ORIGINAL ARTICLE

Oral Health Literacy, Oral Healthcare-seeking Behaviour, and Perceived Oral Health Status of Children With Special Healthcare Needs by Their Carers : A Cross-sectional Study

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ABSTRACT

Introduction: Carers' oral health literacy (OHL) influences the oral healthcare-seeking behaviour (OHCSB) for their children with special healthcare needs (CSHCN). This study aimed to determine carers' OHL, OHCSB, and perception of CSHCN's oral health (OH) status, compare OHCSB scores across OHL levels, and examine the association between OHL levels and carers' perception of CHSCN's OH status. **Materials and methods:** The cross-sectional study involved 82 carers of CSHCN aged 3–17, selected through proportionate sampling based on determined respondent numbers per CSHCN centre and simple random sampling to select the carers. A self-administered Malay questionnaire of OHL Instrument (OHLI-M) Comprehension, OHCSB, and carers' perception of OH status was used, with face-to-face interviews for OHLI-M numeracy. Data were analysed using IBM SPSS version 26.0. Descriptive analyses were performed. One-way ANOVA was used to compare OHCSB with OHL levels. Fisher's exact test was applied to analyse carers' perceptions and OHL levels. **Results:** The OHLI-M mean (SD) score was 75.7 (13.55), with 61% at an "Adequate" level. The OHCSB mean (SD) score was 10.3 (3.18). Most carers perceived the OH status of CSHCN as "Good" (39.0%). There was no significant difference in OHCSB scores across different levels of OHLI-M (p=0.758) and between OHL and carers' perception of CSHCN's OH status (p=0.666). **Conclusion:** The carers showed good OHLI-M scores with an "Adequate" OHL level and perceived a "Good" OH status for their CSHCN. Differences between OHL and OHCSB scores and their perception may stem from various factors needing further exploration to enhance CSHCN's OH status.
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Keywords: Oral health literacy, Oral healthcare-seeking behaviour, Perceived oral health status, Children with special healthcare needs, Carers

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INTRODUCTION

Health literacy (HL) is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (1). It plays an important role in empowering people to improve their health by changing their lifestyles and living conditions (2). Healthy People 2030 places a strong emphasis on HL, particularly on personal and organisational HL. Personal HL is defined as the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others, while organisation HL is the degree to which organisations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (3). Because of its pivotal role in one's ability to recognise oral health information and act upon it, oral health literacy (OHL) is anticipated to affect how caregivers report their children's oral health status, as well as their perception and experience of oral health-related child- and family-level impacts (4).

On the other hand, healthcare-seeking behaviour (HCSB) is any action taken by individuals who believe that they have a health problem or believe that they are ill to seek appropriate treatments or solutions for their illness-being (5). Proper understanding of HCSB particularly for patients of special groups could reduce the delay in diagnosis, improve the treatment needs, and strengthen the strategies for health promotion (6). This understanding has evolved into a tool for analysing

how people engage with healthcare systems. The tool has since become a part of the larger strategy for using healthcare, which includes actions performed to prevent and treat illnesses, maintain physiological state and well-being, or gather information about one's health status and prognosis (7).

With regard to CSHCN, they are highly dependent on their carers to take care of them, especially when it comes to their healthcare and oral healthcare needs (2,8). When the carers are highly literate with good oral healthcare-seeking behaviour (OHCSB), it will benefit the CSHCN they care for, especially in terms of their oral health. In addition, parents' perception of their children's oral health status is very important. Besides physicians and nurses, parents play an important role in the paediatric healthcare delivery team, and they are in a special position to assess the care provided to their children and make decisions on behalf of these children. Parents of CSHCN reported worse oral health and fewer dental visits for their children, and disparities were found in parental perceptions and dental service utilisation between the parents of CSHCN and the parents of children in regular education (9).

However, information on OHL and OHCSB among carers of CSHCN is limited. The perceptions of carers on the oral health status of their disabled children were reported to be associated with both OHL (10,11) and OHCSB (12), which is also related to OHL level (13). Therefore, the current study was conducted to evaluate the two components namely OHL and OHCSB of carers of CSHCN, and to determine the association between OHL with OHSCB and the perception of the carers towards their CSHCN's oral health status. This study is crucial in the effort to better understand the unmet scopes of oral health for this special group.

MATERIALS AND METHODS

A cross-sectional study was conducted from May to June 2022 in Kota Bharu, the capital district of Kelantan, involving seven Community-Based Rehabilitation (CBR) centres, *Pusat Perkembangan Autisme Kelantan* (PPAK), and Special Kidz Rehab Care Centre (SKRCC). The inclusion criteria were primary carers aged at least 18 years who took care of 3–17 years old CSHCN, who were able to read, understand, and communicate in Malay language, and the family member or legal carer/guardian who was most responsible for the day-to-day decision-making and took care of the child including their general health and oral health (14). Carers with physical and mental disabilities were excluded from this study. The sample size needed for the study was calculated using PS software, based on the two proportions formula with an uncorrected chi-square test, accounting for a 30% non-response rate. The total sample size calculated for the study was 138. The proportionate sampling method was used to determine the numbers of respondents from each centre, followed by simple random sampling method to select the participants. As a result, 138 eligible carers of CSHCN from nine centres were selected. However, due to the transition period from the pandemic to the endemic phase of Covid-19, only 82 carers participated in the study.

Next, OHL was measured using the validated Malay version of the Oral Health Literacy Instrument (OHLI-M) by Ramlay *et al.* (2020) (15). The questionnaire had good validity and reliability among adults in Malaysia as it showed good internal consistency (Cronbach's alpha of 0.83 to 0.88) and excellent test-retest reliability (intraclass correlation of 0.80 to 0.86). The original Oral Health Literacy Instrument (OHLI) was developed by Sabbahi *et al.* (2009) in English (16). The OHLI-M questionnaire consisted of two components namely the reading comprehension component and the numeracy component. A self-administered reading comprehension component was delivered to the consented carers. The component included two passages on dental caries and periodontal disease. The dental caries passage contained 13 sentences with 18 test items with words omitted from the sentences, while the periodontal disease passage contained 14 sentences with 20 item words omitted. The carers were asked to choose one correct response for each test item. Four possible choices were offered for all items. On the other hand, the numeracy component, which was administered via face-to-face interview, consisted of a series of prompts: five prescription labels of medicines frequently prescribed by dentists, one dental appointment card, and one printed post-extraction instruction with 19 test items in this section. The prompts were shown to the carers, and around 1–2 minutes were given for them to read each prompt before the interviewer asked questions. The responses were recorded by the interviewer on the scoring sheet. Each correct answer was given "1" (one) mark, while incorrect or missing answers were given "0" (zero) mark. The final score for each section was the sum of all items in the respective section. The total score for reading comprehension was multiplied by 1.316 (50/38), and the total score for numeracy component was multiplied by 2.632 (50/19). This gave the weighted scores for both sections to range from 0 to 50. By summing up the weighted scores for the reading comprehension and numeracy components, the total score for OHLI-M was obtained, ranging from 0 to 100. The higher the OHLI-M score, the higher the functional oral health literacy. Then, the score was categorised into three levels of oral health literacy: Inadequate (0–59), Marginal (60–74), and Adequate (75–100) (15).

Another section of the self-administered questionnaire was the OHCSB, adopting the validated questionnaire developed by Bommireddy *et al.* (2017) (17). The reliability and validity of the questionnaire was reported as good, with Cronbach's alpha = 0.83 and split-half reliability value = 0.78 (6). The scoring of OHCSB

was based on the total score from four items and three subitems, with a minimum score of 2 and the maximum score of 15.

The last section of the questionnaire consisted of questions on the perceived oral health status of the CSHCN by the carers. The questionnaire was adopted from Divaris *et al.* (2020) (19). Three questions were adopted and translated without major changes from the original questionnaire. There were six options for the perception, which were "Excellent", "Very Good", "Good", "Fair", "Poor", and "Don't Know".

The questionnaires on OHCSB and the perceived oral health status of children by their caregivers were translated from English to Malay language following the guidelines by Beaton *et al.* (2000) (18). Initially, two independent translators who were fluent in both languages translated the questionnaires, with one was informed about the study's concept to balance the content accuracy and appropriate language use. The translations were compared, and any discrepancies were resolved, leading to a consensus on a single initial Malay version. This version was then back-translated into English by two different translators. A panel of experts in oral healthcare and linguistics reviewed the back-translation against the original English version to make any adjustments to ensure cultural relevance and conceptual equivalence. Finally, the Malay version was pre-tested on 18 public respondents for their feedback. Researchers deliberated on all versions, considering respondents' input to produce the final Malay questionnaire for the use in the research.

Statistical Analyses

The data collected from the study were keyed-in and analysed using IBM SPSS Version 26.0. Descriptive analyses were employed, with means and standard deviations (SD) or median and inter-quartile ranges (IQR) reported for continuous variables. Meanwhile, frequencies and percentages were reported for categorical variables. A one-way ANOVA was used to compare the OHCSB with the different levels of OHLI-M, while Fisher's exact test was used to analyse the association between the perception of carers and the OHL levels of carers. Statistical significance was set at 0.05. There were no missing data in the study as all variables were fully completed by the participants during data collection.

Ethical Clearance

Ethical approval for the study was obtained from the Human Research Ethics Committee USM (JEPeM-USM) with the JEPeM Code: USM/JEPeM/22010076.

RESULTS

Due to Covid-19 pandemic situation, from a total of 138 eligible carers and their CHSCN in Kota Bharu, Kelantan, only 82 carers were available, yielding a response of 59.4%.

Table I summarises the sociodemographic profiles of the carers and the CSHCN. Most of the carers were Malay (97.6%), and the majority of the carers were female (76.8%) with the mean (SD) age of 41.0 (7.93). The mean age of their CSHCN was 8.9 (4.2) years old. As for the types of disability, most of them (51.2%) who participated in this study were those who have autism, 15.9% with Down syndrome, and 9.8% with cerebral palsy.

TABLE I: Sociodemographic profile of the CSHCN and their Carers (n = 82)

Variables	Frequency (%)
Carers	
Sex	
Male	19 (23.2)
Female	63 (76.8)
Age (year)	41.0 (7.93)[a]
Age of Carers by Age Groups (years)	
18 - 27	1 (1.2)
28 - 37	34 (41.5)
38 - 47	28 (34.1)
48 - 57	17 (20.7)
58 and above	2 (2.4)
Ethnicity	
Malay	80 (97.6)
Chinese	2 (2.4)
Indian	0 (0.0)
Others	0 (0.0)
Marital Status	
Married	76 (92.7)
Never Been Married	0 (0.0)
Divorcee	2 (2.4)
Widow / Widower	4 (4.9)
Education Level	
University	30 (36.6)
Pre-university / Diploma	7 (8.5)
Upper Secondary	25 (30.5)
Lower Secondary	18 (22.0)
Primary School	1 (1.2)
Never Been to School	1 (1.2)
Type of Occupation	
Government employee	21 (25.6)
Private employee	6 (7.3)
Self-employed	14 (17.1)
Unpaid / Homemaker	34 (41.5)
Retiree	4 (4.9)
Unemployed / Not working	3 (3.7)
Monthly Household Income (RM)	2,000 (3,800)[b]
B40 (RM4,849 and below)	60 (73.2)
M40 (RM4,850 – RM10,959)	21 (25.6)
T20 (RM10,960 and above)	1 (1.2)
Number of Children	
1 - 3	47 (57.3)

CONTINUE

TABLE I: Sociodemographic profile of the CSHCN and their Carers (n = 82). (CONT.)

Variables	Frequency (%)
Number of Children	
4 - 6	27 (32.9)
More than 6	8 (9.8)
Relationship with CSHCN	
Father	19 (23.3)
Mother	61 (74.4)
Legal Carer / Guardian	2 (2.4)
CSHCN	
Sex	
Girls	21 (5.6)
Boys	61 (74.4)
Age (years)	8.85 (4.19)[a]
Age Range (years)	
3 - 6	31 (37.8)
7 - 10	24 (29.3)
11 - 14	14 (17.1)
15 - 17	13 (15.9)
Ethnicity	
Malay	80 (97.6)
Chinese	2 (2.4)
Indian	0 (0.0)
Others	0 (0.0)
Type of Disability	
Down Syndrome	13 (15.9)
Cerebral Palsy	8 (9.8)
Autism / Autism Spectrum Disorder (ASD)	42 (51.2)
Attention Deficit Hyperactive Disorder (ADHD)	2 (2.4)
Slow Learner	5 (6.1)
Mental Retardation	0 (0.0)
Speech Problem	3 (3.7)
Visual Impairment	1 (1.2)
Hearing Impairment	1 (1.2)
Others	7 (8.5)

[a]*Mean (SD) SD, Standard Deviation*
[b]*Median (IQR), IQR, Interquartile Range*

The mean (SD) of the OHLI-M scores and the distribution based on OHLI-M levels for all the participants are shown in Table II. The mean (SD) for the reading comprehension component of OHLI-M was 37.44 (5.95), and the mean (SD) for the numeracy component of OHLI-M was 38.26 (10.0). Of 82 carers, 11 (13.4%) of the participants were categorised in the "Inadequate" OHLI-M level, 21 (25.6%) were classified in the "Marginal" OHLI-M level, while more than half (61.0%) had "Adequate" OHLI-M level.

TABLE II: Mean (SD) of OHLI-M Scores and Levels of OHLI-M Among the Carers of CSHCN (n = 82)

OHLI-M	Mean (SD)
Components	
Reading Comprehension	37.44 (5.95)
Numeracy Component	38.26 (10.0)
Total OHLI-M Score	75.70 (13.55)
Levels	
Inadequate (0 – 59)	11 (13.4) [a]
Marginal (60 – 74)	21 (25.6) [a]
Adequate (75 – 100)	50 (61.0) [a]

[a] *Frequency (%)*

Table III demonstrates the mean (SD) of the OHCSB score, which is 10.3 (3.18) out of 15. From the 82 respondents, most of them had visited the dentist (89%), and 39% of them visited the dentist more than two years ago. Twenty six percent came for dental screening/ dental check-ups, while 20.7% came for multiple reasons, and 13.4% came because of toothache. Almost half of the respondents (47.6%) reported they visited the dentist once in more than one year period before the pandemic Covid-19. For the past six months, 40 carers (48.8%) had at least one dental problem. Most of them (36.6%) had multiple problems. Most respondents (41.5%), particularly those who experienced dental problems in the previous six months, had sought dental treatment. The majority of them (14.6%) had more than one treatment, with 23.2% visiting the Ministry of Health dental clinics, and 29.3% were satisfied with the treatments received.

TABLE III: OHCSB Score of the Carers Mean (SD) with minimum and maximum scores and the Responses for the OHCSB components (n=82)

Questions	Response	Frequency (%)
1.Ever visited a dentist in the past	Yes	73 (89.0)
	No	9 (11.0)
1a. Last visit to the dentist	Less than 1 year ago	19 (23.2)
	1 - 2 years ago	22 (26.8)
	More than 2 years ago	32 (39.0)
	Not applicable	9 (11.0)
1b. Reason for the visit	Dental screening / check-up	21 (25.6)
	Dental appointment	11 (13.4)
	Toothache	11 (13.4)
	For scaling	1 (1.2)
	For filling of teeth	6 (7.3)

CONTINUE

Table III: OHCSB Score of the Carers Mean (SD) with minimum and maximum scores and the Responses for the OHCSB components (n=82) (CONT.)

Questions	Response	Frequency (%)
1b. Reason for the visit	For tooth extraction	6 (7.3)
	Others / Multiple reasons	17 (20.7)
	Not applicable	9 (11.0)
1c. Frequency of going to the dental clinic before pandemic COVID-19	Once in 6-months	11 (13.4)
	Once in 1-year	23 (28.0)
	Once in more than 1-year	39 (47.6)
	Not applicable	9 (11.0)
2.Experience of dental problem in the past 6's months	Yes	40 (48.8)
	No	33 (40.2)
	Not applicable	9 (11.0)
2a. Types of dental problems experienced at that time (6 months ago)	Toothache	2 (2.4)
	Swelling	0.0
	Decayed tooth	6 (7.3)
	Missing teeth	1 (1.2)
	Food impaction	1 (1.2)
	Discoloration of teeth	0.0
	Bleeding gums / Calculus	0.0
	Loose teeth	0.0
	Mouth Ulcers	0.0
	Others / Multiple problems	30 (36.6)
	Not applicable	42 (51.2)
3.Seeking of any treatment for the problem above	Yes	34 (41.5)
	No	6 (7.3)
	Not applicable	42 (51.2)
3a. Types of treatment carried out for the problem mentioned above	Tooth extraction	9 (11.0)
	Tooth filling / root canal treatment	5 (6.1)
	Scaling	1 (1.2)
	Prosthesis	0.0
	Tooth extraction	0.0
	Orthodontic treatment	0.0
	Surgery	2 (2.4)
	Medication	5 (6.1)
	Other treatment / More than one treatment	12 (14.6)
	No treatment done	0.0
	Not applicable	48 (58.5)
3b. Place of the last dental problem treated	Ministry of Health Dental Clinic	18 (23.2)
	Ministry of Defence Dental Clinic	0.0
	University's / University Hospital's Dental Clinic	4 (4.9)
	Private Dental Clinic	11 (13.4)
	Others	0.0
	Not applicable	48 (58.5)
3c. Levels of satisfaction with the treatment received	Very unsatisfactory	0.0
	Unsatisfactory	1 (1.2)
	Not sure	0.0
	Satisfied	24 (29.3)
	Very satisfied	9 (11.0)
	Not applicable	48 (58.5)
4.Reason for not undergoing treatment for the dental problem above	Fear	1 (1.2)
	No time	2 (2.4)
	Transportation problem	0.0
	Dental clinic is too far away	0.0
	Expensive cost	0.0
	Not important	0.0
	Other reasons	0.0
	More than one reason	1 (1.2)
	Not applicable	78 (95.1)
5. Existence of current dental problem	Yes	18 (22.0)
	No	64 (78.0)
OHCSB Scores[b]		10.3 (3.18)[a]

[a] *Mean (SD)*
[b] *OHSB score*: minimum is 2 and maximum is 15

CONTINUE

Some of those carers reported that they had no time (2.4%), fear (1.2%), and 1.2% had more than one reason for not seeking treatment for the dental problems they had. When asked about the existence of current dental problem, 64 carers (78%) reported that they did not have any dental problem at the time of the study.

The perception of the carers towards their child's mouth and teeth condition is as shown in Table IV. Most of them perceived the oral health of their children as "Good" (39%), while 2.4% did not know how to perceive the condition and none perceived their children's oral health condition to be "Excellent".

Table V demonstrates the comparison between OHLI-M levels and OHCSB scores of the carers, the association between the OHLI-M scores, and the perception of the oral health status of CSHCN. There was no statistically significant difference between OHCSB scores and

different levels of OHLI-M of carers of the CSHCN, with p= 0.758. Most carers with inadequate, marginal, and adequate OHLI-M levels perceived their children as having "Good" oral health conditions at 4.9%, 11%, and 23.2% respectively. There was no statistically significant association between the OHLI-M levels of carers and their perceptions towards the oral health status of the CSHCN, with p=0.666.

Table IV : Perception on Oral Health Status of the CSHCN by Carers (n = 82)

Question	Responses	Frequency (%)
Perception of carers regarding the condition of the child's mouth and teeth	Excellent	0 (0.0)
	Very Good	7 (8.5)
	Good	32 (39.0)
	Fair	24 (29.3)
	Poor	17 (20.7)
	Don't Know	2 (2.4)

Table V : Association between different levels of OHLI-M with OHCSB and Perceived Oral Health Status of The CSHCN by the Carers

OHLI-M Levels	Frequency (%)	OHCSB Score (Max = 15)			Carer's Perception of CSHCN's OH Status Frequency (%)					*Fisher's Exact Test*	*p-value*
		Mean (SD)	*F-stat (df)*[a]	*p-value*	Very Good	Good	Fair	Poor	Don't Know		
Inadequate (0 – 59)	11 (13.4)	9.73 (3.8)			2 (2.4)	4 (4.9)	3 (3.7)	2 (2.4)	0 (0.0)		
Marginal (60 – 74)	21 (25.6)	10.62 (2.52)	0.278 (2)[a]	0.758	1 (1.2)	9 (11.0)	4 (4.9)	7 (8.5)	0 (0.0)	5.801	0.666
Adequate (75 – 100)	50 (61.0)	10.30 (3.33)			4 (4.9)	19 (23.2)	17 (20.7)	8 (9.8)	2 (2.4)		
TOTAL	82 (100.0)				7 (8.5)	32 (39.0)	24 (29.3)	17 (20.7)	2 (2.4)		

[a]*One-Way ANOVA*

DISCUSSION

Sociodemographic Characteristics of CSHCN and Carers

The current study was conducted at the CBR centres, PPAK, and SKRCC in Kota Bharu, Kelantan. The CBR centres and SKRCC were comprised of all types of disabilities, while PPAK was specific for autistic children. Almost all carers were Malays, which matched the ethnic composition of Kelantan's population to the e-census data by the Department of Statistics, Malaysia (20). Their age range was 27–58 years old, while the CSHCN were 3–17 years old. The age range and gender of the carers involved in this study were almost in the same range of caregivers in a study done by Ying *et al.* (2021), which was 21–64 years old and mostly females, indicative of the mothers as the most primary carers in terms of taking care of the CSHCN (22).

In the present study, in terms of occupation of the carers, most of them (41.5%) were unpaid/homemakers, with the majority (67.0%) of the carers having a monthly household income of below MYR 4,000 and 73.2% were under the B40 income category. This is in agreement with another study by Abduludin *et al.* (2019), where majority of the caregivers in the study of children with cerebral palsy came from the lower socioeconomic status (23). In addition, the CSHCN face greater exposure to family poverty and other adversities compared to their peers without special healthcare needs, and their parents were more likely to have difficulties with child care arrangements that required them to change jobs (24). Due to the challenges of caring the CSHCN, even though most carers of the CSHCN graduated from universities, most of them were unpaid or homemakers. This is consistent with the finding from a study by Ismail *et al.* (2022) who reported that, instead of paying for professional care, the carers chose to care for their child themselves to reduce their financial load (25).

It was similarly found that boys outnumbered girls in terms of the percentage of CSHCN based on gender in this study, a finding which was slightly higher compared to the newly registered people with disabilities in the children age group of 3–18 years old in 2019 (26). As for the type of disability of the CSHCN, most of the CSHCN (51.2%) were with autism, 15.9% Down syndrome, and 9.8% cerebral palsy, a finding which was in concordance with the statistics of highly registered type of disability in CSHCN in Malaysia, which is the learning disabilities or learning difficulties (26).

OHL of Carers of the CSHCN

In the current study, it was found that most of the carers of the CSHCN had "Adequate" OHLI M level. Fabillah *et al.* (2015) reported that 52% of carers of special needs children in Kuala Terengganu, Malaysia had "Adequate" OHLI-M level (2). Compared to another finding by Ramlay *et al.* (2020), the OHLI-M scores in the current study were quite similarly for the reading comprehension and numeracy components as well as the total scores of OHLI-M (15).

There are several factors influencing OHL, such as socioeconomic status, society and culture, and education system, which interact with the healthcare system and are related to the literacy of individuals (27). Meanwhile, OHL is an important indicator of one's dental health (15). In particular, studies have shown that lower OHL is associated with poorer oral health outcomes (28–30), such as lower dental knowledge (16,31), poor self-reported oral health issues (31,32), irregular follow-up dental visits (33), less access to dental care (16,27,30,34), and less seeking of health information (33,35).

CSHCN do not only rely on the carers for their oral healthcare, but also for their daily activities and health decisions. The difficulty in expressing their own oral health needs adds complexity to carers' responsibilities (23). This increases the carers' needs for literacy in oral and general health of the CSHCN to comprehend their unexpressed needs and demands. A study done by J.Y. Lee *et al.* (2012) suggested that knowledge enhancement can increase self-efficacy, particularly by giving people the skills they need in order to find, comprehend, and act on dental-related information. These skills may increase their capacity to handle the demands of oral health maintenance and, ultimately, result in better oral health outcomes (36).

OHCSB of Carers of the CSHCN

The mean (SD) of OHCSB score was 10.3 (3.18), with a maximum score of 15 and a minimum score of 2, as shown in Table 3. The studies by Deolia *et al.* (2020) and Bommireddy *et al.* (2017) reported OHCSB based on the positive and negative OHCSB. Both studies found that the most frequent cause for seeking care was a toothache (6,17). From their observations, oral healthcare services were elective unless there was pain (6,17). The findings differed from the findings of this study where most of the respondents visited dental clinics for dental screening/ dental check-ups.

Bommireddy *et al.* (2017) reported that nearly 45% of participants who had not sought treatment despite having oral health problems expressed the opinion that dental issues were not important enough to warrant attention (17). Furthermore, it was reported that accessibility was one of the main reasons they had chosen the facility at which they had sought care (17).

Moreover, HCSB is also greatly affected by the availability and accessibility of healthcare services. All factors associated with the OHCSB patterns of the population should be further explored in the context of the studied population and Malaysia as a whole. As reported by the Oral Health Programme, Ministry of Health Malaysia (2020), the primary oral healthcare service utilisation was around 25% and had been declining to 14.8% in 2020 due to Covid-19 pandemic (37). In Malaysia, there are still privileges of having subsidised oral healthcare by the government. On the other hand, private dental clinics are also blooming to give more choices for the people in getting dental care. For CSHCN, the accessibility to oral health services is still an undefended issue that needs a great attention especially for children with cerebral palsy who are physically disabled and have limited movements and face difficulties in mobility to access oral health services in the clinics (23). Understanding a patient's health-seeking behaviour allows assessment of their attitude towards oral health and OHCSB (6). A thorough understanding of the OHCSB of the population is essential to providing need-based oral healthcare services to them.

In the process of understanding the OHCSB, the barriers that may be faced by the carers in seeking oral healthcare for the CSHCN should also be considered. Some of the barriers, as reported by Mah *et al.* (2021), are lacking of oral health knowledge and practice among carers, challenges faced by the carers such as during the conduct of toothbrushing due to the fear, inability to keep still and lacking manual dexterity, and cooperation during dental procedures. These barriers may cause difficulties to the dental team in managing the CSHCN in the dental clinics (38). It can also be a challenge and demotivating factor for the OHCSB of the carers if these barriers are not properly addressed.

Perceived Oral Health Status of the CSHCN by the Carers

The current study found that most of the carers perceived the oral health of their CSHCN as "Good" (39.0%), while 2.4% did not know how to perceive the condition and none perceived their children's oral health condition to be "Excellent". Others perceived their CSHCN as having "Very Good" (8.5%), "Fair" (29.3%) ,and "Poor" (20.7%) oral health status.

The findings from the current study were different from the findings from a study by Kenney *et al.* (2008), where fewer CSHCN parents described their children as having "Good" (22%), while most reported the CSHCN as having "Very Good" to "Excellent" (67%) and fewer parents reported "Fair/Poor" (11%) dental health (11). The parents of CSHCN also reported more dental problems, with CSHCN aged 1–5 years old being the least likely to get preventive dental care. Children who receive dental care by the age of one year are less likely to have subsequent restorative or emergency visits (11). Without early and regular preventive services, dental care may be delayed until toothaches or abscesses require more complex and extensive treatment.

Comparing the present study to another study by Divaris *et al.* (2012), it was discovered that 29% of caregivers reported their child's oral health status to be "Good", while most (48%) of them perceived their children to be "Very Good" and "Excellent", and 23% of the caregivers reported their children to have "Fair/Poor" oral health

status (4). It was also found that the caregivers' perception of the children's oral health status may not be at par with the responsibility of determining their young children's need for dental care (4). The perception of the carers on the oral health status of the CSHCN determines the OHCSB for the oral problems of the CSHCN, despite the difficulties the carers may have in bringing the CSHCN to the dental clinics.

An early oral health visit provides an opportunity for clinicians to educate caregivers and sensitise them to the value of their children's oral health and early recognition of deleterious oral health behaviours that can be eliminated or modified before these behaviours lead to disease (4). The parents or the primary carers are the principal decision-makers for their child's oral health. In order to achieve the optimum oral health status of the CSHCN, the carers' perception regarding their children's oral health status, dental problems, and the utilisation of preventive dental care and services should be emphasised (11). Wrong perception will lead to negative OHCSB, which then directs to underutilisation of oral health services and unmet treatment needs that will worsen the oral health of these disadvantaged people.

OHL and the comparison with OHCSB

In the current study, it was found that there was no statistically significant difference between OHCSB scores and different levels of OHLI-M of carers of the CSHCN, with p= 0.758.

Health literacy has been found to be a strong predictor of an individuals' health, health behaviour, and health outcomes. Low levels of literacy have been associated with issues with the use of preventative services, delayed diagnoses of medical illnesses, poor adherence to doctor's orders, poor self-management abilities, increased mortality risks, subpar health outcomes, and high healthcare expenses (30). To some points, the health literacy levels can also have effects on health, the HCSB or the OHCSB.

As highlighted by Blizniuk *et al.* (2014), OHL and its functional aspects can be described as a group of personal competencies and aptitudes that support decision-making and knowledge acquisition in oral health (13). Hence, to increase people's knowledge about ways to prevent disease and maintain their health, as well as to increase their awareness of oral diseases, high OHL is crucial. This will eventually influence people's attitudes and behaviours in a positive direction (13), which includes the people's OHCSB. A limited number of literature has discussed the direct association or comparison of OHL and OHCSB, and even less has discussed these factors concerning CSHCN and their carers. Most literature has discussed OHL and oral health status, OHL and oral health behaviour, and OHL and oral health outcomes. Moreover, OHCSB can be concluded as one of the oral health behaviours. The scarcity of OHL information requires more research to be conducted in this area, as also highlighted by Blizniuk *et al.* (2014) (13), especially to investigate all the associated elements of OHL, including the OHCSB, particularly giving attention to marginalised population, including the CSHCN and their carers.

OHL and Perception of Carers towards Oral Health Status of CSHCN

In terms of the association between OHL and the perception of carers towards the oral health status of CSHCN, the findings demonstrated that the carers who showed "Inadequate", "Marginal", and "Adequate" OHLI-M levels perceived their children as having "Good" oral health condition at 4.9%, 11%, and 23.2%, respectively. However, there was no statistically significant difference between the OHLI-M levels of carers and their perceptions of the oral health status of the CSHCN. The findings from the current study were different from those of Kenney *et al.* (2008), which reported that fewer CSHCN parents described their children as having good to excellent dental health and reported more dental problems compared to children without such needs, despite better odds of having dental coverage and obtaining preventative dental care (11).

Due to more frequent oral infections, periodontal disease, irregularities in the enamel, moderate-to-severe malocclusion, and craniofacial birth deformities, CSHCN are more at risk of poor oral health than children in the general population. A previous study conducted among the CSHCN in Negeri Sembilan, Malaysia found that caries in the permanent dentition (D) started as soon as the permanent teeth broke through, and that caries in the primary dentition (d) was present in CSHCN as early as 2 years old (39). Overall mean dmft (decayed, missing, and filled deciduous teeth) and DMFT (Decayed, Missing, and Filled permanent teeth) indices of CSHCN in Negeri Sembilan were 2.25 and 3.12, respectively. This study showed that there was a high prevalence of dental caries among CSHCN in Negeri Sembilan, with 54.9% out of 574 CSHCN had dental caries. Another study also reported high caries prevalence in children with cerebral palsy (85.3%), hearing impaired (d = 88%, D = 85%), and Down syndrome (d = 57%, D = 74%) (39).

In terms of oral hygiene status among the CSHCN, one study reported that oral hygiene status was generally poor in the children with Autism Spectrum Disorder (ASD) (38). In addition to the problem, children with ASD refused to brush their teeth because of sensory problems, which would cause poor oral hygiene and increase caries and periodontal conditions (38). Their oral health could also be further impacted by drugs

and poor diets. However, access to dental care for their heightened need is often more compromised than access to medical care or prescription medicines (11).

In a study by Divaris *et al.* (2012) in the United States of America, it was discovered that 93% of children with clinical examination results indicating that they were healthy, had excellent, very good, or decent oral health, according to their caretakers (12). This finding reflected the levels of oral health knowledge and OHL of the caretakers in giving a more accurate perception of their children's oral health status.

The carers' perceptions regarding their children's oral health status, dental problems, and the use of preventive dental care are important in achieving optimum oral health of the CSHCN. The wrong perception of good oral health will lead to negative OHCSB, underutilisation of oral health services, and unmet treatment needs that will worsen the oral health of the CSHCN. The more accurate perception will only be achieved with high OHL associated with increased knowledge and awareness of the CSHCN's oral health.

The study has several limitations and offers suggestions for future research. One of the limitations was the use of a self-administered questionnaire that may have introduced response bias, as participants might have provided socially desirable answers or misunderstood questions. In addition, the generalisability of the findings was also limited due to the study's focus on carers of CSHCN in a specific geographical area, which may not represent the diversity of other regions. Therefore, the results may not directly applicable to broader populations. The limited number of participants recruited from CBR and disabled centres, along with recruitment challenges during the Covid-19 pandemic, further restricted the study's generalisability. Further studies with more diverse, geographically varied and larger samples are needed to enhance generalisability. Apart from that, future studies should also include oral health examinations of CSHCN to provide comprehensive assessment of their oral health status, which will better correlate carers' OHL and OHCSB with the actual oral health outcomes of the children. However, the insights gained from this study can provide evidence-based data which are valuable for understanding OHL, OHCSB, and the perception of the carers on their CSHCN's oral health status.

CONCLUSION

The carers showed with "Adequate" OHLI-M level with an acceptable mean (SD) of OHCSB score and perceived "Good" OH status of their CSHCN. The present study had some limitations and suggestions for future research. The insignificant difference between OHL and OHSB scores as well as their perception might be contributed by multifactorial reasons. Factors associated with OHCSB were not only OHL and oral health perception. Therefore, exploring the possible hindering factors and barriers that limit the utilisation of OH care services by the carers of CSHCN would be beneficial in planning the strategies to improve the oral health service utilisation by them, particularly for the improvement of oral health status of the CSHCN.

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REFERENCES

1. Ratzan SC. Health literacy: communication for the public good. Health Promot Int. 2001 Jun;16(2):207-14. https://doi.org/10.1093/heapro/16.2.207
2. Fabillah N, Mustapa N, Rohani MM, Esa R. Oral Health Literacy Among Carers of Special Needs Children in Kuala Terengganu, Malaysia. Ann Dent. 2015 Jun 30;22(1):15–20. doi:10.22452/adum.vol22no1.3
3. Centres of Disease Control and Prevention. What Is Health Literacy? | Health Literacy | CDC [Internet]. 2022 [cited 2022 Apr 6]. Available from: https://www.cdc.gov/healthliteracy/learn/index.html
4. Divaris K, Vann WF Jr, Baker AD, Lee JY. Examining the accuracy of caregivers' assessments of young children's oral health status. J Am Dent Assoc. 2012 Nov;143(11):1237-47. doi:10.14219/jada.archive.2012.0071
5. Uguru N, Onwujekwe O, Uguru C, Ogu U, Okwuosa C, Okeke C (2021) Oral health-seeking behavior among different population groups in Enugu Nigeria. PLoS ONE 16(2): e0246164. https://doi.org/10.1371/journal.pone.0246164
6. Deolia SG, Kela KS, Sawhney IM, Sonavane PA, Nimbulkar G, Reche A. Evaluation of oral health care seeking behavior in rural population of central India. J Family Med Prim Care. 2020 Feb 28;9(2):886-891. https://doi.org/10.4103%2Fjfmpc.jfmpc_990_19
7. Latunji OO, Akinyemi OO. FACTORS INFLUENCING HEALTH-SEEKING BEHAVIOUR AMONG CIVIL SERVANTS IN IBADAN, NIGERIA. Ann Ib Postgrad Med. 2018 Jun;16(1):52-60. PMID: 30254559; PMCID: PMC6143883. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC6143883/
8. Al-Khalifa K S, Alfaraj A. Oral Health Awareness and Practices of Special Needs Caregivers in Qatif, Saudi Arabia. Shiraz E-Med J. 2021;22(9):e107797. https://doi.org/10.5812/semj.107797.
9. Butani Y, Gansky SA, Weintraub JA. Parental

perception of oral health status of children in mainstream and special education classrooms. Spec Care Dentist. 2009 Jul-Aug;29(4):156-62. https://doi.org/10.1111/j.1754-4505.2009.00086.x
10. Rozier RG. Oral health in North Carolina: Innovations, Opportunities, and Challenges. North Carolina Medical Journal. 2012 Mar 1;73(2):100-7. PMID: 22860318. https://doi.org/10.18043/ncm.73.2.100
11. Kenney MK, Kogan MD, Crall JJ. Parental Perceptions of Dental/Oral Health Among Children With and Without Special Health Care Needs. Ambul Pediatr. 2008;8(5):312–20. https://doi.org/10.1016/j.ambp.2008.04.005
12. Divaris K, Lee JY, Baker AD, Vann WF Jr. Caregivers' oral health literacy and their young children's oral health-related quality-of-life. Acta Odontol Scand. 2012 Sep;70(5):390-7. PMID: 22150574; PMCID: PMC3305855. https://doi.org/10.3109/00016357.2011.629627
13. Blizniuk A, Ueno M, Furukawa S, Kawaguchi Y. Evaluation of a Russian version of the oral health literacy instrument (OHLI). BMC Oral Health 2014;14(1):1–7. https://doi.org/10.1186/1472-6831-14-141
14. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005 Jun;115(6):e626-636. PMID: 15930188. https://doi.org/10.1542/peds.2004-1689
15. Ramlay MZ, Saddki N, Tin-Oo MM, Arifin WN. Cross-Cultural Adaptation and Validation of Oral Health Literacy Instrument (OHLI) for Malaysian Adults. Int J Environ Res Public Health. 2020 Jul 28;17(15):5407. https://doi.org/10.3390%2Fijerph17155407
16. Sabbahi DA, Lawrence HP, Limeback H, Rootman I. Development and evaluation of an oral health literacy instrument for adults. Community Dent Oral Epidemiol. 2009 Oct;37(5):451-62. https://doi.org/10.1111/j.1600-0528.2009.00490.x
17. Bommireddy V, Pachava S, Viswanath V, Talluri D, Ravoori S, Sanikommu S. Oral health care-seeking behaviors and influencing factors among south Indian rural adults: A cross-sectional study. J Indian Assoc Public Heal Dent. 2017;15(3):252. http://dx.doi.org/10.4103/jiaphd.jiaphd_52_17
18. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine (Phila Pa 1976). 2000;25(24):3186–91. https://doi.org/10.1097/00007632-200012150-00014
19. Divaris K, Slade GD, Ferreira Zandona AG, Preisser JS, Ginnis J, Simancas-Pallares MA, et al. Cohort Profile: ZOE 2.0—A Community-Based Genetic Epidemiologic Study of Early Childhood Oral Health. Int J Environ Res Public Health. 2020;17(21):8056. https://doi.org/10.3390/ijerph17218056
20. Department of Statistics Malaysia. Statistic Malaysia @ a Glance [Internet]. 2020 [cited 2021 Dec 8]. Available from: https://www.dosm.gov.my
21. Ying K, Rostenberghe HV, Kuan G, Mohd Yusoff MHA, Ali SH, Yaacob NS. Health-Related Quality of Life and Family Functioning of Primary Caregivers of Children with Cerebral Palsy in Malaysia. Int J Environ Res Public Health. 2021 Feb 28;18(5):2351. https://doi.org/10.3390/ijerph18052351
22. Ahmad NA, Mohamad Kasim N, Mahmud NA, Mohd Yusof Y, Othman S, Chan YY, *et al.* Prevalence and determinants of disability among adults in Malaysia: Results from the National Health and Morbidity Survey (NHMS) 2015. BMC Public Health. 2017;17(1):1–10. https://doi.org/10.1186/s12889-017-4793-7
23. Abduludin DMA, Rahman NA, Adnan MM, Yusuf A. Experience of caregivers caring for children with cerebral palsy in accessing oral health care services: A qualitative study. Arch Orofac Sci. 2019;14(2):133–46. http://dx.doi.org/10.21315/aos2019.14.2.381
24. Abdi FM, Seok D, Murphey D. Children with special health care needs face challenges accessing information, support, and services. Child Trends. 2020;110(February):184–6. [cited 2022, June 28] Available from: https://cms.childtrends.org/wp-content/uploads/2020/02/CYSHCN-Brief_ChildTrends_February2020.pdf
25. Ismail A, Sk Abd Razak R, Suddin LS, Mahmud A, Kamaralzaman S, Yusri G. The Economic Burden and Determinant Factors of Parents/Caregivers of Children with Cerebral Palsy in Malaysia: A Mixed Methods Study. Int J Environ Res Public Health. 2022 Jan 1;19(1):475. PMID: 35010732; PMCID: PMC8744799. https://doi.org/10.3390/ijerph19010475
26. Ministry Of Women, Family and Community Development -. Laporan Statistik Kebajikan Masyarakat 2019 [Internet]. 2021 [cited 2022, January 2021]. Available from: https://www.jkm.gov.my/jkm/
27. Horowitz, A.M. and Kleinman, D.V. Oral health literacy: a pathway to reducing oral health disparities in Maryland. Journal of Public Health Dentistry. 2012 72: S26-S30. https://doi.org/10.1111/j.1752-7325.2012.00316.x
28. Kanupuru KK, Fareed N, Sudhir KM. Relationship Between Oral Health Literacy and Oral Health Status Among College Students. Oral Health Prev Dent. 2015;13(4):323-30. doi: 10.3290/j.ohpd.a33444. PMID: 25610917. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25610917
29. Holtzman JS, Atchison KA, Macek MD, Markovic D. Oral Health Literacy and Measures of Periodontal Disease. J Periodontol. 2017 Jan;88(1):78-88. https://doi.org/10.1902/jop.2016.160203

30. Baskaradoss, J.K. Relationship between oral health literacy and oral health status. BMC Oral Health. 2018;18(172). https://doi.org/10.1186/s12903-018-0640-1
31. Divaris, K., Lee, J.Y., Baker, A.D. *et al.* The relationship of oral health literacy with oral health-related quality of life in a multi-racial sample of low-income female caregivers. Health Qual Life Outcomes. 2011;9(1):1-9. https://doi.org/10.1186/1477-7525-9-108
32. Ahmed W, Ali Shah SM, Khayyam U, Sheikh T, Tanzeela, Anwer N. Measuring Oral health literacy in dental patients: Contribution towards preventive dentistry in Pakistan. J Pakistan Dent Assoc. 2018;26(4):176-180. https://doi.org/10.25301/JPDA.264.176
33. Atchison KA, Gironda MW, Messadi D, Der-Martirosian C. Screening for oral health literacy in an urban dental clinic. J Public Health Dent. 2010 Fall;70(4):269-75. https://doi.org/10.1111/j.1752-7325.2010.00181.x
34. Jones M, Lee JY, Rozier RG. Oral health literacy among adult patients seeking dental care. J Am Dent Assoc. 2007 Sep;138(9):1199-208; quiz 1266-7. https://doi.org/10.14219/jada.archive.2007.0344
35. Holtzman JS, Atchison KA, Gironda MW, Radbod R, Gornbein J. The association between oral health literacy and failed appointments in adults attending a university-based general dental clinic. Community Dent Oral Epidemiol. 2014 Jun;42(3):263-70. https://doi.org/10.1111/cdoe.12089
36. Lee JY, Divaris K, Baker AD, Rozier RG, Vann WF Jr. The relationship of oral health literacy and self-efficacy with oral health status and dental neglect. Am J Public Health. 2012 May;102(5):923-9. doi: 10.2105/AJPH.2011.300291. Epub 2011 Nov 28. PMID: 22021320; PMCID: PMC3267012. https://doi.org/10.2105/ajph.2011.300291
37. Oral Health Program Ministry of Health Malaysia. Laporan Tahunan 2020 Program Kesihatan Pergigian KKM [Internet]. 2020 [cited 2022 June 28]. Available from: https://ohd.moh.gov.my/
38. Mah RMF, Rahman NA, Adnan MM, Bakar RS. Understanding the behavioral problems and oral health status of children with autism spectrum disorder: A narrative review. Malaysian J Med Heal Sci. 2021 [Cited 2022 July 6];17(3):286–94. Available from: https://medic.upm.edu.my/upload/dokumen/2021062816070340_MJMHS_0847.pdf
39. Mokhtar SM, Jalil LA, Noor NM, Tan BC, Shamdol Z, Hanafiah HA. Dental Status and Treatment Needs of Special Needs Children in Negeri Sembilan , Malaysia. World J Res Rev [Internet]. 2016 [Cited 2022 Jan 2];2(6):64–70. Available from: https://www.wjrr.org/download_data/WJRR0206030.pdf