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International Journal of Current Research
Vol. 9, Issue, 01, pp.45949-45955, January, 2017

INTERNATIONAL JOURNAL OF CURRENT RESEARCH

ISSN: 0975-833X

RESEARCH ARTICLE

PERCEPTIONS AND KNOWLEDGE OF CAREGIVERS ABOUT ORAL HEALTH CARE FOR SPECIAL CARE PATIENTS

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ARTICLE INFO

Article History:
Received 25th October, 2016
Received in revised form
06th November, 2016
Accepted 17th December, 2016
Published online 31st January, 2017

Key words:
Special Needs,
Dental Care for Disabled,
Dental Care for Chronically Ill,
Dental Health Surveys,
Oral Health.

ABSTRACT

Purpose: The purpose of this survey was to assess the perceptions and knowledge of caregivers who provide oral health care for persons with special needs (PSN) and person with medical conditions (PMC) with regards to the persons with special needs and medical conditions overall oral health care and the factors that affect provision of such care.

Methods: This 33 items item survey consisted of questions to determine the perception and knowledge of the parent/caregivers with regards to the overall oral health care of PSN and PMC. Two-hundred and thirteen parent/caregivers for PSN and PMC and currently treated at King Fahad Medical City, Riyadh participated in this study. This survey included information such as gender, age and number of years helping PSN and PMC. Responses to the questionnaire were tabulated and percent/frequency distributions for responses to each item were analyzed.

Results: The tested knowledge of parents/caregivers was moderate but the majority rated their knowledge as minimal (41.78%) and moderate (35.21%). There was correlation between the gender of caregivers and their self-rating knowledge of oral health care of PSN and PMC (p=0.0012). No correlation between how long a parent/caregiver has been helping PSN and PMC and their self-rating knowledge (P=0.09). There was no correlation of the medical conditions and tested knowledge of caregivers of oral health care of the PSN and PMC (p=0.15). Person's behavior and the level of person's disability/disease were reported as the major reasons why it is difficult to provide care for them.

Conclusions: The knowledge of parents/caregivers was moderate and most individuals who care for PSN and PMC have no formal or informal training and rated their knowledge as minimal. Reported barriers to care should be addressed by continuing education and further training.

Citation: **Marwah S. Almarwan, Faika Y. Abdelmegidand Fouad S. Salama, 2017**. "Perceptions and knowledge of caregivers about oral health care for special care patients", *International Journal of Current Research*, 09, (02), 45949-45955.

INTRODUCTION

The world report on disability estimated that around 15% of the world's population have some form of disability and 2-4% of them suffer from substantial difficulties in functioning (World Health Organization, 2016). It is estimated that 95 million (5.1%) children between 0–14 years have disabilities, of whom 13 million (0.7%) have "severe disability" (World Health Organization, 2016). The International Classification of Functioning, Disability and Health (ICF), defines disability as an umbrella term for impairments, activity limitations, and participation restrictions (World Health Organization, 2016). Some authors divide PSN into two groups: patients with developmental disabilities and patients who have systemic diseases (Pool, 1982). While other authors describe the term PSN as a wide array of physical, developmental, mental, sensory, behavioral, cognitive and emotional disabilities causing disparities to overall health (Mc Pherson, 1998 and AAPD, 2016) and PMC as those who are experiencing chronic illness and exposed to long-term medications such as; congenital heart diseases, leukemia, epilepsy and diabetes mellitus who as well face challenges in maintaining overall health (Dhanuthai, 2009 and Bhateja, 2012). Both categories are at greater threat for devastating poor oral health due to oral infections, periodontal diseases, enamel irregularities, malocclusions, craniofacial birth defects and certain

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medications (Foster, 2005 and Walton, 2000). They also have a greater hazard of developing oral disease because of unfavorable oral hygiene as a result of their medical conditions and associated side effects (Dougall, 2008).Moreover, dental treatment under general anesthesia did not differ for both groups.[10]However, compliance was reported as the greatest difference between patients with systemic diseases compared to those with developmental disabilities where the later were able to cooperate much less (Pool, 1982). An awareness of parents/caregivers perceptions toward their children's oral health care, dental problems, and having preventive dental care is crucial. The perceptions and knowledge of parents/caregivers may have an influence on the preventive care and treatment choices (Jokovic, 2003; Talekar, 2005 and Pahel, 2007). Parents/caregivers focus on the medical treatment of the individual inevitably forgetting about the oral health care which if neglected could have deleterious effect such as acute dental infection with possible life threatening conditions (Parry, 2000). Therefore, it is paramount for parents/caregivers to have satisfactory knowledge regarding oral health care of PSN and PMC (Cetinguc, 2004). Providing oral health care for PSN and PMC requires parents/caregivers to have a good knowledge and accommodative environment to manage them properly, effectively and efficiently at home with high level of care. Oral health care education for caregivers resulted in improvements in the individual' oral health and improved oral health care knowledge and attitudes of caregivers (Frenkel, 2001 and Frenkel, 2002). Parents and caregivers of PSN and PMC should be familiar with all aspects and issues of oral health care to be able to efficiently and effectively manage and improve oral health care of PSN and PMC. A study indicated that individualized needs assessment and education should be provided to address the needs in relation to caregiving (Chien, 2013). There is a deficiency of published research on disability and caregiving. Though, such research is significantly required to organize for proper planning and effective implementation of primary prevention strategies including at home care (Al-Jadid, 2013 and Anderson, 2007). Understanding perceptions and knowledge of individuals who provide oral health care for PSN and PMC would help address factors that motivate these perceptions, improve their knowledge, and overcome barriers that they encounter while providing oral health care. Parents, caregivers and individuals who care for PSN and PMC have an important role in caring for and making decisions about their oral health needs. So, understanding the needs of individuals who care for PSN and PMC is vital in providing necessary support to lessen caregivers' burden. Few studies are available to describe perceptions and knowledge as well as factors affecting provision of oral health care of individuals who deliver oral health care for PSN and PMC. Therefore, the purpose of this cross sectional survey was to assess the knowledge, perceptions and factors affecting oral health care of parents/caregivers who provide oral health care for PSN and PMC.

MATERIALS AND METHODS

This cross-sectional investigation and questionnaire were approved by the Ethical Committee of Human Studies at College of Dentistry Research Center, King Saud University and informed consent was obtained from the parents or legal guardian before the start of the investigation. Participants of this study were a convenience sample of 213 legal guardians or parents who were recruited from patients visiting the Pediatric Hospital at King Fahad Medical City (KFMC), Riyadh, Saudi Arabia. Patients and their parents/caregivers who are seen in KFMC come from different regions in Saudi Arabia to get comprehensive treatment. The power calculation of the sample size when number of participants' equal 200 was 84% and standard deviation 1. Inclusion criteria included Saudi parents or legal guardians of children of both genders ages 7-19 who were diagnosed with medical conditions (PSN and PMC), currently under treatment at KFMC and signed consent form by parents or caregivers. The diagnose of each medical condition was confirmed through review of the patient's medical file. No attempt was made to divide the medical conditions into PSN and PMC. The study data were collected using a validated questionnaire with attitudinal items related to different aspects of oral health care of PSN and PMC. The survey included definitions of PSN and PMC. The questions were created based on reviews of the pediatric dentistry and general dental literature. The validity of the questionnaire was reviewed and tested by three practitioners and modifications to the questionnaire were made based on their review. Also, the survey was pilot tested for test-retest reliability and clarity of the questionnaire by randomly selecting 15 from the target participants who were not included in the main study. Accordingly, revision of the questionnaire was performed to avoid misinterpretation of the questions.

This self-administered structured questionnaire was filled by the parents or caregivers. The questionnaire was composed of 33 items. Parents and caregivers were supervised whilst undertaking the questionnaire. Assistance in completing the questionnaire was offered when needed by offering a structured interview with uniform prompts. The survey consisted of biographical questions such as gender, age, whether parents/caregivers have formal and informal training in the field of oral health care of PSN and PMC, perception and knowledge of oral health care of PSN and PMC, the number of years helping PSN and PMC, and general knowledge regarding oral health care of PSN and PMC. Other questions for parents/caregivers such as what are the major reasons why it is difficult to provide oral health care for PSN and PMC and what would improve your ability to provide oral health care for PSN and PMC were included in the survey. Data were collected, entered in the SAS V 9.3 and analyzed for frequency distributions for responses to each item. Chi-square tests and nonparametric Wilcoxon rank-sum tests were used to analyze the data. Analysis was completed to determine if there were any correlation between how long the caregiver has been helping PSN and PMC and their self-rated knowledge. All statistical analyses were established with a significance level of $p<0.05$.

RESULTS

Of the 213 participants 76.06% (n=162) were mothers, 20.66% (n=44) were fathers and 3.29% (n=7) accounted for others (sister, brother, uncle, and aunt). The majority of the participants were female77.93% (n=166) while male participants being 22.07% (n=47). There was correlation between the gender of caregivers and their self-rating knowledge of oral health care of PSN and PMC ($p=0.0012$). The ages of parents and caregivers were distributed as follows: 6.10% (n=13) between the ages of 19-25 years, 46.95% (n=100) between the ages of 26-35 years, 37.09% (n=79) between the ages of 36-45 years, 8.92% (n=19) between the ages of 46-55 years and0.94% (n=2) more than 55 years.

There was no correlation of the age of caregivers and their knowledge of oral health care of PSN and PMC (p=0.52). The age ranges of the PSN and PMC who were taken care of were between7-10 years{78.40% (n=167)} and11-19 years {21.60% (n=46)}.Most of caregivers/parents 99.53% (n=212) did not receive formal training in the area of oral health care of PSN and PMC, whereas 10.33% (n=22) had received informal training. Of those who had informal training reported that the instructions were mainly from television programs, radio, magazines, newspapers, Internet websites, dental clinics, dental hygienists as well as treating physicians and dentists. The knowledge of caregivers/parents was moderate as the incorrect answers to the 20 questions of knowledge were only 30% or less in 10 questions (Table 1).

medical conditions is presented in Table 2. The most medical conditions were diabetes 16.43% (n=35), cerebral palsy 11.74% (n= 25), autism spectrum disorder 10.80% (n=23), and Down syndrome 8.45% (n=18). There was no correlation of the medical conditions and knowledge of caregivers of oral health care of the PSN and PMC (p=0.15).Table 1 shows the percent and frequency of the incorrect answers of all the questions which reflected knowledge of the caregivers/parents. The highest incorrect answers were 76.06% (n=162) and 72.30 (154) and were reported when the participants were asked the questions "You should begin to brush the child's teeth at age 3" and "Children who do not eat/drink food through their mouth do not need to have their mouth/teeth cleaned twice a day" respectively.Attending regular dental check-ups for PSN

Table 1. Percent and frequency of the correct answers of all the questions which reflect knowledge of the caregivers

Questions	Incorrect Answer Percent (Frequency)
You should begin to brush the child's teeth at age 3	76.06 (162)
You should clean the child's teeth at least twice a day	6.57 (14)
Every child should visit the dentist by age 1	35.21(75)
Oral habits such as tongue thrusting can be damaging to teeth	15.49 (33)
If a baby tooth is knocked out, you should place it back in the socket as soon as possible	25.35(54)
GERD (Gastro-Esophageal Reflux disease) can lead to erosion of teeth	29.58 (63)
An abscessed tooth will not spread infection throughout the body	59.15 (126)
Medications can be a source of bad breath	33.80 (72)
Dry mouth can contribute to tooth decay and gum disease	17.84(38)
Some medications can lead to gingival hyperplasia (overgrowth)	30.52(65)
Bruxism (grinding of teeth) can lead to headaches, muscle spasms, and shoulder pain	31.92 (68)
Only waxed floss can clean between the teeth where a toothbrush cannot reach	14.55(31)
Children with asthma should not rinse after having a breathing treatment or using an inhaler	57.28 (122)
Children who do not eat/drink food through their mouth do not need to have their mouth/teeth cleaned twice a day	72.30 (154)
Electric toothbrushes and flossers may improve oral hygiene	33.33 (71)
Babies should be weaned from a bottle by 12-14 months of age	61.03 (130)
It is good to give the child a juice in sippy-cup all day	69.01 (147)
Does milk have sugar in it?	28.64 (61)
Cavities in primary (baby) teeth can harm permanent teeth	26.76 (57)
health practices should begin as soon as the teeth are present in the mouth	23. 00 (49)

Table 2. Percent and frequency of the medical conditions of the PSN and PMC

Medical Condition	Percent (Frequency)
Diabetes	16.43 (35)
Cerebral palsy	11.74 (25)
Autism spectrum disorder	10.80 (23)
Down syndrome	8.45 (18)
Blood disorders	7.04 (15)
Attention deficit hyperactivity syndrome	6.57 (14)
Global developmental disorder	6.57 (14)
Other syndromes	5.16 (11)
Cerebral palsy with other medical conditions	4.23 (9)
Epilepsy	3.76 (8)
Renal diseases	3.76 (8)
Cardiac diseases	3.29 (7)
Global developmental disorder with other medical conditions	2.82 (6)
Autism spectrum disorder with other medical conditions	2.82 (6)
Craniofacial anomalies	2.35 (5)
Seizures disorders	1.88 (4)
Liver diseases	1.41 (3)
Epilepsy with other medical conditions	0.94 (2)

The majority of caregivers rated their knowledge of oral health care of the PSN and PMC as minimal 41.78% (n=89). While 35.21% (n=75) rated their knowledge as moderate, 5.63% (n=12) rated as extensive, and 17.37% (n=37) did not rate their knowledge (left this question blank). The duration caregivers/parents spent taking care of their PSN and PMC were as follows: less than 5 years {58.22% (n=124)}, 6-10 years {30.52% (n=65)}, 11-20 years {10.33% (n=22)}, and more than 20 years {0.94% (n=2)}. There was no correlation between how long a caregiver/parent has been helping PSN and PMC and their self-rating knowledge of oral health care (P=0.09).Distribution of the percent and frequency of the

and PMC was reported by caregivers/parents as beneficial, realistic, pleasant, and easy by 50.23% (n=107), 18.31% (n=39), 5.16% (n=11), and 1.88% (n=4) respectively. While 14.55% (n=31), 7.51% (n=16), 1.41% (n=3), and 0.94 (n=2) reported that attending regular dental check-ups for PSN was unpleasant, difficult, worthless, and unrealistic respectively. Brushing teeth of PSN and PMC was reported by caregivers/parents as beneficial, easy, relaxing, rewarding, and fast by 67.61% (n=144), 10.33% (n=22), 4.23% (n=9), 3.29% (n=7), and 0.47% (n=1) respectively. While brushing teeth of PSN and PMC was reported by caregivers as frustrating, impossible, and time consuming by 6.10% (n=13), 5.16%

(n=11), and 2.82% (n=6) respectively.Table 3 list the major reasons reported by the caregivers/parents for the difficulty in providing oral health care for PSN and PMC. The person's behavior {38.50% (n=82)} and the level of person's disability/disease {36.62% (78)} were reported as the major reasons why it is difficult to provide oral health care for PSN and PMC. The answer to the question "What improves your ability to provide oral health care for PSN and PMC?" is presented in Table 4.

Table 3. Percent and frequency of the major reasons why it is difficult to provide oral health care for PSN and PMC

Major reason(s) why it is difficult to provide oral health care for PSN and PMC?	Percent (Frequency)
None	5.16 (11)
Level of person's disability/disease	36.62 (78)
Person's behavior	38.50 (82)
Lack of proper equipment or products	6.57 (14)
Experience, training and comfort level	11.27 (24)
Other	1.88 (4)

Table 4. Percent and frequency of what improves the ability of caregivers to provide oral health care for PSN and PMC

What improves your ability to provide oral health care for PSN and PMC?	Percent (Frequency)
Further training	28.17 (60)
Continuing education related to oral health care for PSN and PMC	46.95 (100)
Further education	9.86 (21)
Having equipment or products designed for PSN and PMC	14.08 (30)
Other	0.94 (2)

Almost half of the participants {46.95 (100)} reported that continuing education related to oral health care for PSN and PMC and further training {(28.17% (60)} would improves their ability to provide oral health care for PSN and PMC.The responses to the question "How likely do you believe that the child's oral health is positively impacted by daily brushing", were very unlikely for 12.68% (n=27), unlikely for13.62% (n=29), neither likely nor unlikely for 39.44% (n=84), likely for 2.82% (n=6), and very likely for 31.46% (n=67). These answers indicate that most of the caregivers/parents did not agree that brushing daily would have a positive impact on oral health which is the correct answer. The majority of caregivers/parents answered yes {90.61% (n=193)} to the question "If you were provided information regarding oral health care for PSN and PMC, will it change how you care for the child's teeth at home?" The caregivers/parents answered the question "Do you feel that a training DVD with information regarding oral health care for PSN and PMC would be informative and helpful?" By agree in 53.52% (n=114), strongly agree in 38.97 % (n=83), strongly disagree in 2.35% (n=5), disagree in 1.41% (n=3), and neither agree nor disagree in 3.76% (n=8).

DISCUSSION

Many PSN and PMC for one reason or another are not able of independent oral health care and rely on parents or caregivers to deliver the essential oral hygiene. Therefore, the purpose of this survey was to accomplish better understanding and collect data of the perceptions and knowledge as well as factors affecting oral health care of individuals who provide oral health care for PSN and PMC. Such information would be useful in developing optimal ways to effectively educate individuals who provide oral health care for PSN and PMC. In the present study, the survey included definitions of PSN and PMC. It is important to define such terms in each study to be able to interpret data accordingly. Using a uniform definitions of disability such as the one for the ICF, can permit comparing data from national and international research (Pool, 1982). The US Maternal and Child Health Bureau's Division of Services to Children with Special Health Care Needs has recommended availability of information for families of PSN (Anderson, 2007). Parents and caregivers play a crucial part in the care of PSN (Tung, 2007). Therefore, training and teaching parents and caregivers should become a typical approach for care during the first year.[17] Oral health care education for caregivers resulted in improvements in clients' oral health and improved oral health care knowledge and attitudes of caregivers (Franke, 2016 and Frenkel, 2002). A study investigated several variables including caregiver's educational level and reported reasons why some service requests were not satisfied concluded that PSN have less access to health facilities and services as their caregivers and parents do not recognize or know the need for those services and recommended that an educational part in the form of information and facts at the family level may be an applicable and proper reaction (Porterfield, 2007). Therefore, it is important to teach parents and caregivers how to create a tailored and personalized routine for oral care, considering the amenities available to them, the best time of day to provide the service, the suitable preventive procedures and support as well as variations required to minimize the effect of the person's impairment has on handling their oral hygiene (Frenkel, 2001 and Frenkel, 2002). It is important to note that 96% caregivers consider oral health care is necessary but only 11% of them put oral care into practice on a daily basis (Atsushi, 2003). The term informal caregiving means providing help and assistance to a family member or a friend in a nonprofessional, usually unpaid, part to care and support the capability of an individual to remain at home in the community for as long as possible (McGuire, 2007). Informal caregiving is a part of the infrastructures of health services (Carter, 2016; Talley, 2007 and Schulz, 2004). It is estimated that 16% to 30% of Americans provide informal care (Informal caregiving, 2016). The consequence of poor oral health to general health and costs of health care, oral health practice by caregivers at home is a major factor in dental, oral and general health care which reflect on the quality of life and costs of health care (Ferguson, 2009. The final target is for the health professionals including physicians and dentists as well as caregivers to cooperate with an integrated and combined approach to prevent oral diseases and improving overall health and quality of life for PSN and PMC.The results of the present study showed that most of caregivers were of mothers (76.06%) 26-35 years old, which indicate the importance of teaching them. This is consistent

with another study in Saudi Arabia which showed importance of the knowledge of the mouthers in home care of Down syndrome children and recommended improvement of the deficiency of knowledge among caregivers at different educational levels (Al-Johara, 2006). On the other hand, fathers accounted for 20.66% of the participants in this study and there was correlation of the gender of caregivers and their self-rated knowledge of oral health care of PSN and PMC. Therefore, it is very important to instruct parent for oral hygiene procedures (Arnrup, 1993). In this study, most of the caregivers (99.53%) did not receive formal training in the field of oral health care of PSN and PMC while only 10.33% had received informal training which is inadequate for the caregiver knowledge regarding oral health care of PSN and PMC. This emphasize the importance of lack of informal training as well as formal training which should be implemented through regular visits to the dentist and other possible approaches. The importance of implementing formal training is in agreement with another study which stressed that caregivers should acquire and improve their oral health care knowledge from dental staff through regular dental visits (Murshid, 2005).In the present study, most of the caregivers/parents (58.22%and30.52%) were taking care of the children for less than 5 years and 6-10 years respectively. Conversely, 10.33% and 0.94% of the caregivers/parents were taking care of the children for 11-20 years and more than 20 years respectively.

However, there was no correlation between how long a caregiver has been helping PSN and PMC and their self-rating knowledge of oral health care. In the present study, the majority of caregivers rated their knowledge of oral health care of the PSN and PMC as minimal (41.78%) and moderate (35.21%). Only 5.63% rated their knowledge as extensive. Majority of caregiver (76.06%) answered incorrectly to the question: you should begin to brush your child's teeth at age 3. This is does not follow the recommendation that brushing should be started no later than the time of eruption of the first primary tooth (Guideline on infant oral health care, 2015). Only64.79% of caregivers agreed that every child should visit the dentist by age one year. This is in agreement with the recommendation that the initial visit to the dentist should be by 12 months of age (American Academy of Pediatric Dentistry, 2011). It should be noted and emphasized to the caregivers about the significance of oral health and establishment of oral preventive care as early as possible (American Academy of Pediatrics, 2008). About 25.35%, 59.15% and 69.01% answered incorrectly to the questions; if a primary tooth is knocked out, you should place it back in the socket as soon as possible, an abscessed tooth will not spread infection throughout the body and it is good to give the child a juice in Sippy-cup all day respectively.

All these aforementioned questions were answered wrong indicating lack of knowledge about oral health care (McDonald, 2011). Caregivers need to know appropriate techniques of brushing teeth, behavior modification, as well as diet and dental visits (Murshid, 2005). Approximately 30.52%, 61.03% and 26.76% answered incorrectly to the questions: some medications can lead to gingival hyperplasia (overgrowth), babies should be weaned from a bottle by 12-14 months of age and cavities in primary (baby) teeth can harm permanent (adult) teeth respectively. Caregivers need to know about the effect of different categories of medications on oral health; bad breath, dental caries, gingival overgrowth, and stomatitis (Foster, 2005). In the present study, attending regular dental check-ups for PSN and PMC was reported as beneficial, realistic, pleasant, and easy 50.23%, 18.31%, 5.16%, and 1.88% respectively. While 14.55%, 7.51%, 1.41%, and 0.94 reported that attending regular dental check-ups for PSN and PMC was unpleasant, difficult, worthless, and unrealistic respectively. Children who receive preventive oral measures from parent by the first birthday are less expected to have future restorative or emergency visits compared with first visit at age 2-3 years (Savage, 2004). More knowledge regarding dental care is needed with respect to the importance of regular dental visits (AL-Hussyeen, 2006). In the present study, the major reasons reported by the caregivers for the difficulty in providing oral health care for PSN and PMC were the person's behavior (38.50%) and the level of person's disability/disease (36.62%). Difficulties are encountered when caregivers or parents do the brushing of their children and there is lack of training about controlling the behavior of the children (Murshid, 2005). It is imperative for the dentist to focus on all possible preventive approaches and provide appropriate dental education to caregivers and parents of PSN and PMC particularly regarding oral hygiene care (Altun, 2010). Almost half of the participants (46.95%) reported that continuing education related to oral health care for PSN and PMC and further training (28.17%) would improves their capability to provide oral care for PSN and PMC. The perceptions of parents have a major influence on preventive care and treatment (Jokovic, 2003; Talekar, 2005 and Pahel, 2007). More studies should be conducted for the sake of improving parents and caregivers' perception and knowledge not only in Saudi Arabia but all over the world.

It would be beneficial if more hospitals in different cities of Saudi Arabia are included in future studies. It should be noted that the role of parents and caregivers' beliefs might impact their perceptions of need for oral health care (Andersen, 1995). In addition, educational level of parents and caregivers was another influencing factor that was important and consistent with the health care utilization model including predisposing, enabling, and need factors (Andersen, 1995 and Hughes, 2008).A study reported that parents in the rural areas may have lesser perception of a need for oral care especially preventive measures for PSN than parents in the urban areas (Skinner, 2006). Understanding the belief, perceptions, and knowledge of caregivers and parents may clarify why PSN and PMC do not receive preventive oral health care at home up to the required level (Andersen, 1995). Also, with this understanding, perhaps a plan can be created to improve the belief, perceptions, and knowledge of individuals who provide oral health care for PSN and PMC. Parents and caregivers should be educated about prevention of oral disease in children at an early age (Sharifa, 2012). It has been reported that, in terms of preventive dental care, some PSN particularly those with more complex PSN were more likely to receive only non-preventive care and not receiving any preventive dental care services (Iida, 2010). This may be because preventive dental care is not prioritized or provided in a timely manner for PSN, particularly when a family is faced with other demands related to its child's medical condition (Iida, 2010). Further efforts in providing the proper equipment, products, continuing education, and training to caregivers of PSN and PMC should be a priority as the number of PSN and PMC continues to rise and the presence of oral disease remains evident along with the barriers which hinder their proper care. Caregivers are tense and require patience and understanding to perform their job.

A study reported that autism is accompanied with tension and stress for parents and caregivers of the affected child and the burdens placed by the disability add to a greater overall incidence of anxiety among them (Almansour, 2013). Similarly, a study in the United Kingdom recognized influence upon families as key subjects in caring for a child with an intellectual disability (Willingham-Storr, 2014). Also, a study reported poor quality of life in epilepsy patients and some caregivers were vulnerable and at risk and need assistance (Ohaeri, 2009). The results of this investigation should be considered with some limitations. The findings of this study are restricted by the research design and setting which may affect generalization to a larger group of caregivers' population. However, the results may highlight in general the perceptions and knowledge of caregivers which may be beneficial in Saudi Arabia and other parts in the world. Also, in this study no attempt was made to differentiate between PSN and PMC and collected data was by self-reporting and therefore it was subject to recall bias which may include intentional deception and poor memory. Moreover, participants may or may not have answered questions about their perception and knowledge regarding practicing of oral health care honestly and the difference in backgrounds of the participants may have played a role in answering the questions. No attempt to identify the caregiver's educational level and this may result in the bias of the response from participants who had greater confidence in their understanding and knowledge regarding oral health care for PSN and PMC. Also, although the biographical information of participants was recorded, they were not randomly selected but were interested to contribute and participate in the study as well as satisfy the inclusion criteria. Another limitation is that the questionnaire does not permit determination of the reasons for variations in participants' perception and knowledge.

Conclusions

Within the methodology of this investigation, it can be concluded that the tested knowledge of parents/caregivers was moderate. Most individuals who care for PSN and PMC have no formal or informal training and rated their knowledge as minimal. Person's behavior and the level of person's disability/disease were reported as the major reasons why it is difficult to provide oral health care for PSN and PMC. Reported barriers to care should be addressed by continuing education and further training. No correlation between how long a caregiver/parent has been helping PSN and PMC as well as the medical conditions of PSN and PMC and self-rating knowledge of oral health care of caregivers/parents. There was correlation of the gender of caregivers and their self-rated knowledge of oral health care of PSN and PMC.

Acknowledgement

The authors would like to thank the College of Dentistry Research Center and Deanship of Scientific Research at King Saud University, Saudi Arabia for funding this research project.

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