of the study in detail (thick description), and keeping a record of analytic decisions (audit trail). Ethical approval was

provided by an institutional review board, and the approval from school authorities was obtained. Consent was handled very carefully, since the participants were minors with a disability: Written informed consent was obtained from parents/guardians and institutional heads, and verbal and Braille assent was obtained from the children, who were assured that participation was voluntary and could be withdrawn at any time without consequence. Details have been anonymised and pseudonyms used throughout.

4. Findings

The data was used to develop 5 themes that are interlinked. They all outline the ways in which visually impaired children in this Kerala sample learn about oral health, are pulled between dependence and independence, are influenced by institutional and family environments to either promote or inhibit practice, and are between the child and the health care worker. The themes and sub-themes are represented graphically in Figure 2 and connected to illustrative codes and the level of the health literacy framework in Table 3.

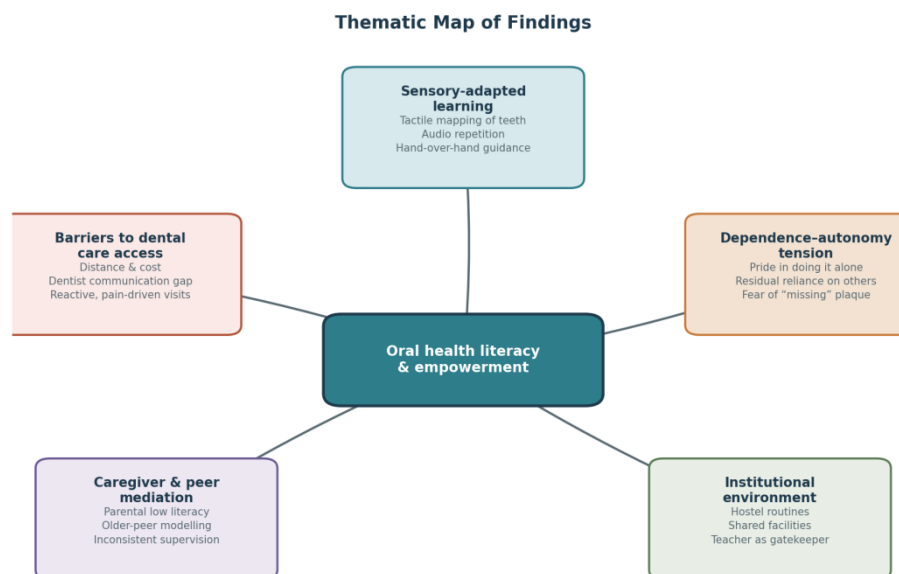


Figure 2. Thematic map showing the five main themes and representative sub-themes generated through reflexive thematic analysis.

4.1 Sensory-adapted learning

Children's learning of oral care was always described in terms of "seeing" without any mention of "seeing" with a hand-on approach. Many remembered experiencing a parent or warden holding their hand and guiding them through the brush, which created a kinaesthetic and remembered routine. Tactile reference points, the "feel" of each tooth surface, the bristles against the gum, the "feel" of a clean tooth against the tongue took the place of the visual feedback that sighted children use.

"No one can show me a picture. My teacher held my hand and moved it, up and down, round and round, until my hand learned it by itself." (Girl, 13, residential)

Children talked enthusiastically about audio instruction and tactile models and remembered the content more confidently when it was provided. Printed Braille material on oral health, however, was limited and some children had only seen a tactile model of teeth once, at a dental camp. Functional know-how (what to do and why) was mostly available, but it was dependent on memory of a single demonstration, and not on readily available and repeatable reference material.

4.2 The tension between dependence and autonomy

One common theme in the emotional aspects was the desire to take care of their oral hygiene and the uncertainty over whether they did so effectively. Older children, particularly in residential homes, talked about the pride they had in being self-sufficient; brushing, rinsing and storing their brush without assistance. But many also expressed a silent unease of "missing" places they did not check.

"I can brush by myself, fully. Only sometimes I think — did I clean the back ones? I cannot see, so I just brush them again to be sure." (Boy, 16, residential)

This tension is very important for empowerment. Children were confident of their ability to execute the behaviour (interactive level), however were unable to provide a reliable non-visual confirmation of the outcome. Some were beginning to use their own strategies to compensate for their weaker abilities, such as systematic counting or checking with their tongs, which were developed spontaneously. Children who were confident even in the absence of a trusted way of providing feedback were still

reliant on being reassured from time to time by others.

4.3 The institutional environment

The oral care program for residential children was very well designed. The fixed morning routines, common washing facilities and wardens' supervision provided consistency and several children attributed the fixed habit to the hostel. Meanwhile, the institution was also a gatekeeper; what and when the children got their teeth cleaned, as well as what was provided and how, was decided largely by the staff. Often toothbrushes and toothpaste was given together, and replacement was based on the staff's initiative not the child's judgement.

"In the hostel everyone brushes at the same time. If the warden says the paste is finished, we wait. We cannot just go and buy." (Girl, 15, residential)

Day Scholars reported on their more flexible schedules and greater autonomy. The institutional context thus allowed for functional practice and also reduced the critical dimension of health literacy, as children had little opportunity to question, choose or advocate and the conducive spaces for habit also limited the opportunity for developing agency.

4.4 Caregiver and peer mediation

Knowledge and confidence were both well mediated by social relationships. Although parents are the first teachers of oral health care, caregiver reports indicated that some parents were not well-versed on the topic of oral health and were not certain about how to teach their child, and, sometimes, well into childhood, parents brushed their child's teeth for them. This good intent substitution had the potential to create dependency. By contrast, Peers proved to

be a strong and untapped tool. In older children living in residential facilities, techniques were often demonstrated to younger children, and focus group participants freely shared tips, such as feeling the amount of paste to be used. The form of peer modelling is an organic and natural health literacy practice which institutions might do more systematically.

"The senior girls taught me how much paste — press a little on the finger first, then you know. Teacher never told me that." (Girl, 12, residential)

4.5 Barriers to dental care access

Although the health infrastructure used in Kerala is relatively good, access to professional dental care was mostly reactive and driven by pain. Only when a child's toothache was so bad did they seek the dentist's care — and not for prevention or routine review. Three barriers recurred. Firstly, distance and cost, especially for families travelling from rural areas with a child who required accompanying. Secondly, there was a communication problem: children reported that dentists talk over them to the parent/guardian, and do not explain the procedures in a manner that is accessible to them without sight, leaving them anxious but passive. Third, some caregivers' general belief that dental issues were not as dire as other health issues.

"The doctor talked only to my mother. No one told me what they were doing in my mouth. I was just scared." (Boy, 14, day scholar)

This theme depicts the boundaries of functional knowledge without critical health literacy and an enabling system. Children were aware of the existence and importance of dental care but not in a way that got them in the right seat or proactively helped them to engage in decisions about their dental care.

Table 3. Themes, illustrative codes, and corresponding level of the health literacy framework

Theme	Illustrative codes	Health literacy level emphasised
Sensory-adapted learning	Hand-over-hand teaching; tactile reference points; reliance on memory; scarce Braille material	Functional
Dependence–autonomy tension	Pride in independence; uncertainty about cleanliness; self-taught checking strategies	Interactive
Institutional environment	Fixed routines; collective supplies; warden as gatekeeper; limited choice	Functional / constrained critical
Caregiver & peer mediation	Parental low literacy; substitution of care; older-peer modelling; tip-sharing	Interactive
Barriers to dental care access	Pain-driven visits; distance and cost; dentist–child communication gap; passivity	Critical (underdeveloped)

5. Discussion

The purpose of this study was to explore the acquisition and utilization of oral information and empowerment level of VI children in Kerala. As you read through the health literacy framework (Nutbeam, 2000), the results show a clear and significant pattern: Functional health literacy is well understood and critical health literacy is mostly unheard of while interactive health literacy is emerging – but not always given equal footing. The general knowledge of children about good oral care and their ability to carry it out was consistent with the results of intervention studies which found that adapted teaching can create knowledge and skills (Sardana et al., 2019; Joybell et al., 2015). It wasn't that it was hard to know, it was hard to know, adapt, and advocate. The analytic center of the study is the dependence–autonomy tension. The children with a visual impairment were able to perform the task of brushing their teeth without assistance, but were unable to have access to an independent source of information that they could trust to verify their brushing. This is an extension of the existing Indian literature that reports poor hygiene outcomes, but not how it happens, which has been mostly quantitative (Shetty et al., 2010;

Prashanth et al., 2011). The present data indicate that there is a part of the outcome gap that is not due to ignorance, but is due to an unsupported feedback gap: children are unable to evaluate their own performance easily, and there is no reliable way for children to learn to assess their own performance in existing instruction. This suggests a specific, teachable skill: a routine for checking and disclosing the tongue or fingers that can be adapted for the non-visual domain and results in long-term and independent functional knowledge.

Results from the institutional and social findings reveal that empowerment is relational and not just individual (Sørensen et al., 2012). The dominant patterns of behavior established at hostels were inconsistent with the development of choice and voice; sometimes parents replaced their hands with the child's, reinforcing dependence; and peers provided just the sort of practical, adaptive knowledge that formal instruction did not. That older children freely share knowledge with younger children points to a potential opportunity: to implement structured peer-mentoring as a way to institutionalize interactive health literacy with minimal cost. On the other hand, the dentist–child communication

gap, that is, when the dentist spoke to the accompanying adult instead of the child, actively prevented the critical literacy and participation required for disability rights frameworks (United Nations, 2006). The findings suggest that with the simple improvement of pamphlets, empowerment will not occur; it must be the result of the interactions between institutions, families, and clinicians with the child. These findings are enhanced by the Kerala context. One would expect that in a state that has the highest literacy rate in India and fairly good health services, that visually impaired children would be relatively empowered. A low level of disability and a significant communication gap suggest that high general literacy and infrastructure do not necessarily equate to a disability-inclusive, empowerment-based oral health. It is access to information and access to clinical communication, not literacy in the abstract, that is the key consideration, in line with other evidence that the form and availability of communication, not impairment per se, are important (DeWalt et al., 2004; Nutbeam, 2000).

In a practical sense, the study-based approach changes the focus from "information delivery" to "capability building. Oral health programmes for visually impaired children should routinely and repeatedly provide tactile and audio resources; explicitly provide and teach self-assessment skills that are non-visual; formalise peer mentoring; coach caregivers to guide rather than do; and train dental professionals to communicate directly with the child and to invite participation. These are congruent with the reinforcing pathway depicted in Figure 1, in which individuals' self-care skills increase with confidence and verification, which then leads to increased understanding of and agency in further learning.

6. Limitations

There are some caveats to note. The results from this study are not statistically generalisable, but rather offer insight into how the issues could be transferred to other institutions in the same state.

Children's self-reports of practice may not have matched observed practice and the use of an adult interviewer may have resulted in socially desirable responses. Cautious transcription has smoothed out minor changes in meaning, but not removed them, between the two languages. Lastly, the study only recorded a single time snapshot and failed to be able to follow children's progress in literacy and empowerment over time. Future studies might include, in addition to observation, a follow-up with a longitudinal qualitative design and might explore sensory-inclusive, empowerment-based interventions in a wider variety of settings.

7. Conclusion

This qualitative study helps to shed light on the lived experiences of the well-documented oral health inequities among children with visual impairments. For a Kerala sample, successful oral health knowledge practices were widespread but limited, and often based on the "one-off" sensory learning of the child; the child was always seeking to do some form of oral health self-care that they did not have sight of; institutions and families supported and constrained the child's agency; and access to professional dental care was reactive and under communicated. From the health literacy standpoint, these children were at the functional and to some extent the interactive level, but the critical level for their ability to appraise, select and promote was less frequently developed. The study concludes that empowerment in oral health for visually impaired children is possible, but not guaranteed. It involves purposeful sensory-inclusive education, tactile and audio resources that can be accessed and repeated, explicit teaching of non-visual self-assessment, using peer mentoring, supportive caregiving (not substitutive), and clinicians who talk to the child and not at him. In a highly-literate, well-resourced state, it is not literacy—per se—that matters most; it is information and care that matters most. Opening up for that accessibility provides a straightforward journey from knowledge into real autonomy and voice.

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