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Exploring Informal Caregivers' Perspectives on Oral Care for Stroke Patients

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Abstract

Stroke often results in physical disability and functional impairment, which may severely limit patients' ability to care for personal hygiene, including oral care. This study aimed to identify the challenges faced by informal caregivers in managing the oral health of stroke patients. This study conducted semi-structured individual interviews with eight home-based caregivers of stroke patients recruited from a community-based clinic facility of a public university in Malaysia. The interviews took 30-45 minutes to complete and were transcribed verbatim. Transcripts were analyzed thematically using a phenomenological approach. Relevant themes that emerged were variations in oral hygiene care, caregivers' concerns in providing oral care, dental clinic utilization, and caregivers' perceived educational and training needs. This study highlights the challenges faced by caregivers in managing the oral health of stroke patients. Improving access to dental services for stroke patients and tailoring educational programs to suit the specific learning needs of caregivers, as identified in this study, may result in improved health outcomes for stroke patients.

Keywords: caregivers, oral care, oral hygiene, stroke care, stroke rehabilitation

Introduction

Stroke is a major cause of impairment and vascular death worldwide, including in Asia.[1] The incidence and prevalence of stroke increase steadily associated with nutritional changes and the aging of the population.[2] Every year, the global incidence of stroke is reported to reach 12.2 million new cases. Furthermore, it is projected that one in four individuals aged older than 25 years will experience a stroke in their lifetime. Stroke is the third leading cause of death in Malaysia, with almost 20,000 fatalities reported annually.[3]

Stroke often leads to physical disability and functional impairment, greatly restricting the patient's ability to maintain their personal hygiene, including brushing their teeth and cleaning their mouths. This limitation has a negative impact on their oral health, as poor oral hygiene can lead to serious complications, such as pneumonia and other infections.[4] In addition, the impact of stroke on alertness, cognition, and perception significantly reduces the patient's ability to independently perform self-care tasks, including oral care routines.[5] It is noteworthy that since the stroke mortality rate in Malaysia is lower compared to the other Southeast Asian countries, the number of patients living with stroke-related disabilities is higher.[3] Therefore, improving the quality of life of stroke survivors through effective oral care practices is urgently needed.

Despite increasing awareness of the importance of oral health in stroke care, it remains under-recognized in Malaysia. The Integrated Care Pathway for Post Stroke patients (iCaPPS ©), omits the oral health component of rehabilitation and routine screening for post-stroke complications.[6] A multidisciplinary approach to oral care, extending beyond professional care to include home-based caregivers, often family members of stroke patients, can significantly enhance oral health outcomes. These caregivers play a key role in early identification, assessment, and referral, complementing the work of occupational therapists, nutritionists, and speech-language pathologists in stroke rehabilitation. However, they often lack adequate knowledge of oral health care due to the absence of tailored guidelines.[7]

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Numerous devices and technologies can assist in post-stroke oral care, but many caregivers are unaware of them.[8] Good oral health contributes to overall well-being and can enhance recovery and rehabilitation outcomes. Therefore, educating both patients and their caregivers is crucial to addressing the challenges of caring for this group's oral health. For these points, this study aimed to identify challenges faced by caregivers in managing stroke patients' oral health and to establish a foundation for creating oral care training guidelines tailored to caregivers' needs, making it significant as it not only addresses specific local needs in Malaysia but also contributes valuable insights and models that can be applied regionally and internationally. It bridges gaps in existing research by focusing on the multidisciplinary and caregiver-inclusive aspects of oral health in stroke rehabilitation, advocating for a more integrated and holistic approach to health care.

Method

This study used the phenomenological approach, a type of qualitative research to explore multiple perspectives and deeply understand individual life experiences. A qualitative methodology was selected to investigate deeply into the perspectives and experiences of caregivers concerning oral care for stroke patients. By conducting in-depth interviews, subjective perspectives, beliefs, and emotions allow a more comprehensive understanding of the caregiver's experiences to be revealed. This approach captured the complex and contextual nature of caregiver's experiences, offering insights that quantitative methods alone might not reveal.

A semi-structured interview guide was developed through consultation with experts in long-term stroke care and dental public health with topics on knowledge and practices regarding the oral health of the patients, challenges faced by caregivers in caring for stroke patient's oral health care, and training needs relating to caring for the oral health of the patient. The interview guide applied the following sequence: introduction and ice-breaking, background information of the stroke patient's condition, caregivers' knowledge and practices regarding the oral health of the patients, their insight on the challenges faced in caring for the oral health of the patients, and their perspectives on training needs related to caring for the oral health of the patients. Two researchers were tasked as interviewers and were provided the necessary training by senior team members with vast qualitative study experience. The interview guide was pilot-tested, followed by minor amendments. Discussions were held to ensure smooth execution and standardization of interviewing techniques.

The participants in this study were recruited from a primary clinic under the Universiti Kebangsaan Medical Centre. The target population consisted of the stroke patients' caregivers. Purposive sampling and snowballing technique were employed to select participants who met specific inclusion criteria, including being a family member or caregiver of a stroke patient with a Modified Rankin Scale (MRS)[9] score of 3 and above, aged ≥18 years, and having provided care for the stroke patient for at least one year. Exclusion criteria included caregivers responsible for patients in the rehabilitative phase and non-Malaysian caregivers.

The MRS score is a tool commonly utilized to assess functional disability and the overall outcome of stroke patients. It provides a measure of the patient's level of disability or dependence after a stroke. The scale ranges from 0 to 6, with each level representing a specific degree of disability. The MRS score is typically determined through clinical assessment and examination of the patient's functional abilities to evaluate the impact of stroke on a patient's daily life and guide treatment decisions and rehabilitation planning. This study took a structured interview to determine the patients' MRS scores.[9]

The interview was structured into five sections, each tailored to a particular level of disability in the MRS,[10] as follows: Section 1: constant care (corresponding to MRS grade 5) includes individuals who are bedridden, incontinent, and require constant nursing care; Section 2: assistance for bodily needs/walking (corresponding to MRS grade 4) involves individuals who are unable to walk without assistance and require help with their bodily needs; Section 3: assistance to look after own affairs (corresponding to MRS grade 3) pertains to individuals requiring some assistance but can walk without assistance; Section 4: usual duties and activities (corresponding to MRS grade 2) refers to individuals who are unable to carry out all previous activities but can manage their own affairs without assistance; and Section 5: symptom checklist (corresponding to MRS grades 1 and 0) includes individuals who can carry out all usual duties and activities despite experiencing symptoms (MRS grade 1) or have no symptoms at all (MRS grade 0).

To recruit caregivers for stroke patients, their contact information was accessed from the primary clinic patient database. Potential participants were contacted via WhatsApp, and online interviews were coordinated by Microsoft Teams or Google Meet, based on the participants' convenience. Each session lasted 30-45 minutes and was recorded with

the participants' consent. The interview process occurred from December 2022 to March 2023, with data saturation achieved after eight comprehensive interviews.

The recorded interviews were transcribed verbatim into a Google Sheet prior to analysis. Field notes were taken down at the time of interviews, and reflexivity was used during data analysis. Referrals to the videos were made whenever there was a need to clarify the pronunciation of words or the way they were spoken. A content analysis of the interview transcripts was then undertaken following the guidelines for thematic analysis specified by Braun and Clarke.[11] First, the interviewers acted as initial analysts by reading and rereading the transcripts to familiarize themselves with the dataset. Second, an initial coding frame was developed from the identified initial codes. To enhance data triangulation, these codes were presented to the senior team members, and any discrepancies in codes were discussed until consensus was achieved. Some of the team members were clinicians treating stroke patients and being familiar with issues related to caregivers' experiences. Third, once all the transcripts had been coded, team members explored possible emerging themes that would reflect the meanings of the participants' words. Fourth, the emerging themes were reviewed, and once again, discrepancies were discussed until consensus was achieved. Data remained in the Malay language during the analysis, and illustrative quotes were eventually translated into English.

Results

Table 1 shows the caregivers' and patients' background information. Eight caregivers participated in this study. Seven of them were either sons or daughters of stroke patients; all of them lived with the patients. One caregiver was a neighbor staying with the patient except for Sundays. More than half of the caregivers were females, attaining higher education, and aged 22-58 years. All the stroke patients were elderly, aged in the range of 64-86 years. They had been diagnosed with stroke within the last 1-20 years, and their MRS scores ranged from 3 to 5. Patients getting an MRS score of 5 were on feeding tubes. All except two of the patients had missing teeth; one patient was fully edentulous. Only two patients used dentures to replace their missing teeth.

Table 1. Background Information of Study Participants

Caregiver's Information					Patient's Information			
Code	**Name**	**Age (years)**	**Highest Education**	**Relation with patient**	**Age (years)**	**Number of years Since stroke diagnosis**	**MRS**	**Using denture**
CG1	Mrs W	58	Secondary school	Daughter	72	5	4	No
CG2	Miss I	41	University	Daughter	78	20	3	No
CG3	Mr S	33	Secondary school	Son	64	14	5	No
CG4	Miss A	24	University	Daughter	66	4	4	No
CG5	Mrs M	41	University	Neighbor	86	1	4	Yes
CG6	Mr R	51	University	Son	78	8	5	No
CG7	Miss Q	22	University	Daughter	66	4	4	Yes (patient is fully edentulous)
CG8	Mrs H	37	University	Daughter	73	2	3	No (having dentures but not using them since the stroke)

Notes: MRS = Modified Ranking Scale, CG = caregiver

A total of four themes and 14 subthemes emerged during the interviews, summarized in Table 2 above and detailed with some selected responses below:

Variations in the Oral Hygiene Care

Ability to clean mouth

The caregivers (CG) reported a mix between the ability of the patients to clean their mouths and teeth and the type of oral hygiene tools that they used. Some were able to brush their own teeth and used standard toothbrushes without any need for modifications, while others required assistance.

Independent

CG1: "Mum uses her left hand to brush (not affected by stroke)."

CG5: "The stroke affects her left side. Her dominant hand is her right hand, so she can brush by herself."

Assisted

CG3: "I have to help her clean her mouth because she uses the feeding tube."

G5: "She has been able to brush by herself from the beginning, but I need to help her with taking water for gargling."

CG6: "My mother is bedridden and has dementia. She cannot brush on her own. I have to do it for her."

Table 2. Summary of Themes and Subthemes in the Study

Theme	Subtheme
Variation in oral hygiene care	• Ability to clean mouth • Types of toothbrush • Other ways of cleaning the mouth • Denture care
Caregivers' concern in providing oral care	• Attentiveness and proactivity • Concern about potential complications • Patient-specific challenge
Dental clinic utilization	• Difficulty in accessing dental services • Denture-related problem • Attitude towards seeing a dentist
Caregivers' perceived educational and training need	• Acknowledged the need for training • Knowledge needed by caregivers • Importance of training • Caregiver's constraint

Types of toothbrush

Most of the caregivers reported the use of standard toothbrushes except for two patients.

Modified

CG1: "I make it (the toothbrush) longer and thicker by attaching a stick to it."

Small-sized

CG3: "She can use a normal toothbrush, but it must be small; otherwise, it will cause her pain."

CG5: "At first, she used a children's toothbrush, but now she can open her mouth wider and use an adult toothbrush."

Other ways of cleaning the mouth

CG2: "He enjoys gargling, and if he feels he cannot brush properly, he opts for gargling instead."

CG3: "Cleaning her mouth is limited because she cannot swallow. I rarely use toothbrushes…, I usually clean her mouth with gauze wet with Listerine."

Denture care

CG7: "He does not want to clean his dentures, so I have to help him with that. It is also hard for him to remove (denture) himself."

Caregivers' Concerns in Providing Oral Care

Attentiveness and proactivity

CG1: "We must always look after the patients; if she becomes quiet, that is a signal to check on her and offer assistance with cleaning her mouth."

CG1: "When she has an ulcer, she will be very quiet. We have to give her barley water or coconut water."

Concerns about potential complications

CG1: "She has challenges eating and drinking. Every time she eats, she will consume slowly and drink a little water. I noticed that ulcers tend to form (due to lack of water)."

CG1: "…heard her choke when she's brushing; this is not good".

CG3: "Brushing has its own risks because my mother wears a feeding tube. The technique is different from ours, and if done incorrectly, it may cause infection in the lungs due to excessive swallowing of saliva, toothpaste, and water during brushing."

Patient-specific challenges

G3: "Sometimes she does not want to open his mouth."

CG3: "Mother eats through the feeding tube. We cannot use toothbrush…"

CG3: "One time, she bit my finger while I was cleaning her teeth. I had to use a small spoon to get her mouth open (and release my finger)."

CG5: "She took a month or two before she is accustomed to using her left hand to brush."

CG5: "Previously had a problem opening mouth adequately."

Dental Clinic Utilization

Difficulties in accessing dental services

CG1: "I do not take her to dental clinics anymore. Most clinics are on the second floor, and there is no lift. And I cannot push her wheelchair up. I used to carry her up, but it made my back hurt."

CG3: "Doctors at the stroke clinic referred her for dental treatment…, she went three times to the dental clinic at the university hospital…, the (private) ambulance took her…, Then, she was referred to the Kajang dental clinic. The dental team from there came for a home visit. They stopped after covid (pandemic)."

CG5: "…Health clinics (government) will take a long team to get an appointment. For private clinics, it is so expensive, and no easy access for wheelchair."

Denture-related problems

CG5: "The denture is unfit as she lost weight due to a stroke. May need to do new denture but have no plans for now."

CG8: "Dad has difficulty chewing as he only has a few remaining teeth left, and he is not wearing his denture because it does not feel good anymore."

Attitude towards seeing a dentist

CG4: "She was supposed to make a denture after pulling out her teeth, but she prefers to just stay at home instead… She is in a wheelchair; most of the time, she does not want to go out."

G5: "I never took her for a dental checkup. Seems she does not have any problem. But do we need to do that? If we need, we can arrange."

Caregivers' Perceived Educational and Training Needs

Acknowledged the need for training

CG1: "Need to have (training program) because this knowledge you got to know cause the stroke over here is not just for a person but two people."

CG2: "Honestly, for me it is (training program) needed because we do not know what is needed for the oral care of the patient."

Knowledge needed by caregivers

CG2: "...I want to know the size of the toothbrush. Because nowadays, there are a lot of sizes for toothbrushes in the market. We do not know what is the suitable one, so maybe the type of toothbrush that is suitable for us? What toothpaste is suitable because maybe there is a presence of sugar in it. We do not know because we could not understand to read the label (on the toothpaste)."

G3: "Expand more programs in the bedridden wards. It is important for the family and caregivers of the bedridden patient to know how to take care of the teeth. If you can, visit each of the bedridden patient's wards. This (oral) knowledge, the exposure needs to be face-to-face then only they can understand."

CG8: "…(important to know about) long term effect of not wearing a denture, because existing denture can only be worn for a few years, so need to inform us (what we should do in this situation)."

Importance of training

G5: "They need to explain the importance of this oral health related to stroke because many people do not understand. For me, people do not know about it…, try to show what will happen if they are not taking care (of oral health), Malaysian people need to be shown the consequences. Just informing them to take care of their mouth, nothing's going to happen, but if showing what is going to happen of not taking care (oral health) then they can understand."

CG7: "Caregivers need to know about oral healthcare because everything starts with a caregiver; if caregivers feel it is not important, then it is very unfortunate for their patients."

Caregivers' constraints

CG2: "If there is a program, if the time at that time is suitable and I am available, I would like to join the program to increase my knowledge."

CG6: "Depends on the time because I am also busy. If the program does not clash with my schedule, I have no problem (to attend)."

G8: "I can come if it is done online."

Discussion

The findings of this study highlighted the challenges faced by caregivers in managing stroke patients' oral health and emphasized the significance of oral care for stroke patients. The qualitative approach allowed for an in-depth exploration of caregivers' experiences, attitudes, and practices related to oral hygiene routines for stroke patients, revealing important insights that quantitative methods alone might not have captured. One key theme emerging from the interviews was variation in oral hygiene practices among stroke patients. While some patients were able to brush their teeth using a standard toothbrush, others required assistance or modified tools. Those with higher dependency scores (MRS grade 5) are the ones who need help, which is not unexpected considering they have limited physical, sensory, and cognitive abilities, which comprise self-care.[12]

Oral hygiene care is a core component of self-care, and extra care is needed for stroke patients with difficulties in carrying out personal oral hygiene care. A review indicated that oral hygiene interventions could have positive effects on stroke patients' oral health status, such as reducing plaque index (PI), gingival index (GI), candida colonization, bleeding gums, and preventing stroke-associated pneumonia (SAP).[13] Moreover, Dai *et al.* advocate for the inclusion of oral hygiene care programs within stroke outpatients as it may improve the patient's oral hygiene and increase the knowledge of the other aids available to help with oral hygiene care.[14] One way is to integrate oral care into iCaPPS ©.[6]

This study featured concern regarding oral care for stroke patients, considering the challenges experienced by both caregivers and care recipients. First, stroke patients' caregivers provide support, encompassing physical aid and psychosocial assistance; yet, this supportive role might impose a significant burden on the patient and caregiver. Such burdens might impact caregivers' health, social life, and overall well-being. Informal caregivers invest substantial time and attention, and any oversight could lead to unwarranted consequences for stroke patients. Not surprisingly, the caregivers in this study expressed worries about potential risks during oral hygiene, such as patients accidentally swallowing saliva or toothpaste, which poses a health threat, particularly for those with systemic conditions such as aspiration pneumonia. These concerns emphasized the caregivers' commitment to the patient's well-being, highlighting the need for effective interventions to help caregivers manage challenges associated with patients' considerable cognitive and emotional adjustments.[15]

Additionally, patient-related challenges in oral care stem primarily from inadequate dexterity skills. Post-stroke, hand function abnormalities arise due to lesions in the motor cortex and corticospinal tract, crucial for independent finger movements.[16] Technology such as powered oral care tools, non-powered tools, and modifications to non-powered tools are accessible to help overcome barriers in post-stroke oral care.[8] In fact, various training and rehabilitation strategies have explored the impact of finger and hand training in chronic stroke patients to address deficits in dexterous movement.[17] Therefore, enhancing hand dexterity is beneficial for achieving positive outcomes in oral health care, and its role in oral care could be integrated into the overall rehabilitation of patients.

In this study, the findings related to dental clinic utilization highlighted several key issues that the stroke patients' caregivers faced. They reported various barriers to accessing dental services, including physical accessibility issues (e.g., clinics located on upper floors with no lift access), closure or renovation of clinics, long waiting times for appointments at public health clinics, and high costs at private clinics. These findings align with a previous study indicating that physical, systemic, and financial barriers can significantly hinder access to dental care for individuals with disabilities.[18] Several caregivers noticed that their care recipients had problems with their dentures, such as ill-fitting dentures due to weight loss after a stroke and difficulties in chewing due to few remaining teeth, but did not associate this with the need to be seen by a dentist.

Most caregivers sought dental care when the care recipient was in pain, suggesting a reactive rather than preventive approach to oral health care. These attitudes might reflect less awareness or understanding of the significance of routine dental checkups and preventive oral health care. These findings highlighted the need for interventions to improve dental service access for stroke patients and caregivers, which includes making dental facilities more accessible, streamlining appointment systems, and providing affordable care options. Consideration should be made to initiate dental hygiene care even while patients are in the acute stroke wards. Additionally, education can bolster caregivers' understanding of routine checkups, preventive care, and effective denture management.

On this note, effective caregiver training has proven to improve the oral health and plaque control performance of stroke patients.[19] Providing targeted training programs covering topics such as oral care techniques, proper tool selection, and the importance of oral health for stroke patients can significantly elevate the caregivers' knowledge, skills and commitment.[20] Many caregivers turn to health professionals, such as physicians, nurses, and therapists, for information to navigate through unfamiliar situations. However, the success of oral care training hinges on its accessibility to caregivers. The caregivers in this study expressed some constraints on their availability to attend classes. Thus, relevant training should consider various platforms and timings, for example, offline sessions on weekends that include practical demonstrations or more flexible e-learning modules or online webinars. This tailored approach enhances the program's effectiveness and boosts the caregivers' motivation to actively participate in the training.

Given the current stroke burden in Malaysia, addressing oral health in stroke care is of utmost importance. Similar to many countries, Malaysia witnessed a rising incidence of stroke attributed to lifestyle changes and an aging population.[3] With stroke being a major cause of impairment and vascular death, prioritizing holistic care for stroke patients, including their oral health, becomes essential.[3] In Malaysia, where home-based informal caregivers, often family members, play a significant role in the care of stroke patients, their knowledge and skills in oral care are central to ensuring positive outcomes.[21] As primary caregivers of stroke survivors, these individuals often experience significant physical, mental, and social impacts, even more so when they share the same residence with the patients and are expected to provide care around the clock. A local study identified two major needs emerging for these caregivers: the need for information on comprehensive stroke care at home and the need for psychological support for themselves.[21] Without proper care and support for them, caregivers will psychosocially suffer from burnout, anxiety, and depression, ultimately worsening the patient's physical and psychological conditions.[22-25]

This study found a prominent gap in the availability of support and guidelines for caregivers to deliver oral care, emphasizing the need for tailored educational programs. At the same time, informal caregivers in Malaysia encounter multiple unmet needs beyond the learning aspects of oral care for stroke patients. The literature has vast reports on significant concerns of caregivers, such as financial constraints, insufficient information regarding home-based stroke care, lack of psychological support, barriers for survivors to return to work, and a shortage of community-based rehabilitation therapies.[22-27] Addressing these unmet needs is critical to improving the quality of life for both stroke survivors and their caregivers.

The COM-B model, a theoretical framework used in behavioral science to comprehend and interpret behavior,[28] can be applied to expand the conclusions of this study. This model outlines four prerequisites—behavior, opportunity, motivation, and capability—that must exist in order for a voluntary behavior to take place. This study proposes that the term "capability" refers to the psychological and physical capacities of stroke patients' caregivers to offer oral care, probably impacted by their knowledge and abilities. "Opportunity" may refer to external variables that make dental care possible, for instance, the accessibility of tools and resources such as dental clinics for post-stroke dental care. "Motivation" describes the conscious and unconscious cognitive processes of caregivers that lead and encourage them to facilitate oral hygiene care or seek professional dental care, particularly for their family members. These factors may be addressed through tailored educational programs, as discussed before in the previous paragraph. The COM-B model acknowledges that many factors impact behavior and that for behavioral change to take place, at least one of these components is modified. As such, the model provides a useful framework to interpret the findings of this study and formulate strategies to improve caregivers' oral health practices for stroke patients.[28]

While this study provides valuable insights into the experiences of caregivers of stroke patients, it is pivotal to acknowledge some potential limitations related to the small sample size. An inherent limitation of small-sized studies is that they may limit generalizability; nonetheless, the aim of qualitative study is depth of understanding, not breadth. Furthermore, this study employed purposive sampling, ensuring that participants were selected based on their ability to provide rich, relevant, and diverse data. This, combined with rigorous data analysis techniques, contributed to the

achievement of saturation, indicating a comprehensive capture of experiences and perspectives. However, future studies could benefit from larger or more diverse samples and longitudinal studies to validate this study's findings in different contexts and over time.

To enhance the caregiver's role in facilitating rehabilitation for stroke patients, particularly concerning oral care and overall oral health, several recommendations to consider are developing targeted caregiver education programs focusing on specific challenges of oral care for stroke survivors; emphasizing the integration of oral health into the broader stroke care framework to stress its importance in rehabilitation; fostering open communication channels between caregivers and healthcare professionals to address concerns promptly; establishing the community-based support networks and resources for caregivers to provide ongoing assistance; and disseminating regular updates on the latest advancements in oral care and rehabilitation strategies to keep caregivers informed and empowered.

Conclusion

This study sheds light on difficulties that caregivers face while providing oral health care for stroke patients, emphasizing how essential effective oral care is. With stroke posing a considerable burden in Malaysia, providing holistic care that includes addressing oral health needs becomes imperative. Improving dental service access for stroke patients and tailoring educational programs to match the specific learning needs of caregivers, as identified in this study, can lead to improved health outcomes for stroke patients.

Abbreviations

iCaPPS ©: Integrated Care Pathway for Post Stroke patients; MRS: Modified Rankin Scale; CG: caregivers.

Ethics Approval and Consent to Participate

Permission to conduct the study was obtained from the Universiti Kebangsaan Malaysia Research and Ethics Committee (REF NO: UKM PPI/111/8/JEP-2022-374) prior to the commencement of the study. Prior to the commencement of the online interviews, caregivers were provided with a study information sheet explaining the study's objectives and procedures. They provided a digital signature on the informed consent form once they agreed to participate.

Competing Interest

The authors declare that there are no competing interests in this study.

Availability of Data and Materials

Data and materials used in this project may be available from the corresponding author upon reasonable request.

Authors' Contribution

HR, SNMZ, EO, and TNMD contributed to the design and implementation of the research and the analysis of the results. AFAA and MFA verified the study instruments, analytical methods, and data interpretation. SNMZ, EO, and TNMD were responsible for preparing the manuscript, and all authors discussed the results and contributed to the final manuscript. All authors approved of the final manuscript.

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References

1. Donkor ES. Stroke in the 21st Century: A Snapshot of the Burden, Epidemiology, and Quality of Life. Stroke Res Treat. 2018; 3238165. DOI: 10.1155/2018/3238165.
2. Yousufuddin M, Young N. Aging and Ischemic Stroke. Aging. 2019; 11 (9): 2542–2544. DOI: 10.18632/aging.101931.
3. Tan KS, Venketasubramanian N. Stroke burden in Malaysia. Cerebrovasc Dis Extra. 2022; 12 (2): 58–62. DOI: 10.1159/000524271.
4. Son M, Jo S, Lee JS, et al. Association between Oral Health and Incidence of Pneumonia: A Population-Based Cohort Study from Korea. Sci Rep. 2020; 10: 9576. DOI: 10.1038/s41598-020-66312-2.
5. Moldvai J, Orsós M, Herczeg E, et al. Oral Health Status and Its Associated Factors Among Post-Stroke Inpatients: A Cross-Sectional Study in Hungary. BMC Oral Health. 2022; 22: 234. DOI: 10.1186/s12903-022-02259-2.
6. Aziz AFA, Nordin NAM, Ali MF, et al. The Integrated Care Pathway for Post Stroke Patients (iCaPPS): A Shared Care Approach between Stakeholders in Areas with Limited Access to Specialist Stroke Care Services. BMC Health Serv Res. 2017; 17: 35. DOI: 10.1186/s12913-016-1963-8.
7. Balwanth S, Singh S. Caregivers' Knowledge, Attitudes, and Oral Health Practices at Long-Term Care Facilities in KwaZulu-Natal. Health SA. 2023; 28: a2147. DOI: 10.4102/hsag.v28i0.2147.
8. Gurgel-Juarez N, Egan M, Wiseman M, et al. Technology for Maintaining Oral Care After Stroke: Considerations for Patient-Centered Practice. Disabil Rehabil Assist Technol. 2022; 17 (8): 916-926. DOI: 10.1080/17483107.2020.1822450.

9. Broderick JP, Adeoye O, Elm J. Evolution of the Modified Rankin Scale and Its Use in Future Stroke Trials. Stroke. 2017; 48 (7): 2007–2012. DOI: 10.1161/STROKEAHA.117.017866.
10. Wilson JL, Hareendran A, Grant M, et al. Improving The Assessment of Outcomes in Stroke: Use of A Structured Interview to Assign Grades on The Modified Rankin Scale. Stroke. 2002; 33 (9): 2243-2246. DOI: 10.1161/01.str.0000027437.22450.bd.
11. Braun V, Clarke V. Using Thematic Analysis in Psychology. Qual Res Psychol. 2006; 3 (2): 77–101. DOI: 10.1191/1478088706qp063oa.
12. Kim HT, Park JB, Lee WC, et al. Differences in The Oral Health Status and Oral Hygiene Practices According to The Extent of Post-Stroke Sequelae. J Oral Rehabil. 2018; 45 (6): 476–484. DOI: 10.1111/joor.12634.
13. Eriyani T, Shalahuddin I, Pebrianti S, et al. Impact of Oral Hygiene Interventions on Stroke Patients: Rapid Review. J Ilmu Kesehat. 2023; 8 (4): 1574–1584. DOI: 10.30604/jika.v8i4.2378.
14. Dai R, Lam OLT, Lo ECM, et al. A Randomized Clinical Trial of Oral Hygiene Care Programmes During Stroke Rehabilitation. J Dent. 2017; 61: 48–54. DOI: 10.1016/j.jdent.2017.04.001.
15. Xu T, O'loughlin K, Clemson L, et al. Therapists' Perspectives on Adapting the Stepping on Falls Prevention Programme for Community-Dwelling Stroke Survivors in Singapore. Disabil Rehabil. 2019; 41 (21): 2528–2537. DOI: 10.1080/09638288.2018.1471168.
16. Yoo YJ, Kim JW, Kim JS, et al. Corticospinal Tract Integrity and Long-Term Hand Function Prognosis in Patients with Stroke. Front Neurol. 2019; 10: 374. DOI: 10.3389/fneur.2019.00374.
17. Moggio L, de Sire A, Marotta N, et al. Exoskeleton *Versus* End-Effector Robot-Assisted Therapy for Finger-Hand Motor Recovery in Stroke Survivors: Systematic Review and Meta-Analysis. Top Stroke Rehabil. 2022; 29 (8): 539-550. DOI: 10.1080/10749357.2021.1967657.
18. Bhadauria US, Purohit B, Priya H. Access to Dental Care in Individuals with Disability: A Systematic Review. Evid Based Dent. 2024; 25: 111. DOI: 10.1038/s41432-024-00970-3.
19. Kuo YW, Yen M, Fetzer S, et al. Effect of Family Caregiver Oral Care Training on Stroke Survivor Oral and Respiratory Health in Taiwan: A Randomised Controlled Trial. Community Dent Health. 2015; 32 (3): 137-142. DOI: 10.1922/CDH_3572Kuo06.
20. Chen HJ, Chen JL, Chen CY, et al. Effect of an Oral Health Programme on Oral Health, Oral Intake, and Nutrition in Patients with Stroke and Dysphagia in Taiwan: A Randomised Controlled Trial. Int J Environ Res Public Health. 2019; 16 (12): 2228. DOI:10.3390/ijerph16122228.
21. Ghazali SB, Abdullah KL, Abd Aziz AB, et al. Burden of Caregivers of The Elderly with Chronic Illnesses and Their Associated Factors in an Urban Setting in Malaysia. Malays J Med Sci. 2015; 15 (1): 1–9.
22. Sidek NN, Kamalakannan S, Tengku Ismail TA, et al. Experiences and needs of the caregivers of stroke survivors in Malaysia—A phenomenological exploration. Front Neurol. 2022; 13: 996620. DOI: 10.3389/fneur.2022.996620.
23. Wan-Fei K, Hassan ST, Sann LM, et al. Depression, Anxiety and Quality of Life in Stroke Survivors and Their Family Caregivers: A Pilot Study Using an Actor/Partner Interdependence Model. Electron Physician. 2017; 9 (8): 4924–4933. DOI: 10.19082/4924.
24. Zawawi NS, Aziz NA, Fisher R, et al. The Unmet Needs of Stroke Survivors and Stroke Caregivers: A Systematic Narrative Review. J Stroke Cerebrovasc Dis. 2020; 29 (8): 104875. DOI: 10.1016/j.jstrokecerebrovasdis.2020.104875.
25. Omar O, Aziz AF, Ali MF, et al. Caregiver Depression Among Home-Bound Stroke Patients in an Urban Community. Cureus. 2021; 13 (9): e17948. DOI: 10.7759/cureus.17948.
26. Lobo EH, Frølich A, Abdelrazek M, et al. Information, Involvement, Self-Care and Support—The Needs of Caregivers of People with Stroke: A Grounded Theory Approach. Plos One. 2023; 18 (1): e0281198. DOI: 10.1371/journal.pone.0281198.
27. Haji Mukhti MI, Ibrahim MI, Tengku Ismail TA, et al. Family Caregivers' Experiences and Coping Strategies in Managing Stroke Patients during the COVID-19 Pandemic: A Qualitative Exploration Study. Int J Environ Res Public Health. 2022; 19 (2): 942. DOI: 10.3390/ijerph19020942.
28. Keyworth C, Epton T, Goldthorpe J, et al. Acceptability, reliability, and validity of a brief measure of capabilities, opportunities, and motivations ("COM-B"). Br J Health Psychol. 2020; 25 (3): 474-501. DOI: 10.1111/bjhp.12417.