

Empowering Caregivers to Enhance Daily Functions in Elderly Stroke Patients: A Guidebook's Development and Validation for Occupational Therapists

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ABSTRAK

Penjaga yang kompeten memainkan peranan penting untuk menyokong penglibatan warga emas dalam aktiviti harian. Penurunan keberdikarian dalam aktiviti harian dalam kalangan warga emas yang mengalami strok dikaitkan dengan pelbagai masalah kesihatan, tempoh tinggal hospital yang lebih lama, kemasukan semula ke hospital dan seterusnya menyebabkan peningkatan beban terhadap sistem penjagaan kesihatan. Justeru itu, latihan yang berkesan bagi penjaga sangat penting. Kajian ini bertujuan untuk membangunkan dan mengesahkan sebuah buku panduan untuk ahli terapi cara kerja bagi membantu penjaga untuk meningkatkan kompetensi penjagaan harian dalam warga emas yang mengalami strok. Kami menggunakan pendekatan multi-metod melalui tiga fasa untuk membangunkan buku panduan ini. Semasa fasa pertama, kami mengenal pasti isi kandungan dan ciri-cirinya dengan menjalankan kajian literatur sistematik dan temu bual mendalam dengan ahli terapi cara kerja dan penjaga. Fasa kedua melibatkan penilaian kesahan muka dan kandungan melalui perbincangan kumpulan berfokus dengan pakar. Fasa ketiga memberi tumpuan pada penyempurnaan kejelasan buku panduan, sensitiviti budaya dan interpretasi pengguna melalui temu bual kognitif. Buku panduan ini terdiri daripada tiga bahagian yang merangkumi 11 topik dan 72 subtopik. Ciri-cirinya yang unik, termasuk latihan penjaga yang terstruktur, pendekatan yang berpusatkan klien dan berorientasikan matlamat, sokongan selepas discaj, persediaan untuk kecemasan, dan strategi untuk daya tahan dan adaptasi penjaga, menunjukkan kesahan muka dan kandungan yang cemerlang. Ciri-ciri ini mencapai skor sempurna 1.0 dalam Indeks

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Kesahan Kandungan (CVI) dan Indeks Pengetahuan Kandungan (CKI). Buku panduan ini mempunyai potensi untuk aplikasi klinikal, memerlukan kajian lanjut untuk menilai kebolehgunaan dan keberkesanannya dalam tetapan klinikal.

Kata kunci: Latihan penjaga; rehabilitasi; strok; terapi cara kerja; warga emas

ABSTRACT

Competent caregivers play a pivotal role in supporting the functional abilities of older individuals. A decline in functional activities among older adults with stroke links to various health issues, prolonged hospital stays, re-hospitalisation and ultimately contributes to an increased burden on the healthcare system. Therefore, effective training of caregivers is crucial. This study aims to develop and validate a guidebook for occupational therapists to help caregivers improve daily functioning in older stroke patients. We developed the guidebook through a three-phase, multi-method process. Phase 1 defined its content and features using literature reviews and interviews with therapists and caregivers. In Phase 2, we validated the guidebook with expert focus groups. Phase 3 improved its clarity, cultural relevance and user understanding via cognitive interviews. The guidebook comprises three sections encompassing 11 topics and 72 subtopics. Its unique attributes, including structured caregiver training, a client-centered and goal-directed approach, post-discharge support, emergency preparedness, and strategies for caregiver coping and adaptation, demonstrated outstanding face and content validity. These features achieved a perfect score of 1.0 in both Content Validity Index (CVI) and Content Knowledge Index (CKI). The guidebook holds potential for clinical application, necessitating further research to evaluate its feasibility and effectiveness in clinical settings.

Keywords: Caregiver training; occupational therapy; older adult; rehabilitation; stroke

INTRODUCTION

A stroke is an abrupt neurological impairment resulting from damage to blood vessels in the central nervous system, leading to either a blockage or bleeding (Murphy & Werring 2020). It is a major cause of death and disability worldwide, with increasing prevalence in Malaysia (Tan & Venketasubramanian 2022). Stroke risk rises with age, and recovery in older adults is challenging due to aging effects (Yousufuddin & Young 2019). By 2040, the population aged 60 and over in

Malaysia will nearly equal those under 15 (19.2% vs. 17.6%), and by 2050, the older population will exceed the younger (23.1% vs. 17.4%) (Mansor et al. 2022). This demographic shift underscores the importance of addressing stroke-related issues in older adults, who face significant impairments in daily activities compared to younger individuals (Zhou et al. 2022). These functional impairments make older adults more vulnerable to adverse health events, including deconditioning, delirium, pneumonia, malnutrition, urinary

tract infections, sarcopenia, depressive symptoms, cognitive decline and falls (Osakwe et al. 2019; Pezzulo et al. 2019; Sato et al. 2019; Swinnerton & Proce 2023; Socha et al. 2018; Tavares et al. 2021; Vojtkiv & Arsovska 2018). Consequently, this results in prolonged hospitalisation, recurring admissions, heightened caregiver burdens, compromised quality of life, increased healthcare expenses, and elevated mortality risk (Çelik & Kara 2019; Hu et al. 2022; Lekander et al. 2017; Tonkikh et al. 2016). Therefore, encouraging daily activity in older adults during stroke recovery is crucial and should be taken seriously.

Fostering engagement in older adults who have had a stroke becomes a more challenging, demanding increased support, including the presence of competent caregivers. The caregiving role is extensive and demands a significant time commitment. The caregiving role now encompasses emotional support, assistance with tasks, home health care, navigating healthcare systems, care coordination, and taking on a surrogate decision-making role with legal implications. Caregivers handle diverse tasks across these domains, involving ongoing cognitive and interpersonal processes like problem-solving, decision-making, communication, and vigilance over the care recipient's well-being. Due to its breadth and complexity, ensuring caregivers are well-prepared is crucial (Schulz et al. 2016). Therefore, the support system for older adults recovering from a stroke must be robust, incorporating trained, knowledgeable, and empathetic caregivers who can effectively navigate the intricacies of both stroke recovery and the aging process. However, the situation

in Malaysia is concerning, as reported by Tan et al. (2020), there is a high percentage (87.3%) of caregivers lack basic knowledge of stroke care, and the majority (75.8%) have not received any caregiving training. Surprisingly, caregivers with prior training have a higher likelihood of experiencing health issues, indicating the need for better caregiver training overseen by healthcare professionals (Tan et al. 2020).

Occupational therapists (OTs) play a vital role in enhancing caregivers' competencies (Edwards 2015; Smith-Gabai 2016). The Ministry of Health Malaysia has issued guidelines and manuals, such as "Panduan untuk penjaga warga emas" (2008) and "Manual latihan bagi penjaga: Jagaan asas orang kurang upaya di institusi dan di rumah" (2007). Additionally, "Panduan Penjaga Warga Emas" was published by Malaya University (Hairi et al. 2019). However, these modules are outdated, too general, and insufficient for OTs, whose work involves assessment, intervention, and outcomes (Boop et al. 2020).

Studies by Sidek et al. (2022) and Ahmad Ainuddin et al. (2021) emphasise the need for comprehensive caregiver education on stroke care, improved risk assessments and home interventions. Additionally, to the best of our knowledge, there are no specific guidelines for OTs in Malaysia regarding caregiver training for older adults with stroke. This is supported by the Delphi study by Daud et al. (2016), which found that Malaysia still lacks guidelines for OTs to provide functional-based care, including caregiver training. Hence, increasing resources for caregiver training in geriatric daily functioning should be a primary focus in occupational therapy. This will help to improve geriatric

health services and support Malaysia's progress towards becoming a prosperous aging nation. In light of previous studies, this study aimed to develop and validate a guidebook to enhance the quality of caregiver training provided by OTs.

MATERIALS AND METHODS

Research Design

The study received ethical approval from the Research Ethics Committee, listed in the National Medical Research Register (NMRR ID-21-02430-FLU (IIR)), and was also approved by the Medical Research and Innovation Secretariat at Universiti Kebangsaan Malaysia (JEP-2021-573). A three-phase approach was taken in the development of the guidebook, utilising both quantitative and qualitative methodologies. Phase 1 aimed to define the contents and characteristics of the guidebook. To accomplish this objective, the study executed a systematic literature review and conducted interviews with OTs and caregivers. In Phase 2, a focus group discussion (FGD) with experts was held to assess the guidebook's validity, encompassing face and content validity. Before the evaluation, a discussion took place between the experts and the researcher to review and enhance the guidebook before proceeding with the validity assessment. Phase 3 involved cognitive interviews to enhance the guidebook's clarity, cultural sensitivity, and user interpretation, ensuring effective communication and learning outcomes.

Phase One: Guidebook Contents and Characteristics

(i) Systematic Literature Review

The initial information of the caregiver training guidebook for OTs in this study is based on a systematic literature review of peer-reviewed articles from 2011 to 2021, focusing on informal caregivers and guided by OT expertise. We considered sources like Scopus, WoS, CINAHL, MEDLINE, and Cochrane, emphasising both RCTs and quasi-experimental studies.

(ii) In-depth Interview

Evaluating user experience is pivotal in assessing healthcare quality and system efficiency, significantly impacting care quality, safety and effectiveness (Doyle et al. 2013; Papoulias 2018). Moreover, collaboration between developers and users enhances innovation and satisfaction (Fylan et al. 2021). This research undertook a detailed investigation via interviews with OTs and primary caregivers of older adults stroke survivors, aiming to identify current practices, challenges, needs and improvement opportunities for integration into a caregiver training manual. In phenomenological research, where understanding participant perspectives is key, a sample size between five and fifty is advised for thorough insight (Alase 2017; Dworkin 2012).

To conduct the study, purposive sampling was used to select both OTs and caregivers. For OTs, the criteria required at least five years of experience in geriatric stroke care. IHG and RM selected six OTs from various clinical networks, ensuring regional representation. Contact details were obtained from hospital websites, and informal invites resulted in five responses, with one additional participant joining

after a follow-up call. Formal permissions and invites were sent to superiors, and individual virtual meetings were scheduled with preparatory materials and Zoom links. OT interviews were held virtually in private rooms at their workplaces, with the interviewer also in a private room to ensure privacy and confidentiality. Earphones were recommended to protect shared information.

For caregiver recruitment, main caregivers of older adults with stroke were included, excluding those unable to communicate in Bahasa Malaysia or English. IHG collaborated with two OTs from each university and district hospital. These therapists suggested potential participants based on the set criteria, and IHG conducted briefings with potential caregivers when they accompanied older adult patients to occupational therapy outpatient appointments. If the caregivers agreed to participate and provide consent after the briefing, interviews were scheduled immediately while waiting for the older adult to finish their therapy session. A private room was prepared for these interview sessions. For caregivers who agreed to participate but were not ready to be interviewed immediately, alternative arrangements for home visits or virtual platforms were offered.

The average duration of the interview was 48 minutes and 30 seconds with the occupational group, and 42 minutes and 15 seconds with the caregiver group. During the interview session, IHG explained study objectives and used semi-structured questions validated by all authors. Participants could take breaks and were encouraged to elaborate on their responses. All interviews were digitally recorded and transcribed verbatim by

IHG, with field notes taken for reference during debriefing and coding sessions. Transcripts were emailed to OTs for member checking, and they returned the verified transcriptions. For caregivers, to ensure their comfort and avoid the need for returning validated transcriptions via email, member checking was conducted during the interviews. As noted by Candela (2016), member checking can also occur during interviews to validate interpretations of responses in real time.

An inductive approach with thematic analysis was used, following six steps: familiarising with data, generating codes, searching for themes, reviewing themes, defining themes and writing the report. To ensure trustworthiness, we applied Lincoln and Guba's criteria, conducted peer reviews, and engaged participants for member checking. An audit trail and continuous researcher communication were maintained for diverse perspectives and enriched results (Lincoln & Guba 1985).

Phase Two: Evaluate Guidebook Validity in a Focus Group with Experts

In the second phase, occupational therapy experts with at least five years of experience in geriatric stroke care were selected for a virtual FGD to critically evaluate the guidebook, in line with the criteria set by Siti Farhah and Saedah (2015) for expert reviewers, which included relevant expertise, participation willingness and communicative efficacy. The suggestion of the experts were based on their well-known expertise in stroke care and geriatrics, as discussed among the research team. All ten experts agreed to join the FGD after a briefing on WhatsApp.

The first author created a WhatsApp group including all experts and the authors for communication. They discussed potential dates for the FGD and provided several options. A poll was conducted in the WhatsApp group to select the preferred date and time, with the most popular choice being finalised. After setting the date, the first author sent a formal invitation letter including the zoom link for the FGD, consent form, sociodemographic form, research information sheet, guidebook, and Content Validity Index (CVI)/ Content Knowledge Index (CKI) forms via email. Experts were given approximately two weeks to review these materials before the FGD.

Nine experts attended the FGD, as one had an emergency task the day before. The session, led by the first and third authors, aimed to gather detailed feedback, was recorded with consent, and focused on specific questions to ensure thorough discussion and consensus. The session lasted 3 hours and 28 minutes, with a short break. After the FGD, a summary of the discussion was emailed to the experts for verification, ensuring accurate reflection of their opinions (member-checking). The research team conducted thematic analysis and incorporated the feedback into the guidebook. This amendment process took almost two months. The revised guidebook, along with an amendment list, was sent via email to all experts, who had one week to complete the CVI and CKI forms before returning them to the main author via email.

The revised guidebook underwent expert evaluation for face validity, focusing on font size, layout, and clarity, with consensus percentages measuring agreement. The CVI assessed relevance,

clarity, simplicity, and ambiguity using a 4-point Likert scale, with analysis limited to scores of 3 or higher. The Item-Content Validity Index (I-CVI) and Scale Content Validity Index (S-CVI) were calculated following Polit & Beck's (2006) approach, ensuring comprehensive validation. Agreement levels were classified as excellent (0.90-1.00), high (0.80-0.89), and moderate (0.70-0.79), based on Sirajudeen et al. (2012) and were applied in this study.

Phase Three: Refine Guidebook Clarity and Cultural Sensitivity

In the third phase, OTs involved in geriatric stroke care and caregiver training were purposively selected to evaluate and enhance the guidebook. The first author identified these clinicians through LinkedIn and professional connections with alumni from the National University of Malaysia who manage the Occupational Department at private hospitals and centers. On LinkedIn, the author identified several OTs in Malaysia with backgrounds in stroke care and geriatrics and sent them private messages briefing them about the study. Several clinicians provided feedback, but only one agreed to join, and formal consent was obtained from her hospital.

For the alumni, the author sent a brief text about the study via WhatsApp, and both agreed to participate by recommending staff members. Within a week of receiving verbal consent, the author initiated the formal consent process at the department or hospital level. Once all consents were obtained, the author created a WhatsApp group for all participants. Multiple dates and times were proposed for individual cognitive

interviews via Zoom, allowing clinicians to select their preferred slots. The author then collected emails from each clinician and sent a formal invitation letter, including the Zoom link for the interview, consent form, sociodemographic form, research information sheet, and guidebook, two weeks before the scheduled virtual interviews to allow thorough review.

During the individual virtual cognitive interviews, clinicians were randomly asked to elucidate specific sections to test clarity and identify ambiguities. Any discrepancies in interpretation led to discussions to reach a clear consensus. Key insights and recommendations were confirmed verbally with participants in a member-checking process to ensure accurate reflection and possible amendments. Therapists were encouraged to provide constructive feedback for guidebook refinement. After the interview sessions, clinicians were given one week to return all completed documents via email.

The transcribed interview data underwent thematic analysis to extract pertinent themes from the discussions. The research team meticulously evaluated all inputs from the OTs for relevance and applicability. Through collective deliberation, the researchers agreed on the final themes, leading to essential updates in the guidebook's design and content to better meet its intended purpose and user needs.

RESULTS

Phase One: Guidebook Contents and Characteristics

(i) Systematic Literature Review

The initial search yielded 2823 studies, but only five met the inclusion criteria for the final review. These included five studies (four Randomised Controlled Trials and one Quasi-Experimental) that spanned various intervention settings such as hospitals, combined hospital and community, and community environments. The analysed interventions revealed that strategies like tailored goal setting, caregiver education (covering stroke knowledge, prevention of iatrogenic complications, training for basic and instrumental activities of daily living, necessary adaptive aids, and cognitive stimulation), structured multidisciplinary team management, home visits, personalised home-based interventions, coaching for caregivers on problem-solving and coping mechanisms, and home modifications had significant positive outcomes. These benefits manifested as improved patient functioning, successful goal attainment, reduced caregiver strain, diminished confusion, and lower hospital service demand. Table 1 summarised the key findings for each analysed study.

(ii) In-depth Interview

- Demographic Characteristics

The interview phase of this study engaged OTs (N=6), selected to provide diversity in backgrounds and education levels. The participants in Phase 1 interviews included one Ph.D. candidate (N=1), four individuals with degrees (N=4), and one with a diploma (N=1). All participants had a minimum of nine years of work experience, with two therapists (B and F) (N=2) had extensive experience in government hospitals before transitioning to university hospitals. The mean age of the OTs was 35.7 years.

TABLE 1: Interventions and key findings from each study

Author	Intervention	Key finding
Abizanda et al. 2011	<p>Experimental group</p> <ul style="list-style-type: none"> - Tailored goals directed - Caregiver education and training on latrogenic prevention Basic and instrumental ADL training Adaptive aids needed at home Cognitive stimulation <p>Control group</p> <ul style="list-style-type: none"> - Treatment as usual 	<ol style="list-style-type: none"> 1. Cardiopulmonary patients in experimental group: improved function (post hoc analysis). 2. Others: reduced acute confusion.
Vluggen et al. 2021	<p>Experimental group</p> <ul style="list-style-type: none"> - Structured MDT management - Education and training for patient and caregiver Tailored approach with Goal Attainment Scaling Home based self-management training Stroke education Home visit <p>Control group</p> <ul style="list-style-type: none"> - Unstructured MDT management 	<ol style="list-style-type: none"> 1. Subscale autonomy outdoors of IPA showed a significant effect (-2.15, P = .047). 2. Caregiver Self-Rated Burden vas scale demonstrated a significant favourable effect (1.23, p = .048).
Wenborn et al. 2021	<p>Experimental group</p> <ul style="list-style-type: none"> - Tailored home-based intervention. - Caregiver coaching for problem-solving skills and coping strategies <p>Control group</p> <ul style="list-style-type: none"> - Treatment as usual 	<ol style="list-style-type: none"> 1. Dyads in the experimental group set an average of 4.09 goals each, of which 91% were fully or partially achieved.
Ben Mortenson et al. 2018	<p>Experimental group</p> <ul style="list-style-type: none"> - The home-based Assistive Technology Provision, Updating, and Tune-Up (ATPUT) Program - Tailored goals directed - Working collaboratively with the care recipient and family caregiver, problematic activities were identified and prioritized. Recommendations for AT Financial assistance to repair or acquire new AT Receipt of AT in a prompt manner and training Additional follow-up visits. <p>Control group</p> <ul style="list-style-type: none"> - Customary care 	<ol style="list-style-type: none"> 1. The experimental intervention addressed significantly more dyad-identified problematic activities. 2. Caregivers' activity-specific and overall burden decreased significantly for both group
Lee et al. 2018	<p>Experimental group</p> <ul style="list-style-type: none"> - Home-based intervention. - Structured MDT management - Tailored goals directed - Caregiver education and training on Basic and instrumental ADL Adaptive aids - Home Modification <p>Control group</p> <ul style="list-style-type: none"> - No active rehabilitation service 	<ol style="list-style-type: none"> 1. Experimental group showed significant improvements in all outcomes. 2. The experimental group demonstrated a significant reduction in hospital services utilization.

This study also involved caregivers (N=10), predominantly female, except for one male (N=1). The mean age of the caregivers was 46.6 years, with an average caregiving duration of 17.5 months. The older adults cared for by these caregivers had a mean age of 68.9 years. Caregivers were either daughters or spouses, with five single daughters (N=5) among the female caregivers. Furthermore, six caregivers (N=6) lived in urban areas. The demographic details of these participants were presented in Table 2.

- Themes and Subthemes

In this study there were five themes and 23 sub-themes were derived and illustrated in Figure 1.

Theme 1: The importance of caregiver training in activities of daily living

The OT highlighted the importance of caregivers in involving older adults in daily tasks, like hair brushing, to maintain their abilities and self-esteem, adhering to the “use it or lose it” principle. The conversation also underscores the critical importance of caregiver training to prevent complications such as deconditioning, pressure sores, deformities, stiffness, cognitive decline and caregiver burden. The OT pointed out that caregivers helped to maintain treatment by implementing home programs and making instructions clearer for the elderly.

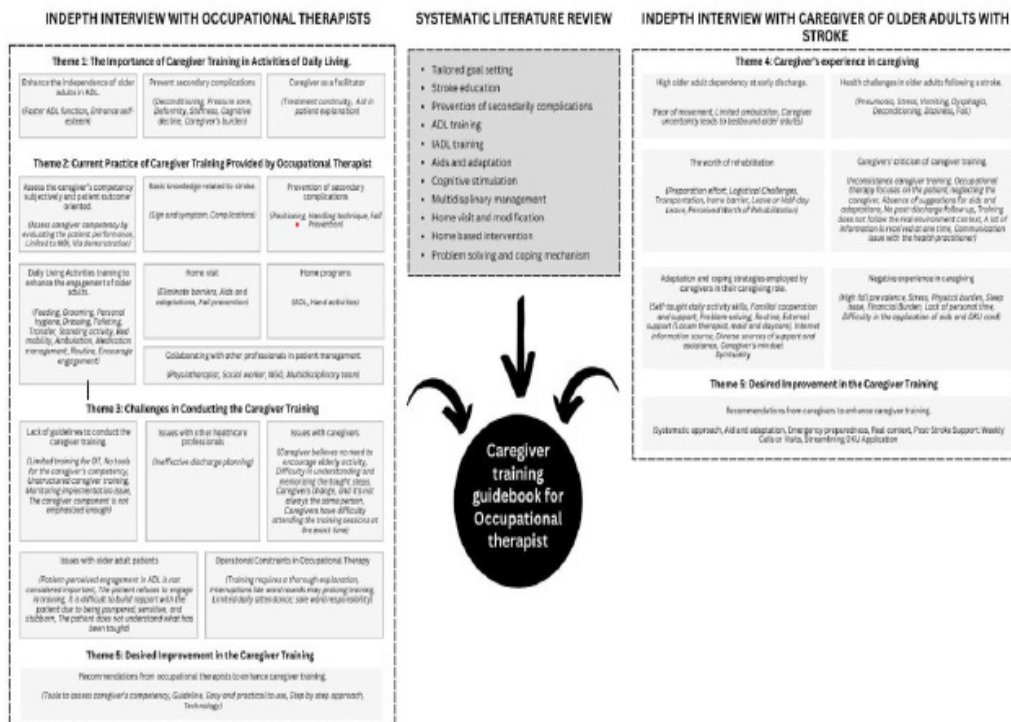


FIGURE 1: Framework of the guidebook

TABLE 2: Demographic information of the participants following study phase.

Phase 1: In-depth Interview	Occupational Therapist (n=6)	Age	Race	Gender	Marital status	Educational level	Working Duration	Place of work	
	OT 1	33	Others	F	Single	Bachelor's Degree	9 years	Private hospital	
	OT 2	32	Malay	M	Single	Ph.D. candidate	10 years	Government and university hospital	
	OT 3	33	Malay	F	Married	Diploma	11 years	University hospital	
	OT 4	43	Others	F	Married	Bachelor's Degree	18 years	University hospital	
	OT 5	36	Malay	F	Married	Bachelor's Degree	14 years	University hospital	
	OT 6	37	Chinese	F	Married	Bachelor's Degree	15 years	Government and university hospital	
	Caregiver /Patient (n=10)	Age	Race	Gender	Marital status	Education level	Caregiving Duration	Relationship	Area
		C P		C P					
	C1	36	Malay	F	Single	Bachelor's Degree	4 years	Daughter	Urban
	C2	57	Malay	F	Married	High school	1 year	Spouse	Urban
	C3	63	Malay	M	Married	Diploma	2 years	Spouse	Non urban
	C4	29	Malay	F	Married	Diploma	1 month	Daughter	Urban
	C5	52	Malay	F	Single	High school	6 months	Daughter	Urban
	C6	51	Malay	F	Married	High school	3 years	Spouse	Non urban
	C7	56	Malay	F	Single	Bachelor's Degree	1 year	Daughter	Urban
	C8	25	Malay	F	Single	High school	3 months	Daughter	Non urban
	C9	32	Chinese	F	Single	Bachelor's Degree	9 months	Daughter	Urban
	C10	65	Chinese	F	Married	High school	2 years	Spouse	Non urban

continued...

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Phase 2: Focus Group Discussion	Expert (n=10)	Age	Race	Gender	Marital status	Education level	Working experience	Clinician/ Academician
	E1	37	Malay	F	Married	Ph.D Candidate	5 years	Academician
	E2	37	Malay	M	Married	Ph.D	5 years	Academician
	E3	37	Malay	M	Married	Bachelor's Degree	12 years	Clinician
	E4	35	Malay	F	Married	Bachelor's Degree	11 years	Clinician
	E5	32	Malay	M	Married	Master	5 years	Clinician
	E6	33	Malay	F	Married	Diploma	6 years	Clinician
	E7	33	Malay	F	Single	Bachelor's Degree	9 years	Clinician
	E8	33	Malay	M	Married	Bachelor's Degree	8 years	Clinician and the founder of the Center for Caregiver Service
	E9	46	Malay	F	Married	Master	6 years	Clinician
Phase 3: Cognitive Interview	Occupational Therapist (n=6)	Age	Race	Gender	Marital status	Educational level	Working duration	Place of work
	COT1	24	Chinese	F	Single	Bachelor's Degree	1 year	Private hospital
	COT2	38	Chinese	M	Married	Bachelor's Degree	14 years	Private hospital
	COT3	25	Malay	M	Single	Bachelor's Degree	2 years	Private rehabilitation centre
	COT4	25	Malay	F	Single	Bachelor's Degree	2 years	Private rehabilitation centre
	COT5	26	Malay	F	Single	Bachelor's Degree	3 years	Private rehabilitation centre
	COT6	25	Malay	F	Single	Bachelor's Degree	3 years	Private rehabilitation centre

C: Caregiver; P: Patient; F: Female; M: Male; Ph.D: Doctorate of Philosophy

“Caregiver training is crucial because the involvement of family members at the early stage is vital. Without their participation, there won’t be continuity in what we do, and the patient won’t improve.” (OT1, 33, O, F)

Theme 2: Current practice of caregiver training provided by occupational therapist

Theme 2 explored the current practices of caregiver training provided by OTs. The assessment of caregiver competency is conducted through subjective evaluations with a patient outcome-oriented focus, involving the observation of patient performance and demonstrations. The scope of the assessment is limited to the Modified Barthel Index (MBI).

“Usually, we use the Modified Barthel Index (MBI). Then, we provide training to the caregiver, and after two or three days, we review the patient. If there’s improvement and we have already taught the caregiver in terms of that training, it means the caregiver has assisted.” (OT 2).

“Commonly we use MBI.” ((OT1, 33, O, F), (OT2, 32, M, M), (OT4, 43, O, F), (OT6,37, C, F)).

Caregiver training included basic education on stroke, covering signs, symptoms, and risk factors, as well as the prevention of secondary complications. The training also incorporated a comprehensive focus on daily living activities to enhance the engagement of older adults, covering various tasks such as feeding, grooming, personal hygiene, dressing, toileting, transfer, standing activities, bed mobility,

ambulation, medication management, routine establishment and encouragement of engagement. Additionally, the training included guidance on correct positioning, handling techniques and strategies to prevent falls. The OT noted that they conducted home visits, physically or virtually, to pinpoint obstacles, thereby ensuring safe engagement in daily activities at home. These visits also involved suggesting appropriate aids and adaptations. The OT in this study emphasised home programs, particularly those focusing on activities of daily living (ADL) and hand-related exercises, as part of caregiver training, a point also confirmed by the caregivers.

“First, I educate and train the patient. Then, we train the caregiver and incorporate the activities we practiced into the home program.” (OT2,32, M, M)

“The therapist always tells her to do exercises, like lifting balls and all that.” (C1, 36, M, F)

Finally, occupational therapists collaborated with professionals such as physiotherapists, social workers, non-governmental organisations (NGOs), and other members of the multidisciplinary team to ensure a comprehensive and well-coordinated care plan for stroke patients.

“I collaborate with social workers or any social welfare, including non-government organisations, to help patients.” (OT4, 43, O, F)

“If a patient is planning for a long stay in the hospital within three weeks, then we will have a family conference together with all

multidisciplinary team members involved to ensure our goals are communicated to the caregiver and other team members.” (OT5, 36, M, F)

Theme 3: Challenges faced by occupational therapists in providing caregiver training

OTs experienced difficulties in providing caregiver training due to limited guidelines, instructions, and materials for assessing caregiver competency. Monitoring these implementations was challenging, and caregivers' needs often went unaddressed. Additionally, there are breakdowns in communication with multidisciplinary teams, especially when planning post-discharge services. OTs also often faced difficulties with caregivers who believed that elderly activities were unnecessary, had trouble in understanding and remembering instructions, frequently changed and struggled with punctuality. Some older adults may disregard the importance of daily activities, refused to participate in training, or had trouble in following instructions. OTs may also find it challenging to build rapport with patients they perceived as pampered, sensitive, or stubborn. Operational constraints, like time limitations, interruptions from ward rounds, and a limited number of OTs, made it even harder to provide effective caregiver training. Overcoming these challenges was essential to improving and refining training programs.

“We focus on the patient. Then, we are not aware that the caregiver also needs to be assessed and intervened with.” (OT3, 33, M, F)

“Sometimes, patients are discharged suddenly without our knowledge.” (OT2, 32, M, M)

“During caregiver training, the caregiver is not always the same person; it constantly changes. As therapists, we have to train again and again for the same things.” (OT4, 43, O, F)

“As sometimes we are (OT) not in the ward (attend to other patients in different wards), affecting communication about patients with other medical practitioners such as doctors.” (OT3, 33, M, F)

Theme 4: Caregiver's experience in caregiving and training

Caregivers faced significant challenges in post-stroke care due to high dependency, fear of movement, limited mobility, and uncertainty about caregiving skills, leading to bedbound patients. Older adults' health issues post-stroke, such as pneumonia, stress, vomiting, dysphagia, deconditioning, dizziness, and fall risks, complicating caregiving further. Caregivers reported struggle with rehabilitation sessions due to preparation efforts, logistical issues, and work-related challenges but find them beneficial for patient progress. Feedback on caregiver training highlighted inconsistencies and a focus on the patient over the caregiver. There was a lack of suggestions for aids and adaptations, insufficient post-discharge follow-up, and training that did not reflect real-life environments. Caregivers also claimed they feel overwhelmed by the volume of information and report communication issues with health practitioners.

Throughout the caregiving experience, caregivers implemented their own adaptation and coping strategies, including self-taught skills, familial cooperation, problem-solving, routines, external support, internet resources, diverse assistance sources, caregiver mindset and spirituality. However, they also faced negative experiences such as patient's falls, stress, physical burden, sleep issues, financial strain, lack of personal time, and difficulties with aids and OKU card application.

"In the initial weeks, we lacked confidence in transferring him, particularly for bathing." (C9, 32, C, F)

"Getting to follow-up rehab is tough because we don't have lift in our flat. My childrens have to carry my husband up and down the stairs, which is hard. They also need to take time off work, and it's affecting their job record." (C2, 57, M, F)

"My dad does better with professionals at the hospital than with us; he doesn't take us as seriously. But getting ready for a one-hour session can take up to half a day. It's a sacrifice, but as long as it helps, we're willing to manage it." (C9,32, C, F)

"The therapist only train my husband (patient) to stand up but no me." (C6, 51, M, F)

"The therapist just shows us once and has us try it, but it doesn't feel like real training. We often need to repeat it. The hospital setup doesn't match our home, like the bed position, so we have to adjust back home. It's all done in a hospital room, not like our actual home setting. It feels similar

to just watching a tutorial on YouTube. But are we doing it right at home? We can't record in the hospital, so we have to rely on memory, which makes doing it on our own quite different." (C9,32, C, F)

"C9: It was trial and error (car transfer). I used to try and find out what was suitable for us. That was the biggest challenge during the first time when we were discharged because no one taught us how to transfer in small spaces or to the car. The therapists only taught us how to do it when discharged from the bed to the wheelchair." (C9,32, C, F)

"I also feel hurt when siblings are not very helpful in caregiving." (C5, 52, M, F)

Theme 5: Desired improvement

Theme 5 addressed the desired improvements in conducting caregiver training, featuring recommendations from both OTs and caregivers. OTs proposed enhancements such as the introduction of tools to assess caregiver competency, clear guidelines, user-friendly resources with a step-by-step approach, and the integration of technology for effective learning. On the other hand, caregivers suggest a systematic training approach, guidance on aids and adaptations, emergency preparedness training, real-life context relevance, and post-stroke support mechanisms like weekly calls or visits.

"I want to learn a systematic way to care for elderly stroke patients and know which structured home activities can improve their performance." (C7,56, M, F)

"We should receive education on how

to lift a stroke survivor when they fall.” (C7,56, M, F)

“Right after the stroke, a weekly visit or call for 1 or 2 months to answer our care questions would be really helpful.” (C6, 51, M, F)

Additionally, caregivers recommended streamlining the application process for the OKU (Persons with Disabilities) card.

“Finding out late about my dad’s OKU eligibility was tough. A simpler process and better communication on OKU could really help.” (C9, 32, C, F)

Based on the findings from Phase One, a framework guiding the guidebook’s development was established, informed by a systematic literature review and interviews with OTs and caregivers. This framework was illustrated in Figure 1.

Phase Two: Evaluate Guidebook Validity in a Focus Group with Experts Demographic Characteristics of the Expert in Focus Group Discussion

Nine experts (N=9), comprising OTs (N=7) and academicians (N=2), participated in the FGD. The experts included one Ph.D. holder (N=1), one Ph.D. candidate (N=1), one with a Master’s degree (N=1), four with Bachelor’s degrees (N=4), and one with a diploma (N=1). The mean working duration among these experts was 7.4 years, and one (N=1) was also the founder of a caregiving company. The mean age of the experts was 35.9 years. Their diverse backgrounds enriched the data, as detailed in Table 2.

(i) Focus Group Discussion

Two major themes emerged from the FGD session consisted of (i) information sufficiency, and (ii) words and sentences preciseness.

Theme 1: Information sufficiency

The insights from experts underscored the need for improved information in the guidebook. Expert E6 advocated for the use of specific examples, such as food, safety, and emotional connection, to elucidate the concept of human needs. Another expert (E2) suggested organising human needs according to Maslow’s hierarchy, providing a structured framework for therapists.

“I think if just noted human need, it is too broad. You can put an example to make it easier to understand. For example human needs such as foods, safety, and love.” (E6, 33, M, F)

“Yes. You also can put human need in the bracket (Maslow Theory). So, OT will easily note what human need that you mentioned.” (E2, 37, M, M)

Additionally, E4 recommended employing visual aids, like pictures, to enhance learning.

“For every single activity, I suggest you incorporate one or two pictures of dos and don so that easily to see the mistakes during the activity. Better learn with the pictures.” (E4, 35, M, F)

The experts highlighted the importance of detailed information and proposed a

focus on delirium management, with a suggestion from E9 to consolidate this information into a single infographic page. Multiple experts supported this idea (E3, E4, E6, E9), emphasising its effectiveness in summarising key points about delirium.

“Delirium is common in elderly stroke patients, and some OTs might not know the best management strategies. Focusing on this, especially on behavioral and environmental adjustments, could be beneficial, as appropriate treatment can greatly improve outcomes.” (E5, 32, M, M)

“We agree as well. You can put it in infographic form” ((E3, 37, M, M), (E4, 35, M, F), (E6, 33, M, F), (E9, 46, M, F))

Experts highlighted the importance of fall prevention at night, suggesting the use of glow-in-the-dark markers for safer pathways. E5 emphasised adding strategies for preventing falls during night-time bathroom visits. E9 recommended practical night safety measures like illuminated paths, bedside mobility aids, and sensor lights. E1 called for a broad safety approach in homes, focusing on flooring, furniture, lighting and stairs, and stressed the need for effective anti-slip solutions while cautioning against some mats' limitations. Besides fall prevention, ensuring overall housing safety and recommending anti-slip floors for those able were also advised. Experts also advocated for including home visit training for caregivers to enhance OTs' skills comprehensively.

“Is it okay, if you add on fall prevention at night as there are many cases of older adults falling at night when they want

to go toilet. For example, by tagging the pathway with glowing in the dark.” (E5, 32, M, M)

“Or can suggest switching on the light for the pathway and toilet at night? And also, can put the mobility aid or commode chair aside patient's bed.” (E9, 46, M, F)

“Usually, we will provide them with sensor light. Put the sensor at the pathway and toilet. When older adults go through the pathway, the sensor will detect the movement and switch on automatically. It is much better and sensor also you can get in a low price.” (E1, 37, M, F)

“There are several important elements that you have to focus which include flooring, furniture, lighting, bathroom, staircase, and stairway” (E1, 37, M, F)

“We generally advise against anti-slip mats for patients due to the risk of tripping, as they often don't fit well in the bathroom. Instead, we recommend keeping the floor dry. For those who can afford it, switching to anti-slip flooring is a safer option.” (E1, 37, M, F)

“There is an anti-slip mat that is safe. It is the large and heavy types and fits into the size.” (E5, 32, M, M)

“But if you want to use the anti-slip mat, it needs to be specially customised accordingly to the size of the bathroom.” (E1, 37, M, F)

Theme 2: Words and sentences preciseness

The experts agreed on the need to

make the training materials clearer by changing the front page layout. E4 pointed out that the materials seemed to be aimed at caregivers, which could be confused. The recommendation was to clearly state "Occupational Therapist's Guidelines" on the front page to show it's meant for therapists. E9 suggested using "Occupational Therapist Approach" as another clear indicator. All experts backed this change, emphasising the importance of clarifying the training's target audience right from the start to avoid confusion.

"I think this training is focused on occupational therapist guidelines but somehow the front page still looks confusing. It looks like the caregiver is the first user. So, I suggest that you highlight 'occupational therapist's guideline word on the front page" (E4, 35, M, F)

Experts agreed to highlight "Occupational Therapist Approach" on the front page, but E4 suggested to clarify that stroke was not an age-related issue. E9 found the depression explanation unclear, and E2 recommended a chart for better understanding.

(ii) Face and Content Validity

After the FGD session, corrections were made based on the expert's suggestions and a final discussion among all authors. In the end, the guidebook consisted of separate 3 Parts (Part A: Psychoeducation, Part B: ADL Training, Part C: IADL, Stress Management of Caregiver and Home Program). Altogether this guidebook consisted of three parts, 11 topics, and 72 subtopics.

- Face Validity

Table 3 showed the results for face validity and content validity of the guidebook which included the percentage of agreement among expert reviewers. The results showed excellent face validity for the developed guidebook for OTs to conduct caregiver training. The results also showed excellent content validity for all items (72 items) whereby both the I-CVI and S-CVI scores were 1.00. Content and description of all subtopics obtained an excellent degree of agreement among experts.

Phase Three: Refine Guidebook Clarity and Cultural Sensitivity

(i) Demographic Characteristics of the Occupational Therapists (Cognitive Interview)

In the third phase of our study, which focused on cognitive interviews, six OTs (N=6) participated. The mean age of the OTs was 27.2 years, and the mean duration of working experience was 4.2 years. Additionally, all participants held bachelor's degrees and worked in private hospitals (N=2) and rehabilitation centers (N=4). The demographic details of these participants were presented in Table 2.

- Cognitive Interview

Three major themes emerged from the cognitive interview with the OTs consisted of (i) Optimising the guidebook clarity, (ii) Recommendation to enhance the practicality of the guidebook in clinical settings, (iii) OTs' appreciation of the guidebook

TABLE 3: Face validity, content validity for I-CVI and S-CVI scores for each subtopic of the guidebook

Expert opinion	Yes		No	
	(No. of expert)	(%)	(No. of expert)	(%)
Suitability of the font size	9	100	0	0
Suitability of the font type	9	100	0	0
Topic and subtopic arrangement and tidiness	9	100	0	0

Topic	I-CVI				S-CVI/UA
	Relevance	Clarity	Simplicity	Ambiguity	
Part A: Psychoeducation					
1. Introduction of the package	1.00	1.00	1.00	1.00	1.00
2. Aging	1.00	1.00	1.00	1.00	1.00
3. Stroke among older adult	1.00	1.00	1.00	1.00	1.00
4. ADL among older adults with stroke	1.00	1.00	1.00	1.00	1.00
5. Caregiving of older adults with stroke	1.00	1.00	1.00	1.00	1.00
6. Sheets	1.00	1.00	1.00	1.00	1.00
Part B: ADL Training					
7. The basic principle in caregiver training	1.00	1.00	1.00	1.00	1.00
8. ADL training	1.00	1.00	1.00	1.00	1.00
Part C: IADL, Stress Management of Caregiver and Home Program					
9. IADL	1.00	1.00	1.00	1.00	1.00
10. Stress management	1.00	1.00	1.00	1.00	1.00
11. Home program	1.00	1.00	1.00	1.00	1.00

Theme 1: Optimising guidebook clarity

The OTs emphasised the overall clarity and ease of understanding for their profession. They also addressed the initial confusion regarding the intended audience and the need for alternative instructional methods for caregivers.

“From a therapist’s perspective, it’s very straightforward.” (COT 1, 24, C, F)

“The Malay words used in this guidebook are easy to understand, like everyday language. The pictures are also clear.” (COT 3, 25, M, M)

“At first, I thought this guidebook was for caregivers.” (COT 6, 25, M, F)

“In this guidebook, it is stated to place the walking frame 15 cm in front, as we occupational therapists have learned. However, when explaining to caregivers, is there another way to describe the distance without using measurements, making it easier for them to visualise?” (COT 5, 26, M, F)

“I believe this is more about grammar or word usage. ‘Alat mandi mudah untuk dicapai’ is preferable to ‘alat mandi mudah capai.’ Additionally, another sentence

that requires grammatical improvement is 'meningkat keberdikarian' rather than 'tingkat keberdikarian.' (COT 6, 25, M, F)

Theme 2: Recommendation to enhance the practicality of the guidebook in clinical settings

The OT claimed the current guidebook was effective for OTs but too detailed for caregivers. If a caregiver version is developed, it should be simpler. Additionally, an English version was suggested, as some caregivers did not understand Bahasa Malaysia. Therapists also suggested to include the techniques for shoes and stockings, a flowchart for applying for a disability card, general healthy food information for older adults, body mechanics reminders in the ADL techniques section, ADL strategies for stroke patients with visual perception issues, awareness of medication side effects, and strategies for caregivers with musculoskeletal issues like back pain.

"The current version is comprehensive and works well for occupational therapists. However, for a caregiver and patient guidebook (in the future), it might be too information-heavy. A simpler version would be easier for caregivers to use. (COT 2, 38, C, M) I think it would be better to include a flowchart for the process of applying for a disability card, as many caregivers and even occupational therapists are unsure about the procedure." (COT 1, 24, C, F)

Theme 3: Occupational therapists' appreciation of the guidebook

The OT, during the cognitive

interview, appreciated the guidebook's comprehensiveness in addressing often-overlooked health issues related to older adults with stroke. The therapist highlighted the actual burdens faced by caregivers and the psychological and financial supports available to them. Additionally, the importance of the caregiver competency assessment developed for the guidebook was emphasised.

"Occupational therapists know the techniques, but sometimes we can get off track and skip steps. This guidebook serves as a reminder of the steps and helps us highlight important points without over-explaining, which can confuse caregivers and patients." (COT 1, 24, C, F)

"The content is comprehensive, including aspects such as oral hygiene. When I read it, I realised that oral hygiene is also part of our roles as occupational therapists." (COT 5, 26, M, F)

"I personally believe the assessment in this guidebook is fundamental. Occupational therapists can start the training early, before caregivers develop their own techniques, which might be unsafe. Starting training early prevents the need to change incorrect behaviors later on, which can be more challenging for occupational therapists." (COT 1, 24, C, F)

DISCUSSION

This guidebook's content and characteristics integrate insights from a systematic literature review, input from both OTs and experienced caregivers, and validation by experts in the fields of stroke and geriatric occupational therapy.

In the field of research, the involvement of service users is in line with the democratic principles of implementation research and underlines the importance of contextual understanding for the success of interventions (Grindell et al. 2022; Ramos et al. 2020; Singh et al. 2023). Consequently, the guidebook incorporates essential elements such as structured caregiver training, a client-centered approach, goal-directed strategies, post-discharge support, emergency preparedness, and caregiver coping and adaptation strategies. In general, this guidebook is designed for self-learning and does not currently require training. However, future studies on its feasibility will determine its appropriateness for self-learning as preparation for caregiver training and its use during training. A checklist for each topic ensures that the OT has reviewed the guidebook. The guideline should be used as early as possible after a medical officer refers the patient to occupational therapy for ADL training or caregiver training in the ward. The caregiver training, guided by this book, involves a minimum of three sessions, each lasting 30 minutes to 1 hour. After discharge, the training continues for at least one month, with weekly sessions lasting 30 minutes to 1 hour. These outpatient sessions can be conducted in person or virtually, focusing on the progression of caregiver competency in three selected ADLs and discussing any caregiving issues at home.

This study has identified several issues in current caregiver training, highlighting inconsistencies that result in caregivers either not receiving any training or receiving incomplete training. Contributing factors to this problem include the absence of training for OTs and a lack of available

guidelines. The authors also observed that in this study, OTs often encounter challenges due to the absence of tools to assess caregivers, leading to unstructured training and challenges in monitoring progress. As highlighted by Asaba et al. (2017), assessment tools are integral for OTs, aiding in intervention planning and providing baseline and outcome measures for progress tracking. In response to this issue, the guidebook introduces a caregiver competency assessment tool, ensuring a structured approach to intervention and facilitating progress monitoring.

The interview findings underscore the inadequacy of education on stroke complications, extending beyond subluxation and falls to encompass prevalent issues in older adults like pneumonia, dysphagia, delirium, apathy, and depression. As a result, this guidebook brings attention to the aging process and provides insights into how strokes can influence various health conditions and psychological well-being for both older individuals and their caregivers. Furthermore, this guidebook provides detailed step-by-step guidance for critical ADL, making it a useful tool for both directing and referencing in ADL training (Razaob et al. 2020).

Additionally, the findings emphasise the crucial role of health practitioners in supporting caregivers during the early stage of stroke, especially within the initial month post-discharge. Given the chronic nature of stroke and aging, coupled with the significant caregiving demands immediately following discharge, caregivers grapple with physical, mental, and psychological fatigue. Additional challenges arise for those who are married or employed, impacting their family and

work responsibilities. This aligns with findings from a study by Farahani et al. (2020), indicating that the highest need for professional support is identified within the first two weeks post-discharge.

Therefore, this guidebook underscores the significance of post-stroke support by incorporating weekly phone calls or virtual rehabilitation sessions by OTs during this crucial period. Furthermore, addressing the financial concerns highlighted in this study, this guidebook meets caregivers' needs by furnishing information on the OKU (Orang Kurang Upaya - "disabled person") application and delineating other available financial support options in Malaysia. Moreover, concerning the psychological support required for caregivers in this study and another study in Malaysia (Sidek et al. 2022), this guidebook also offers information on available free psychological support services in Malaysia to aid caregivers in building resilience in their caregiving role.

In the present study, there is a recognised deficiency in current caregiver training, particularly in the aspect of emergency preparedness. Interviews with caregivers have underscored a significant occurrence of post-stroke falls, aligning with prior studies that have identified falls as a common consequence of strokes (Ahmad Ainuddin et al. 2021). A noteworthy aspect revealed in these discussions is caregivers expressing uncertainty not only about fall prevention but also about the actions to take if a patient fall. This includes concerns about proper lifting techniques and post-fall measures, such as whether to transport the older adults to the hospital. The ambiguity extends to medication management, with caregivers questioning what steps to take if a patient experiences

low blood glucose, specifically whether insulin should still be administered. Consequently, the guidebook addresses these uncertainties by guiding actions caregivers should take in the event of a patient fall and in managing medications. This discovery prompts a revolution in how OTs approach education related to falls and medication management.

The findings in the present study also recognise the importance of training within the actual home environment and acknowledge caregivers' adaptation strategies. The guidebook integrates these strategies to aid OTs in comprehending and supporting caregivers, promoting resilience, and alleviating the burden associated with caregiving. However, the study also warns against self-learning daily activities, noting instances where patients implemented incorrect techniques in activities of daily living, particularly in ambulation. Earlier studies have identified numerous complex components of gait, including gait kinematics, asymmetries, and spasticity, as contributors to the risk of falls (Wang & Bhatt 2022; Wei et al. 2017). Therefore, underscoring the importance of proper ambulation training provided by professional rehabilitation practitioners becomes essential compared to self-learning. This emphasis is vital to ensure that caregivers receive the necessary training to prevent unsafe adaptations.

Limitation

This study focused on family caregivers for the elderly but missed domestic workers' perspectives, a key group in Malaysia's informal caregiving. Despite including Malay, Chinese, and other ethnicities, it excluded Indian community insights.

Recognising these gaps, future research should broaden to capture diverse caregiver experiences, enriching the guidebook's depth and cultural relevance.

CONCLUSION

In summary, the guidebook has been developed by incorporating reviews of previous studies and insights from OTs and caregivers in Malaysia. The contents and features of the guidebook have been refined through revisions guided by input from experts and clinicians. Strong evidence of face and content validity underscores the guidebook's suitability for practical use. OTs can utilise its contents to empower caregivers, thereby improving the daily functional abilities of stroke-affected older adults. To strengthen its reliability, additional validation through feasibility and effectiveness studies would further affirm the guidebook's effectiveness and usefulness.

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