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Experience of Caregivers Caring for Children with Cerebral Palsy in Accessing Oral Health Care Services: A Qualitative Study

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ABSTRACT

Maintaining oral health (OH) is a serious issue in children with cerebral palsy (CP) for their inability to perform effective OH care as well as for lack of accessibility to dental services. This study explored the experience of the caregivers on accessibility towards OH facilities for their children with CP in Kota Bharu, Kelantan. A purposive sampling technique was utilised. In-depth interviews using guided questions captured with audio-recorder were conducted on caregivers of children with CP. Verbatim transcription of the interviews were reviewed with field notes, and themes were developed using NVivo software. Ten caregivers of children with CP aged 32–64 years old participated, which were mostly from low socio-economic status and low level of education. The age of children with CP in this study were between nine to 18 years old. From the ten verbatim transcripts, five themes emerged which were dental experience, family support, mobility, ability to pay and social value. The caregivers experienced both demanding and unique challenges in acquiring OH care services for their children with CP according to their experiences in obtaining OH services in Kota Bharu, Kelantan. Therefore, attentions are needed to address these problems that are hindering the access to OH facilities for children with CP.

Keywords: *Accessibility; cerebral palsy; dental; oral health; qualitative research*

INTRODUCTION

Cerebral palsy (CP) is one of the leading causes of childhood physical disability with an incidence of 2.11 per 1000 live births globally (Oskoui *et al.*, 2013). There are three major types of CP: spastic, dyskinetic and ataxic. Other than movement disorder, CP is accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and by secondary musculoskeletal problem (Rosenbaum *et al.*, 2007). The Gross Motor Function Classification System (GMFCS) is the gold-standard tool to classify the severity of CP in children based on the motor function ability of children with CP to self-initiate movement focusing on sitting, transferring and mobilising (Palisano *et al.*, 1997).

The neurodevelopmental disability that affects children with CP draws a significant challenges towards their oral health care (Dougherty, 2009). They are often associated with poor dental plaque control, oral motor dysfunction, and development of parafunctional habit as well as lack of accessibility to oral health services (Dougherty, 2009; Du *et al.*, 2010; Ruiz *et al.*, 2018). Dental decay is a burden in individuals with CP and affects at least one primary or permanent tooth (Moreira *et al.*, 2012; Diniz *et al.*, 2015). Diniz *et al.* (2015) reported that the mean caries experience among children with CP for deciduous teeth was 1.70 (3.30) and for permanent teeth was 0.70 (1.60) which were higher compared to normal children. The prevalence of gingivitis among children with CP in Riyadh, Saudi Arabia was recorded at 83.6% (Alhammad and Wyne, 2011). Furthermore, periodontal treatment need was found to be statistically significant among children with CP aged 15–18 years in Serbia (Santos *et al.*, 2010).

Maintaining good oral health of children with CP requires systematic oral hygiene practices and close supervision which eventually must be performed by the caregivers (Abanto *et al.*, 2014). Children with CP should receive their first dental consultation within six months or upon the first tooth eruption. Therefore, it is advisable for the caregivers to get early referral and routine dental check-up for these children with CP (OHD, 2004; American Academy of Pediatric Dentistry, 2012). However, caregivers with lack of oral health literacy and awareness as well as with inability to prioritise oral health need might hinder the oral health needs of their children (American Academy of Pediatric Dentistry, 2012).

Unmet oral health care need among children with CP would deteriorate their general health and quality of life (Newacheck *et al.*, 2000; Okunseri *et al.*, 2015). Even though there has been an improvement in the oral health status of Malaysians, there is still a gap in provision of oral health care amongst individual with special needs leading to highly unmet dental services yet very much needed (OHD, 2004; Tan, 2015). Therefore, this study sought to explore the experience of caregivers in accessing oral health services for their children with CP in Kota Bharu, Kelantan. Findings from this study would yield better understanding on factors that impede or promote the caregivers in getting oral health services for their children with CP.

MATERIALS AND METHODS

The present study was conducted in Kota Bharu, Kelantan which is located on the East Coast of Peninsular Malaysia. Qualitative phenomenological approach was utilised to explore the experiences of the caregivers on the accessibility towards oral health care services for their children with CP. The caregivers in the present study were the primary caregivers who provide constant and exclusive care for their children with CP (Alaee *et al.*, 2015; Resch *et al.*, 2010). The caregivers were identified through the list of children with CP who are registered with the Cerebral Palsy Research Cluster, Universiti Sains Malaysia, Malaysia. The eligible caregivers were identified based on the inclusion and exclusion criteria of this study. Hence, caregivers who were able to communicate in Malay language or English and have children with CP aged 18 years old and below were recruited. Caregivers presented and diagnosed with physical or intellectual disability were excluded from the study.

Purposive sampling technique was utilised in the present study among the caregivers of children with CP who shared common experiences in daily management of their children. This sampling technique is able to enrich the range of perspectives and provides rich descriptions of the experience that are being studied. In addition, this technique provides better understanding of the phenomenon expressed by the selected caregivers who share their common experiences intended by the study (Patton, 1990). In qualitative study, the sample size was determined by the allocated time, resources availability, and study objectives (Creswell, 2007). Williams and Jeanetta (2016) suggested that qualitative research should be concerned with gathering an in-depth understanding of the experience rather than the number of participants.

Data Collection

The caregivers of children with CP were contacted via telephone and appointment was given depending on the feasibility, availability or location that was most comfortable for the caregivers (Williams and Jeanetta, 2016). Written informed consent was obtained, and participant had the right to withdraw from the study at any time. Pseudonym was given to each of the caregivers and their children with CP for assurance of anonymity and confidentiality (Yusuf *et al.*, 2013). A face-to-face interview was conducted and socio-demographic profiles of the caregivers and their children with CP were obtained. Additionally, the Gross Motor Function Classification System (GMFCS) level of the children with CP was assessed.

In-depth interview was conducted based on the open-ended interview guide and involved probing to gather further information regarding the experiences of caregivers in obtaining oral health services for their children with CP (Boyce and Neale, 2006). The interview guide was constructed as suggested by Levesque *et al.* (2013) which included five domains that were found to be appropriate for the caregivers of the children with CP. The domains were 'ability to perceive', 'ability to seek', 'ability to reach', 'ability to pay' and 'ability to engage'. The domains were then undergone a linguistic validation process adapted from Beaton *et al.* (2000) whereby the translation process involved forward translation, synthesis, backward translation and consolidation to produce a Malay version of the interview guide. The expert review committee members involved were two dental public health specialists and a qualitative researcher expert. A pilot interview was performed on five caregivers which they were asked for their opinions, suggestions and comments regarding the interview guide. Any word in the interview guide that was difficult for the caregivers to comprehend and was inappropriately used, was probed in detail (Rosnani *et al.*, 2019). An expert review meeting was held to resolve the above issues in producing the final Malay version of the interview guide. Apart from the interview guide, additional questions were asked of the parents about their child: 'having toothache' and 'last dental visit', and their 'experience when bringing the children with CP to dental clinic' and 'opinion on dental fee'. The duration of the interviews lasted between 45–60 minutes per session. Digital voice recorder was used for each interview session. In order to enhance data interpretation, field notes were taken appropriately and carefully during the interview session (Mulhall, 2003). Recruitment of the caregiver was stopped once the data achieved saturation which gave a total of 10 caregivers participated in this study. Follow-up interview was conducted to validate the caregivers interpretations as well as served as an opportunity to probe further on any significant issues (Huang *et al.*, 2012). Ethical approval was obtained from Human Research Ethics Committee USM (USM/JEPeM/17120727) and registered with National Medical Research Register (NMRR-19-1627-49153). Data collection was conducted from 29 March to 1 May 2018.

Data Analysis

In the current study, primary data analysis was carried out simultaneously with data collection. This was beneficial to integrate the issues found in the primary analysis with the new issues in the subsequent interviews (Yusuf *et al.*, 2013). Verbatim transcription of the interviews on all audio tapes were reviewed by the research team and analysed according to phenomenological coding guidelines (Moustakas, 1994). From each transcript, quotes from the caregiver in terms of accessibility to oral health services for their children with CP were identified. Selected quotes were translated into English and translations were checked for accuracy in meaning by a research team member who is fluent in English (Huang *et al.*, 2012). Meaningful units from the quotes were underlined and assigned as codes. Themes were developed by examining the categories of codes (Creswell, 2007). NVivo 12 Pro software was used for a better overview, management, facilitation and analysis of themes, and for systematic comparisons across transcripts (Yusuf *et al.*, 2013). To ensure validity and reliability of the data analysis, all researchers independently analysed the interview transcript in generating the themes. Any inconsistency or conflicting findings were discussed and clarified among the researchers (O'Connor and Gibson, 2003).

RESULTS

Socio-demographic Profiles of Caregivers and Children with CP

In the present study, the data were saturated at the 8th caregiver, but the interview was continued until the 10th caregiver to ensure no new data emerged. The socio-demographic characteristics of the caregivers and their children with CP are as shown in Tables 1 and 2, respectively. All the caregivers were Malay with age ranging between 32 to 64 years old. The caregivers' monthly household income was in the range of RM1,000.00 and below. Moreover, none of the caregivers had tertiary education level. Their children with CP were between 9 to 18 years old predominantly with CP in GMFCS Level IV.

Factors Associated with Accessibility to Oral Health Care Services

The caregivers expressed and shared various experience relating to factors that promote or hinder them from obtaining oral health care services for their children with CP. Based on the findings, five domains emerged: dental experience, family support, mobility, ability to pay and social value. Table 3 shows examples of direct quotes by the caregivers describing hindering and promoting factors according to the five domains emerged from thematic analysis.

DISCUSSION

This study aimed to explore the experience of caregivers on accessibility towards oral health care services for their children with CP in local setting, in the state of Kelantan, Malaysia. This qualitative study was conducted mostly at the caregiver's home. The children with CP involved in the present study were between the age of nine to 18 years old and majority of them were in Group IV and V of GMFCS, which demanded assistance and were fully dependent on their caregivers. The occurrence of CP was prevalent in a more deprived socio-economic population with a large proportion of patients had cognitive impairment (Odding *et al.*, 2006). Accordingly, the present study found majority of the caregivers were from the lower socio-economic status and low education level. Furthermore, most of the caregivers have three or more children which directly incurred the total expenditure of the family thus increasing the caregiver financial burden. In addition, various studies have stated that grandmothers raising grandchildren with disabilities faced problems of respite needs, behaviours and/or language difficulties (Gallagher *et al.*, 2010; Kresak *et al.*, 2014). Various experiences related to factors that promote or hinder the caregivers from getting oral health care services for their children were shared by the caregivers during this qualitative study. Several factors were uncovered and identified during the interview sessions including dental experience, family support, mobility, ability to pay and social value.

Table 1 Socio-demographic profiles of the caregivers (n=10)

Participant†	Age (Year)	Relationship with the child	Number of children	Education level	Occupation	Monthly household income (RM)
MCP I	53	Daughter	4	Secondary school	Tailor	1,000.00
MCP II	53	Daughter	5	Secondary school	Housewife	1,500.00
MCP III	60	Son	1	Secondary school	Retiree	3,000.00
MCP IV	39	Daughter	6	Secondary school	Housewife	700.00
SCP V	32	Siblings	2	Primary school	Housewife	800.00
MCP VI	37	Son	2	Secondary school	Housewife	2,000.00
GCP VII	57	Grandson	3	Secondary school	Housewife	600.00
GCP VIII	53	Grandson	1	None	Housewife	1,000.00
FCP IX	64	Son	3	Secondary school	Self-employed	950.00
MCP X	43	Son	5	Primary school	Housewife	1,000.00

† All the names are pseudonyms; MCP – Mother of CP children, FCP – Father of CP children, GCP – Grandmother of CP children, SCP – Sister of CP children.

Table 2 Socio-demographic profiles of children with CP (n=10)

Participant†	Age (Year)	Gender	Number of siblings	Race	GMFCS
CP I	14	Female	4	Malay	Level IV
CP II	14	Female	5	Malay	Level IV
CP III	18	Male	1	Malay	Level IV
CP IV	16	Female	6	Malay	Level IV
CP V	16	Male	2	Malay	Level V
CP VI	9	Male	2	Malay	Level I
CP VII	10	Male	3	Malay	Level V
CP VIII	10	Male	1	Malay	Level IV
CP IX	17	Male	3	Malay	Level II
CP X	13	Male	5	Malay	Level V

† All the names are pseudonyms; CP = Cerebral Palsy.

Dental Experience

a) Promoting factors: pleasant dental service and dental outreach programme

Most of the caregivers had pleasant experience while utilising dental services in a public hospital and dental outreach programme in Kelantan. Effective communication is essential when dealing with the CP children because the information provided by their caregivers prior to dental appointment would greatly help in the dental management of their children (American Academy of Pediatric Dentistry, 2012). In the present study, several caregivers had encouraging experience where the dental personnel discussed with them in constructing a treatment plan and in making decision for their children. The approach empowers them and decreases the feeling of powerlessness and uncertainty among the caregivers (Suriati *et al.*, 2011).

In Malaysia, children with CP attending the Community Base Rehabilitation (CBR) centre benefit from the dental outreach program offered by the public dental clinic.

Table 3 Examples of direct quotes by the caregivers describing hindering and promoting factors according to the five domains emerged from thematic analysis.

Domains	Most commonly cited hindering and promoting factors	Quotes
	1. Dental experience	
Promoting		
Pleasant dental service	*"The dentist did the dental checkup. All the staff were nice and helpful. We received free Oral B electric tooth brush and toothpaste from the dental clinic"*	GCPVII
Dental outreach programme	*"There are visiting dentists to the community-based rehabilitation centre and they referred the patients to the dental clinic or hospital for further dental treatment if needed."*	MCP VI
Hindering		
Inability to express dental need	*"I do not know whether he experienced tooth-ache before because he is not able to speak."*	GCP VII
	"All his teeth are decayed and black in colour. He has swollen gum and smells bad in the morning."	GCP VIII
Unpleasant dental experience	*"During our last dental visit, we need to wait for about two to three hours even though there was no patient around there. When we asked the staff, they just told us to wait."*	MCP II
	"Sometimes the staff overlooked our registration on the appointment day. I was in hurry as I need to fetch my other kids at school. However, they did not call us until we asked them. I was so frustrated."	MCP IV
	2. Family support	
Promoting		
Physical support from family member	*"I help him to brush his teeth three times a day especially after meal and before he goes to bed at night."*	MCP IV
Hindering		
Unsupportive interactions among family member	*"His father and mother don't care anymore, and they have been divorced since he was two years old."*	GCP VIII
	"I'm the only siblings taking care of him, the other siblings do not want to take the responsibility."	SCP V
	"I feel difficult to take my son to dental clinic. I have to take care of my sick wife and also my other kids who are still at schooling age. My eldest son is working, and he is not able to help.	FCPIX
	3. Mobility	
Promoting		
Equipment and facility	*"We have a special wheelchair to ambulate him."*	GCP VII
Hindering		
Equipment and facility	*"I have a problem to park my car and the valet parking service provided by the hospital is always occupied."*	MCP III
Difficulty to ambulate	*"Now it's difficult. When he was 1, 2 and 3 years old, I brought him by myself for the appointment. Now he is growing and heavier, I can't lift him anymore."*	GCPVII
	'When he was at the age of less than 3 years, I was able to bring him by myself to the dental clinic. But now he has grown up that causes difficulties for me to lift him up to the clinic."	MCPI

(*Continued on next page*)

Table 3 (*Continued*)

Domains	Most commonly cited hindering and promoting factors	Quotes
	4. Ability to pay	
Promoting		
Free treatment fee and benefit from the allowance	*"She is disabled. She receives a disabled identity card that covers for her medical and dental treatment."*	MCP IV
	"We registered for a school that entitled him to receive the money allowance from the government."	MCP III
Hindering		
Financial implication	*"I'm not working and need to take care of my grandson. The expenses incurred is very high. For example, diapers cost us at about RM34 per pack and he needs three packs a month. The cost for formula milk was around RM28 per pack that at least one pack a month together with cereals are required."*	GCP VII
	"If we have to attend dental clinic, I will loss the payment for that day as I need to take leave of absence from job."	FCP IX
	5. Social value	
Promoting		
Encouraging support	*"Praise to God as our family support and understand our condition. The doctors and staff also helped us during our visit to the clinic."*	MCP X
Building social support network	*"When we met other parents with the same problems, we would be able to share our experience. We support each other so much. When our son attended the school, he knew how to socialise and play with his friends."*	MCP III
Hindering		
Stigma	*"Actually, I have accepted his condition. Sometimes I feel ashamed as other kids mock him. That is why I do not want to bring him out from home."*	MCP X

Dental check-up, oral health education programme and referral to nearby dental clinic for further treatment are routinely performed (OHD, 2004). The set-up of the special needs dentistry service in the community facilitates the delivery and provision of oral health care for those individuals with mild to moderate disabilities in Malaysia (Hamzah, 2012). However, patients with severe disabilities face more difficulties in obtaining the much-needed dental services.

Therefore, a growing demand for care among children with CP makes the home care becomes more cost-effective and is a more preferred approach by the caregivers (Genet *et al.*, 2011). Due to the advancement of portable dental equipment and increasing number of dental personnel in public sectors, dental home care seems to be feasible and realistic to be implemented widely in Malaysia (OHP, 2018). Consequently, most of the caregivers in this study agreed with the feasibility of dental home care in the future.

b) Hindering factors: inability to express dental need and unpleasant dental experience

During the interview, majority of the caregivers claimed that they were not able to identify and recognise early signs of dental problem in their children with CP. Furthermore, the children with CP in the present study were unable to communicate and express their dental need. Haak *et al.* (2009) stated that speech disorder or dysarthria was the most common communication disorders in children with CP. For instance, a participant, GCP VII, acknowledged that she was unaware if the child had ever experienced any toothache since she was unable to speak and consequently the dental caries was left untreated. Thus, as concluded by Bersell (2017), oral health literacy is important towards identifying oral health problem that lead to the accessibility to oral health services especially among the caregivers.

It was very likely that, some caregivers endured unpleasant experience while seeking dental treatment in public hospital for their children with CP. Long waiting time while attending the dental appointment was commonly reported during the interview. Additionally, some caregivers stated that dental personnel showed impatience, lack of empathy and gave unclear oral health care instructions during the appointment. This finding is supported by other studies that receiving inconsistent oral health information and lack of skill amongst dental professionals in managing children with CP would disempowered the caregivers and denied their access to proper dental care (Huang *et al.*, 2012; Ahmad *et al.*, 2015). Therefore, continuous training need to be emphasised for dental personnel in improving their communication skills, awareness and attitudes towards appreciating and respecting people with disabilities (Cumella *et al.*, 2000).

Family Support

a) Promoting factor: physical support from the family member

Most of the children with CP in this study were fully dependent on their caregivers. A study from Newcastle stated that commitment and support from caregiver's of children with CP is paramount (Lawlor *et al.*, 2006). Moreover, Resch *et al.* (2010) reported that the well-being of individual with disabilities is closely related to the well-being of the family members (Resch *et al.*, 2010). Thus, physical support from the caregiver or family member is required in performing their daily activities. Consequently, the caregivers play an important role in assisting the children with CP to perform their daily routine such as tooth brushing, feeding as well as attending dental appointment.

b) Hindering factor: lack of support from family member

In the present study, several caregivers were alone in taking care of the children with CP. One of the respondents was a grandmother of the child with CP who had to take the responsibility of caring for the child after the child's parents separated. Moreover, the other members of the family, including the siblings of this child with CP did not participate in taking care of their younger brother with CP. It is found that some parents faced challenges in getting support from their spouses. Handling children with CP is a burden for the caregiver and physical support from the spouse or other family members is extremely needed.

Some of the caregivers in the present study highlighted their burden with other commitments and responsibilities such as taking care of their ailing parents or unhealthy spouse and fulfilling other basic needs as well as other demanding daily routines. As a result, the dental need of children with CP becomes of a less of a priority for the caregivers leading to inability to access dental care services. An interesting observation is that there was no noticeable difference of experience in parenting children with CP between a father and mother, which was similar to the finding by Davis *et al.* (2010).

Mobility

a) Promoting factor: possession of assistive device and vehicle

The caregivers reported that having a mobility aid such as a wheelchair as assistive equipment device increased mobility of their children with CP. This finding is supported by Lawlor *et al.* (2006) which stated that having a wheelchair would facilitate the children to obtain dental treatment at oral health care facilities. In the meantime, caregivers who own vehicles have a great advantage in mobilising their children with CP to attend any programme at community-based rehabilitation (CBR) centre or attend hospital or dental appointment as well as fulfilling other needs.

b) Hindering factor: inability to ambulate

The caregivers have raised some issues which are concerned with the limited number of parking spaces provided by the public hospital. An inadequate parking slot dedicated for a person with disability would discourage them from attending dental appointment. This issue was in agreement with the study performed in England which reported that lack of parking facilities would disrupt the social activity of disabled child (Alaee *et al.*, 2015). Additionally, some of the caregivers in the present study faced transportation barrier while several were incapable of driving. Thus, the caregivers emphasised the importance of having support from families to help and assist them while attending dental appointment. Without the help, the appointment might need to be postponed or the dental need of the children with CP could not be met. It has been suggested that widening of doorways, installation of ramps or wheelchair lifts, addition of rails to stairs and bathrooms, improvement of signage and lighting as well as lowering the reception desk for easy access by wheelchair users could be done to assist them (Dougall and Fiske, 2008).

Ability to Pay

a) Promoting factors: free treatment fee and benefits from the financial allowance

High out-of-pocket cost of medical, dental and support service for people with complex illness was reported in Southwestern states in the United States as well as in South Australian states (Pradhan *et al.*, 2009; Resch *et al.*, 2010). In Malaysia, the children with CP who are registered with Department of Social Welfare, are entitled for medical/dental fee exemption in every public health facility (JPOKU, n.d.). Moreover, they also receive financial allowance by attending CBR programme and financial assistance in purchasing assistive devices (JPOKU, n.d.; Kamaralzaman *et al.*, 2018).

b) Hindering factor: financial implication

Providing basic essentials for children with CP place a financial implication for the caregiver (Davis *et al.*, 2010; Sukeri *et al.*, 2017). Most of the caregivers needed financial help for purchasing food or special equipment for their child with disability (Suriati *et al.*, 2011). Consistent with Suriati *et al.* (2011), the caregivers experienced financial implication in providing basic necessities such as formula milk, diapers and supplementary diet for their children with CP. During the interviews, several caregivers revealed that accompanying and attending their children with CP to their dental appointments would incur additional living cost such as for parking service and fuel for their transport. As most of the caregivers in this study were either self-employed or unemployed, with monthly household income of below than RM1,000.00, which would contribute to financial strain among them.

Social Value

a) Promoting factor: encouraging support and building social support network

The caregiver emphasised the importance of having support from the family members, relative and community in managing children with CP. In the present study, some of the caregivers had the opportunity to share their experience with other caregivers while attending their children's dental appointments. They developed friendships with other families of children with special needs. Subsequently, this will boost their confidence and the ability in taking care and managing their children with CP. Our finding is in agreement with other study where the caregivers preferred to have social support especially from other parents who have similar condition with their children (Suriati *et al.*, 2011). Hence, social resources and emotional security helped to manage and decrease the stress and worries faced by the caregivers (Alaee *et al.*, 2015).

Additionally, children with CP attending the CBR had the advantage to expose themselves to the environment and to develop basic learning skills. Cooperation with organisation or institutions supporting people with disability may facilitate and expose the caregiver in gaining dental service (Ahmad *et al.*, 2015). The Special Smiles of Special Olympics in the United States is one of the initiatives that provides comprehensive oral health care information, creating awareness and improving access to dental care especially to participating Special Olympics athletes (Ahmad *et al.*, 2015; Special Olympics, n.d.). Moreover, presence of supportive environment might alleviate the overwhelming feeling faced by the caregivers in parenting tasks, influencing coping strategies of parents and providing emotional support (Rentinck *et al.*, 2007).

b) Hindering factor: stigma

Negative attitude of strangers towards children with CP altered the choice of social activities among the caregivers. Thus, in the present study, another hindering experience of the caregiver was stigma that appears in the form of unusual attitudes by people who stared at them or were patronising. Therefore, the caregivers choose to be isolated and secluded from their surroundings. According to Huang *et al.* (2012), Taiwanese mothers of children with CP felt powerless and frustrated when they become victims of personal prejudice and stigma by the surrounding people. Furthermore, the caregivers in the current study confessed the lack of sensitivity, respect and empathy among the society members towards their children with CP. The caregivers felt helpless, socially isolated and rejected which consequently caused even more unmet needs in various aspects of their lives (Sukeri *et al.*, 2017). Therefore, supportive programme needs to be developed and established to overcome this issue and to elevate understanding of the public regarding people with disability.

It is important to note that this study was limited to caregivers from a single district of the Kelantan state on the East Coast of Malaysia. As Malaysia is a country with various ethnics, further sampling among different population groups may contribute to additional and greater insights regarding accessibility in dental services for people with disabilities. In addition, the caregivers might be having recalled bias in sharing their previous experiences, uncooperative and feeling uncomfortable during the interview. Given the nature of qualitative studies and the small number of participants, our finding cannot be generalised and does not represent all the caregivers of children with CP.

CONCLUSION

This study identified five domains of promoting and hindering factors relating to accessibility of children with CP to oral health care facility which are dental experience, family support, mobility, ability to pay and social value. Widespread oral health literacy, appropriate oral health services, better oral health outreach programme and prospect of oral health care home services are important to encourage and increase the accessibility of the caregivers to oral health care services for their children with CP. In Malaysia, most of the children with CP are exempted from medical/dental fee and benefit from various allowances which allow further accessibility to dental services. Nonetheless, highly dependent children with CP require physical support in which unsupportive interactions amongst family members jeopardise the fulfilment of their dental needs. Therefore, social support will assist the caregivers in their demanding parenting duty. On the other hand, poor social support, restriction on mobility and costly necessities could bring detrimental effects to their children's oral health need. In the meantime, poor dynamics support from the surrounding community and stigma could impair the need for dental treatment of children with CP.

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