UNIVERSITI TEKNOLOGI MARA

A QUANTITATIVE AND QUALITATIVE STUDY ON THE ORAL HEALTH KNOWLEDGE, ATTITUDES, PRACTICES AND PERCEIVED BARRIERS FACED BY CAREGIVERS OF INDIVIDUALS WITH SPECIAL NEEDS IN SELANGOR

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Dissertation submitted in partial fulfilment
of the requirements for the degree of
Doctor in Special Care Dentistry

Faculty of Dentistry

July 2024

ABSTRACT

Caregivers play an important role in the quality of life of individuals with special needs (IWSN). Therefore, understanding caregiver's knowledge, attitudes and practices including challenges is vital to improve health outcomes. This research aimed to investigate caregivers oral health knowledge, attitudes and practices (KAP) for themselves and their IWSN, determine the current and preferred methods of oral health education and explore the barriers caregivers face in Selangor. Data was collected from 1 community-based rehabilitation centres in each of the 9 districts in Selangor. This 2-part study consisted of a quantitative portion (validated bilingual-questionnaire on the oral health KAP (caregiver and IWSN) and information on methods of learning caregivers have used and preferred methods. Open-ended questions discussing dental services provision to IWSN was also explored. In the qualitative portion, focus group discussions involving 3 to 5 participants, was done where barriers faced by caregivers were discussed until saturation was achieved. The data was then analysed statistically (quantitative) and thematically (qualitative) to interpret findings. Results of the quantitative study achieved 71% (n=195) of the intended sample size. Sociodemographic findings showed that majority of participants had good oral health knowledge and practices but poor attitudes. In this study, females performed better than males in all three KAP aspects. Malay participants had statistically better knowledge scores than Chinese participants while caregivers caring for more than 5 years had significantly better attitude scores than those caring for shorter periods. Oral health practices for the IWSN were not ideal with shorter periods of brushing but inappropriate timing secondary to uncooperative behaviours, communication issues and gingivitis and halitosis. As for methods of learning, most practiced trial-and-error followed by training from the centre. Also, majority or caregivers felt training was necessary and preferred audio-visual and practical means. From the open-ended questions, themes derived pertaining to the dental services for IWSN discussed issues with healthcare services, accessibility and awareness of the community to these dental services for IWSN. As for recommendations, caregivers suggested specific facilities at hospitals, treatment at the centres by special care dentists as well as schemes for treatments to be done in private facilities, financial aid for the unseen cost of dental treatment like transportation and better training for undergraduate dentists to be willing and equipped to manage IWSNs. As for results of the thematic analysis, 32 participants were involved in the focus group discussions and the main themes identified were related to healthcare services both from the infrastructure and staff, support systems like family, government, within the centre from the community, caregivers' personal factors like stress and guilt, and IWSN's behaviour issues. From the results of the study, statistical significant findings related to gender were noted for KAP due to the prevalence of women in caregiving roles. As for knowledge, Malays performed better due to the lack of practice of the Malay language in lower income Chinese communities. Poor attitudes of caregivers were related more to a lack of symptom and time which was secondary to the burden of care. Most barriers experienced pertained to the lack of preparedness of healthcare facilities and staff as well as social support which worsens anxiety of mortality and guilt ultimately, impairing health of caregivers conclusively effecting the IWSN negatively.

Keywords: barriers, caregivers, IWSN, oral health knowledge, attitudes, practices

ACKNOWLEDGEMENT

All praises be to Allah SWT for giving me the opportunity to go into this field and perform a study near and dear to me. My faith has kept me going even when there seemed to be too many obstacles and I am forever better for it. I would like to firstly thank my mother and late father, and the late Omar Khattab Khan, for always believing in me and praying for me. They have been my strongest cheerleaders and always kept me centred. For that I am ever so grateful. Specifically, to Papadom, I will always be your chellam and carry you with me in every chapter of my life.

I would like to express my deepest gratitude to my supervisors, AP Dr Mas Suryalis and Dr Nawwal Alwani for giving me the guidance and support I needed. This row of strong, successful, and intelligent women kept me on track, motivated and were amazing role models. It has been and honour and privilege to would under them. Special thanks to my initial co-supervisor, AP Dr Ilham Wan Mokhtar, for her contributions to the study and continuous support for me and this study.

My highest appreciation goes to the former Dean of the Faculty of Dentistry, Universiti Teknologi MARA, Professor Dato Dr Mohamed Ibrahim Abu Hasan for giving me this opportunity to pursue my specialist training in-house because of my familial obligations. To the current Dean, Professor Dr Aida Nur Ashikin, thank you for always supporting my postgraduate journey.

To my husband, Subash Adrian, I thank you for being there through the good and bad. Supporting me when I had deadlines and was not the most present partner. You have been nothing but amazing throughout and I am so lucky to have married you during this journey. You are truly the icing on the cake. Thank you to my siblings and amazing friends for holding the fort when I could not and keeping me in check when I needed. Finally, to my fellow Special Care Dentistry postgraduates, respondents, and managers of the centres, I express my humble gratitude to you all for the assistance and support. Thank you all and may Allah bless you.

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CHAPTER 1
INTRODUCTION

1.1 Introduction

In this first chapter, an overview of the study will be provided. The study background and problem statement are discussed to emphasise the importance of this study and the impact of it toward the current information on caregivers' knowledge, attitudes, and practices towards oral health as well as burdens they face in their roles. This chapter also contains the problem statements, research questions, objectives, and significance of the study. The scope of the study is discussed as a guidance for clarity in the upcoming chapters.

1.2 Research Background

In 2011, the World Health Organization's (WHO) published a report exclaiming that the scope of disability has moved from a medical model to a more social model. Disability itself was re-defined as a complex, dynamic, multidimensional, and contested concept that was influenced by social and physical barriers (World Health Organization, 2011). This perspective placed less emphasis on the disability being a result of the impairment, but instead looked at the limitations faced by the disabled as more than a health condition that affects basic functions and structures of the body. The newly introduced social model instead, investigates the barriers created by society that prevents individuals from participating in social and economic activities. Adopting the social model is a paradigm shift in the concept of disability where a person's health is seen to encompass both biological and social aspects such as access and utilisation of healthcare (Han et al., 2022).

In terms of general health, reports have shown that individuals with disabilities have poorer health and higher susceptibility to health problems than the general population. Also, individuals with disabilities also had less health care screenings (Kim & Ho, 2023; Krahn et al., 2015). As disability can be either acquired or congenital, the complexities of the health problems associated with the disability are varied and unpredictable, making it more complicated. Complexities in individuals with disability