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Supporting caregivers of people with dementia: insights from Demensia KITA mobile application online content development

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Dementia significantly impacts caregivers, particularly in low and middle-income countries where support is often inadequate. Given the gap in affordable and culturally relevant digital resources for Malaysian dementia caregivers, we developed "Demensia KITA," a mobile application (app) specifically tailored to their needs. This study utilized a theoretical framework proposed from existing literature and the "Model of Carer Stress and Burden". This paper discusses our app content development, highlighting key findings and challenges. To assess caregivers' needs, the Nominal Group Technique (NGT) with five dementia caregivers was conducted, followed by a Focus Group Discussion (FGD) with eight medical professionals. Both sessions were conducted online via Google Meet. In the NGT, ideas were generated, organized, prioritized, reviewed, and refined by medical professionals in the FGD. Content relevant to addressing the complexities of dementia caregiving was then discussed. Topics were either adapted from established modules or newly developed from credible sources. Subsequently, these were organized into modules and themes, and subsequently underwent expert validation. From the NGT, three key domains emerged: Knowledge, Services, and Support. These were further organized into two modules: 'Patient Care for Caregivers' and 'Caregiver Wellbeing'. Within these, twelve sub-modules were identified, covering a range of topics including basic knowledge on dementia, patient care, nutritional management, oral and dental care, simple exercises, daily activity and memory rehabilitation, service directories, support groups, emotional and stress management, welfare assistance, and daily motivation. This framework was developed to address the specific needs of dementia caregivers in terms of psychoeducation, psychosocial and caregiving skills, incorporating expert opinions in the field. This study corroborates the feasibility of online methods for mobile health app content development and encourages similar research. Future studies should evaluate Demensia KITA's effectiveness in alleviating caregiver burden across all regions, assess users' acceptance, and ensure it meets the evolving needs of Malaysian caregivers with regular updates.

Keywords Dementia, Mobile applications, Caregiver support, Health education, Content development

Dementia, though not a normal part of aging, is closely linked with old age¹. It affects approximately 7% of adults over 60^{1,2} and is a growing concern, significantly as the global population in this age group is projected to reach 2.1 billion by 2050^{3,4}. The burden is most predominant in low- and middle-income countries, home to 60% of people living with dementia (PLwD)¹. Its impact extends beyond patients to caregivers and families. Informal caregivers, often family, spend many hours each day on dementia care, a task intensified by the

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cognitive and behavioural challenges of dementia, making it a more strenuous experience than caregiving for other chronic conditions^{1,5–7}. Despite increasing dementia prevalence and an aging population, caregiver needs are often overlooked⁸. Caregiver stress, influenced by factors like inadequate support systems, high caregiving strain, limited coping skills, and behavioural issues of care recipients, can lead to PLwD social isolation^{8,9}. This isolation heightens the risk of elder abuse and often escalates the probability of institutionalization as dementia progresses, thereby increasing both care needs and associated costs⁹. In Malaysia, it has been reported that 8.5% of the seniors population is affected by dementia¹⁰; the lack of a national dementia strategy, combined with the expected increase in the aging population by 2044¹¹, underscores a significant gap in preparedness. This greatly impacts the quality of life for PLwD and their caregivers. Therefore, it is crucial to have accessible support in place to address this urgent need.

While the pace is slow, the importance of supporting dementia caregivers to enhance the well-being of PLwD is increasingly being acknowledged. Though interventions such as telemedicine, in-person consultations, psychoeducation, and emotional support exist to aid PLwD caregivers, their wide dissemination is limited, leading to inaccessibility¹². Nevertheless, with the rise in the use of mobile devices, the development of medical software applications (apps) for these platforms has enhanced, offering a new path for health education and intervention delivery^{13,14}. This surge in the use of mobile technology has significantly altered many aspects of health practice, including but not limited to health education, promotion, and interventions for dementia caregivers within community settings.

Following the context mentioned above, research shows that healthcare mobile apps, including those for dementia care, can effectively enhance the quality of life (QOL) of patients and caregivers while reducing caregiver burden^{5,15–18}. However, lower- and middle-income countries (LMIC) still lack access to such modern supports. Prior research highlights the significant challenges encountered by primary caregivers in areas with scarce dementia care resources, where the caregivers lack sufficient support^{19–21}. Many available resources overlook the specific socio-cultural and linguistic needs of caregivers, particularly in low- and middle-income countries (LMIC), highlighting the critical need for culturally specific apps designed for particular settings like Malaysia^{10,22}. Most current app contents are mainly in English, disregarding local caregiving traditions, social customs, and cultural values, and can be costly^{16–18,23}, which is also the case in Malaysia. Based on our findings, the few available apps in Malaysia often overlook essential elements such as basic dementia knowledge, caregiving techniques, and coping strategies for home-based care^{24–27}. Based on the literature, enhancing caregivers' knowledge could improve their stress and burden^{28–31}. Nevertheless, finding a mobile application that offers comprehensive content on the complexities of dementia caregiving knowledge, while being tailored to the specific needs of caregivers particularly in Malaysia, remains a significant challenge.

The development of mobile app content for caregivers of PLwD involving multiple stakeholders is challenging for several reasons. Clinicians and caregivers are often constrained by their responsibilities and may not be able to leave their workplaces or homes, which makes it necessary to use research methodologies that can accommodate their availability^{32,33}. Online meetings can be a practical solution in this case as they enhance collaboration and participation in research activities. The literature review reveals that online methods for qualitative research have not been utilized to their full potential, but there is a growing trend towards their adoption. However, developing countries face several challenges, including poor connectivity, unstable internet, varying technical skills among participants, audio-visual issues, and platform limitations, as highlighted in recent literature³⁴. In terms of content development, understanding the specific needs of dementia caregivers in local contexts is crucial. Caregiver-focused apps differ from patient-centred ones, as they require the inclusion of stress management, coping strategies, and practical tips while also considering the varying health literacy levels of users^{35–37}. This means that such content should range from basic dementia knowledge to correct caregiving techniques, tailored to and accessible for caregivers of varying culture, educational and technical backgrounds. Thus, designing an app that is both informative and educational while simultaneously meeting the varied needs of users in an accessible manner presents a substantial challenge.

There is a lack of suitable apps available for Malaysian PLwD caregivers and limited applicability for LMIC. Therefore, there is a critical need to develop culturally sensitive, language-accessible digital solutions that address their unmet needs. To achieve this, this study employs a theoretical framework combining social network and support theories^{38,39}. The focus was on the importance of psychosocial support and knowledge in direct caregiving skills³⁸. The 'Model of carer stress and burden'³⁹ was used to examine how enhanced caregiver knowledge and psychoeducational interventions can mitigate caregiver burden and improve their overall health and wellbeing. These insights informed the development of "Demensia KITA", aiming to strengthen caregiving skills, psychosocial and psychoeducation support for Malaysian caregivers. This paper aims to: (i) elaborate on the content development of "Demensia KITA" using an online platform; and (ii) discuss challenges and insights from the online content development process.

Methods

The overall development of the mobile app was done in three-phases, which were outlined in our study methodology protocol published elsewhere⁴⁰. This paper describes Phase I, which involved content development, and shares the process and outcomes of this phase, as well as the insights gained during the various steps we undertook. During the app content development, we integrated findings from previous literature on caregiver needs. Based on previous literature, dementia caregivers have three distinct needs: medical, educational, and psychosocial^{41–44}. Medical needs encompass increased knowledge of the care recipients' disease and condition^{45,46}. Educational needs involve acquiring communication skills and managing cognitive and behavioural disorders^{41,42,44}. Psychosocial needs include social support and resources^{41,43,44,47,48}.

We conducted a need assessment among Malaysian dementia caregivers using the nominal group technique (NGT)⁴⁹ to validate alignment with existing literature and identify any new or different needs. Additionally, we held focus group discussions (FGD)⁵⁰ with professional clinical stakeholders to gather insights, perspectives, and achieve consensus based on the NGT findings. The researcher leading both NGT and FGD session had some experience with both methodologies. Moreover, the sessions were conducted in guidance and consultation with a team member who had expertise in qualitative research. This ensured the sessions adhered to appropriate methods, offered clear guidance, minimize bias, and facilitated accurate execution. Both sessions were held online to accommodate participants' preference and overcome logistical constraints and busy schedules³³. The study commenced in September 2022, and the content development process took 7 months to complete.

Study participants

Figure 1 depicts the overall process of recruiting participants and collecting data for the study. The study participants were recruited from two Malaysian public hospitals that specialize in geriatric and dementia care and offer a special clinic for PLwD—Hospital Kuala Lumpur (HKL) and University Malaya Medical Centre (UMMC). Both hospitals are located in central Peninsular Malaysia, serving the densest populations in Malaysia. Liaison officers from HKL and UMMC were appointed to facilitate the recruitment process and to take on the primary role of experts responsible for supervising the content of the mobile app.

Nominal group technique sessions

NGT participants were recruited based on purposive sampling, guided by these inclusion criteria:

- i. Malaysian.
- ii. Aged 18 years or older.
- iii. Primary caregiver (primary caregiver in this study is defined as a person who helps in personal care of an older adult with dementia, regardless of their education or experience for a period of 1 month or more during the last 12 months^{51,52}) to moderate to severe dementia patients aged 60 years and above.
- iv. Have a smart mobile phone (smartphone) and knows how to use any mobile apps.
- v. Have a good understanding of Malay or English.

Additionally, we sought participants with diverse demographics and experiences with different dementia types to gain broader insights. Although the NGT sessions have been conducted with groups of between two and fourteen people, a maximum of seven has been recommended⁵³. In this study, five participants were successfully enlisted and informed consent was obtained prior to any information publication in an open access journal. Communication between researcher and participants was facilitated through Google Meet, email, and WhatsApp. Participants were briefed on Google Meet, ensuring an efficient session from their homes with stable

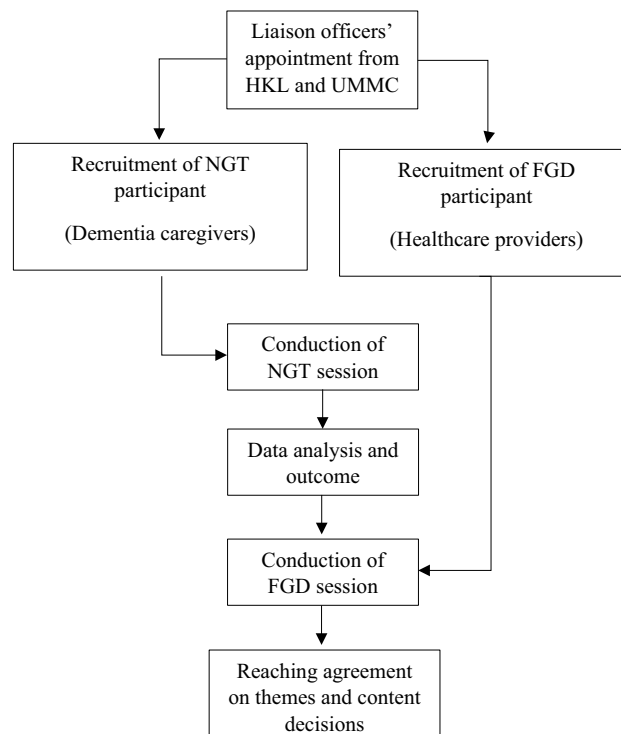


Figure 1. A process overview of participant recruitment and data collection for NGT and FGD.

audio-visual connectivity. The researcher served as a moderator and used a PowerPoint presentation to explain the process of NGT which is a four-step structured method of focusing on idea generation, recording, discussion, and voting, and address any queries.

i. Idea generation

In a 20-min independent brainstorming session for the key features of the app, participants were asked to reflect on the question, "What information or features would you include in a dementia caregiving app to aid in your daily task?". Ideas were written using preferred methods at home (papers or digital devices) fostering diverse and unbiased remote idea generation.

ii. Recording

Ideas were gathered and shared in a 'Round-Robin Sharing' session, then organized into a table, and entered into a PowerPoint presentation in real-time. The session was also audio-visually recorded for thorough documentation purposes.

iii. Group discussion

The moderator facilitated a grouping of ideas, organizing them into a few domains and presenting them in real-time for in-depth assessment. For instance, statements such as "More information about what is dementia itself", "Which drugs and supplements are safe to give to my parents", and "How to change adult diapers and care for bedridden families with dementia" were grouped under the domain "Knowledge". Meanwhile, "Location of hospitals with doctors with expertise in dementia" was categorized as "List of services", and "Finding friends to talk to when stressed out" was classified under "Support". All domains were finalized by constructing and validating the meanings of the ideas with all participants.

iv. Voting for prioritization

In a continuously moderated online session, participants ranked the app features from one (least important) to five (most crucial), with the moderator documenting these on the same presentation to prioritize key app content.

Focus group discussion session

Two weeks following an NGT session with dementia caregivers, experts convened an online FGD session through Google Meet, following methods adopted from an established guideline⁵⁰. The participants selected for the FGD session included healthcare providers with specialized expertise from various disciplines, each having a minimum of 3 years of experience in their respective fields, particularly in caring for older adults or providing specialized care and consented for participation. The liaison officers were among the eight selected experts, who contributed to the selection process to ensure a comprehensive representation from all relevant disciplines for addressing dementia caregiving complexities.

The FGD was conducted in a single session, beginning with a presentation of the NGT findings. Following this, key domains were introduced and agreed upon, as the results were consistent with existing literature. This alignment led to the selection of essential topics and content. Decisions included (i) incorporating sub-specialties from each of the eight experts as sub-modules, (ii) utilizing existing resources for content, and (iii) constructing new topics for sub-modules lacking existing guideline with other credible sources. The session ended with the experts concurring that the app's purpose would be to serve as a single hub for dementia caregiving knowledge, delivering essential, validated information in a mobile-friendly format.

Following the FGD, the researchers' team organized the app content into two main parts: one focusing on patient care for caregivers (Module 1) and the other on caregivers' support (Module 2). Subsequently, this decision was revisited and reaffirmed in consultation with the expert panels. The researcher then compiled information from expert consultations and external resources, developing content for each sub-module under their guidance. These iterative processes involved multiple editing and communications with each expert individually at different periods, through various means such as email, WhatsApp, or video calls, to seek their approval and validation for the newly developed sub-modules relevant to their expertise. English sources were translated into Bahasa Malaysia using simplified terms to increase linguistic accessibility. Certain health information and topics were summarized and converted to infographics via Canva for clarity and visual appeal. After the content was finalized, it was reviewed and approved by the liaison officers. The content development process is summarized in Fig. 2.

Ethics declarations

The study was conducted in accordance with National Institutes of Health (NIH) standards and approved by the Malaysian Research and Ethics Committee (MREC), Registration ID-22-00546-EBB (IIR) on 8 August 2022, and the Research Ethics Committee of University Teknologi MARA (UiTM) on 13 July 2022, Ethics Reference No.: REC/07/2022 PG/MR/153. Written consents were obtained from all the participants.

Results

Nominal group technique sessions with dementia caregivers

Recruitment efforts resulted in five HKL participants, with none from UMMC due to various reasons like time constraints and schedule conflicts. Despite this, the study continued with the existing participants, considering the similar profiles at both institutions. Participant demographics and characteristics are detailed in Table 1.

Ideas were generated independently and tabulated. Table 2 demonstrates that four domains emerged from the NGT session: services, knowledge, appointment system, and support.

The final step of NGT sessions, namely the voting process, had identified the most crucial and widely agreed-upon ideas from the PLwD caregivers, shaping the mobile app's content focus. Table 3 displays the top three highest-scoring domains voted on, which were support, services, and knowledge. The session concluded with a recognition of all the domains established.

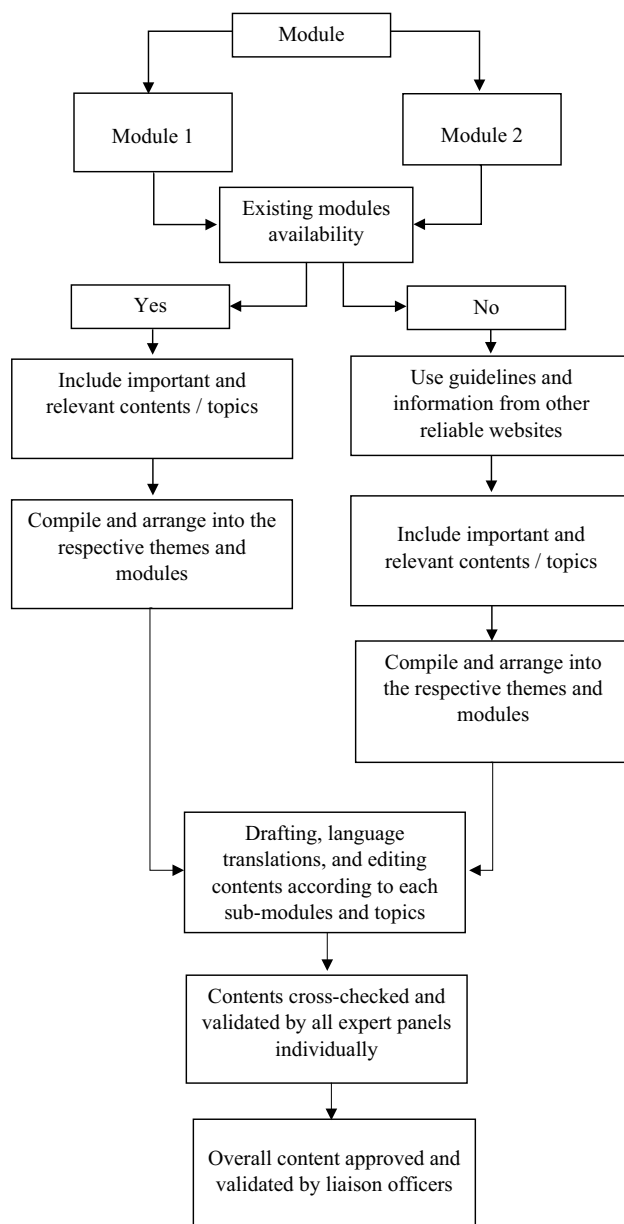


Figure 2. Content development based on module availability.

Participant	Gender	Age	Ethnicity	Monthly household income (RM)	Relationship with PLwD	Types of dementia	Years of caregiving experience
P1	Female	44	Malay	2000–2999	Children	Alzheimer’s	11
P2	Male	31	Chinese	2000–2999	Children	Parkinson	5
P3	Female	50	Malay	≥ 3000	Children	Alzheimer’s	7
P4	Female	54	Malay	≤ 999	Children	Moderate cognitive impairment	2
P5	Male	53	Indian	≥ 3000	Children	Vascular	9

Table 1. Nominal group technique participants (PLwD caregivers).

Focus group discussion sessions with an expert panel

The FGD featured the participation of eight experts from diverse specialties and disciplines, all with professional experience in geriatric care or specialized services spanning 3–21 years (Table 4). Additionally, the mobile app developer was invited to facilitate two-way communications with the expert panel team during the session, ensuring a mutual understanding of overall content outcome, interfaces, and desired features for the app.

Participants' ideas	Domains
List of available respite/NGO	Services
List of medical supplies/specialist	Services
Basic things about dementia	Knowledge
Appointment and reminders	Appointment system
Communication/chat groups	Support
How to care for families with dementia at home	Knowledge
Support groups	Support
Inspiration from others/motivation	Support

Table 2. Documentation and domain categorization of NGT session ideas.

Domains	P1	P2	P3	P4	P5	NGT scores
Support	5	5	5	5	5	25
Services	5	5	4	5	5	24
Knowledge	4	4	5	5	5	23
Appointment system	3	4	3	4	3	17

Table 3. Results of voting on app domain prioritization.

Expert panel (in random order)	Qualification/department	Years of experience (with older adults/special care)
E1	Physiotherapist (with certified optional credentialing in geriatric physiotherapy rehabilitation), Geriatric Unit, Medical Department, Hospital Kuala Lumpur	18
E2	Staff Nurse U29 Geriatric Unit, Medical Department, Hospital Kuala Lumpur	6
E3	Consultant Geriatrician (Liaison officer), Geriatric Unit, Medical Department, University Malaya Medical Centre	8
E4	Senior Lecturer and Older Adult Psychiatrist, Department of Psychiatry Faculty of Medicine, UiTM Sungai Buloh	3
E5	Head of Unit and Specialist in SCD, Special Care Dentistry Unit, Department of Oral & Maxillofacial Surgery, Hospital Kuala Lumpur	21
E6	Occupational Therapist, Occupational Therapy Unit, Medical Department, Hospital Kuala Lumpur	16
E7	Consultant Geriatrician (Liaison officer), Geriatric Unit, Medical Department, Hospital Kuala Lumpur	20
E8	Dietician (sub-unit under geriatric), Dietetics and Food Services Department, Hospital Kuala Lumpur	5

Table 4. Focus group discussion participants (expert panel members).

The app's content, derived from NGT session findings and expert agreement on essential domains, was structured into two main modules: first module focusing on patient care for caregivers (aiming to reduce caregivers' stress by enhancing knowledge and caregiving skills for home-based dementia care) and second module focusing on caregivers' wellbeing (covering caregivers' wellness, addressing mental, emotional health support, and other relevant information dissemination). These modules, enriched with expert knowledge from FGDs, covers various of topics vital for addressing dementia caregiving challenges. Table 5 presents the structure and composition of all 12 sub-modules (seven in first module and five in second module), detailing the topics addressed.

Discussion

This paper presents the development process of mobile application content aimed at supporting dementia caregivers. The results revealed three principal findings: (i) the remote construction of digital educational materials is viable and effective, (ii) NGT sessions with Malaysian caregivers revealed three dominant domains: support, services, and knowledge, and (iii) FGD with medical professionals/experts proposed two modules with 12 sub-modules addressing the three themes, covering areas of psychoeducation, psychosocial and caregiving skills.

Many studies have focused on developing mobile applications for public health education and interventions; however, most have typically relied on methods conducted in-person to shape their content^{54–59}. The COVID-19 pandemic has brought about a shift towards digital technologies. While face-to-face methods are inherently flexible⁶⁰, our study highlights the distinct advantages of remote sessions. These include improved accessibility and convenience, which are particularly significant for individuals who face mobility challenges or have caregiving responsibilities. Our findings reveal that similar approaches have been relatively scarce^{61–63}. Nonetheless, these

Module	Sub-modules (specialities)	Highlights	Domains (derived from NGT)	Component
(Module 1) Patient care for caregivers	About dementia (geriatrics)	Basic knowledge on dementia, including common types in Malaysia, symptoms, risk factors and early prevention	Knowledge	Psychoeducation
	Dementia behavioural problems (psychogeriatric)	Managing dementia's progression, addressing aggressive behaviours, their causes, and suggests activities for engaging dementia patients	Knowledge	Psychoeducation, Psychosocial and caregiving skills
	Basic patient care (nursing)	Importance of PLwD basic care, outlines caregiver responsibilities, and provides examples of basic nursing care practices at home for caregivers	Knowledge	Psychoeducation and caregiving skills
	Patient nutritional management (dietetics)	Highlights importance of a balanced diet for PLwD, offering guidance on managing dietary challenges, addressing nutritional deficiencies and hydration, evaluating dietary status and BMI calculation	Knowledge	Psychoeducation and caregiving skills
	Oral and denture care (dental/special care dentistry)	Insights on dementia's effect on oral health, introduces Special Care Dentistry (SCD), offers guidance for caregivers on SCD clinic visits and accessing services in Malaysia. Includes oral health education and tips for identifying dental issues in non-communicative PLwD	Knowledge and services	Psychoeducation and caregiving skills
	Simple exercises (physiotherapy and rehab)	Introduction to physiotherapy and its services for PLwD, covers common treatments, guides on clinic referrals, and provides examples of suitable home exercises for caregivers and PLwD	Knowledge	Psychoeducation and caregiving skills
	Daily activity and memory rehabilitation (occupational therapy)	Introduction to occupational therapy for dementia, including treatment options, referral guidance, home activity examples, and tips for home adjustments and cognitive rehabilitation for PLwD	Knowledge	Psychoeducation and caregiving skills
(Module 2) Caregivers' wellbeing	Support groups	Awareness on caregiver burden, the importance of support groups, and lists of PLwD caregivers' support groups in Malaysia	Knowledge, support and services	Psychoeducation and psychosocial
	Service directories	Directories with addresses and contact numbers for dementia organizations, geriatric hospitals, respite care options, and other dementia-related web resources	Services and support	Psychoeducation
	Emotional and stress management	Deeper insights on dementia caregiver burden, healthy caregiving practices, managing false accusations, signs of caregiver stress and compassion fatigue, mitigation strategies, and a list of relevant hotlines for caregivers	Knowledge, support and services	Psychoeducation and psychosocial
	List of welfare assistance	List of zakat offices and contacts across Malaysia, specifically for Muslim users	Services	Psychoeducation
	Daily motivation	Features daily motivational quotes from various scholars, religions, and cultures as pop-ups during startup, presented in a universal context for all caregivers	Support	Psychosocial

Table 5. Breakdown of Demensia KITA contents according to modules, sub-modules, topics, themes, and the main component.

studies and our experience suggest that, using online platforms equipped with recording tools and interactive features such as screen sharing can enhance the research process and offer benefits similar to in-person meeting. This method is not limited to dementia care, but it also has the potential for research expansion and novel developments in various domains. It also promotes the involvement of a diverse participant base, enhancing accessibility and outcomes⁶⁰.

The domains and outcomes of the NGT session align with existing literature^{29,38,43,44}, and highlight the emotional and mental support needs of Malaysian caregivers who care for people with dementia. Although there were initial concerns about the app's focus on patient care, our findings emphasize the importance of educating caregivers in dementia care. Caregivers frequently turn to various sources for guidance, including websites, social media, and peer advice, which can result in guidance that is inappropriate or impractical to address their

concerns or needs^{64,65}. This lack of adequate knowledge among caregivers in managing newly diagnosed patients and providing care for bed-bound individuals can result in suboptimal care, potentially leading to slower patient recovery or even deterioration in health conditions⁶⁶. This situation not only worsens the patient's condition but also increases the caregiver's burden.

During the FGD, it was revealed that there are many specialized areas lack comprehensive modules and public guidelines, rendering them inaccessible to Malaysian PLwD caregivers. Although some information exists, it is fragmented across multiple reputable sources, leaving key topics such as dietary guidance, rehabilitation practices, and caregiver helplines largely unknown. Additionally, information on basic nursing skills for caregivers of older people and managing behavioural issues at home was particularly scarce and difficult to locate, necessitating a thorough search to extract and emphasize vital information for caregiver support. The lack of accessible knowledge in psychoeducation, psychosocial, and caregiving skills, crucial for local PLwD home care, intensifies caregiver stress and drives some towards institutionalizations^{67,68}. Hence, Demensia KITA's comprehensive content serves to bridge existing gaps by providing a holistic "one-stop-centre" for caregivers, enabling convenient access to a wide range of dementia caregiving information and support for their well-being through handheld devices.

Demensia KITA's app content is tailored to align with local customs, ensuring cultural sensitivity and language accessibility for Malaysian caregivers of people living with dementia, catering to their specific unmet needs. Previous studies underline the significance of respecting the unique cultural values in diverse ethnic groups for effective dementia care^{69,70}. Our content is tailored to incorporate values pertinent to Malaysian culture and context in general. In addition to being fully functional in Bahasa Malaysia, the national language, Module 1 for instance, provides detailed dementia information relevant to Malaysia, including the five most common dementia types in the country. It also mentions additional content on dementia prevention, illustrated with examples of religious and cultural practices in Malaysia, such as religious rituals, traditional cultural games, and customary cultural activities. This module also offers dietary advice reflective of local cultures, featuring common Malaysian foods, local delicacies, and menus. Module 2 lists diverse Malaysian support groups and respite care, emphasizing local services and also introducing "zakat" for Muslim users, with plans for broader financial assistance information. The module's motivational quotes and visuals are also culturally inclusive, catering to Malaysia's multiracial demographic¹⁰.

While institutionalized care is an option for some families, financial constraints and cultural values emphasizing familial responsibility and respect for parents and senior citizens often necessitate home-based care for individuals with dementia^{69,71-73}. To address these challenges, "Demensia KITA" aims to educate and support both unpaid home caregivers and paid institutional caregivers, particularly new trainees. By engaging with Module 1, users can acquire or deepen their understanding of dementia, along with learning essential caregiving and nursing techniques. Should caregivers seek support for their mental well-being or require guidance, Module 2 offers foundational assistance. In short, the app serves as a comprehensive source of information on dementia and caregiving, supporting the Malaysian Ministry of Health's efforts in healthcare digitalization and creative innovation^{74,75}. It aims to enhance dementia awareness and prepare the population for the challenges of an aging society in the coming years, while also supporting the Ministry of Health's policies^{70,76}.

Study challenges and limitations

During the research, we encountered several challenges and limitations. A main challenge was the absence of established modules or clinical guidelines in various sub-specialties related to the sub-modules we intended to include in the caregiving mobile app content. This gap in pre-existing resources necessitated the development of new content tailored specifically for this application, which was both time-consuming and complex due to the need for comprehensive and accurate information. Furthermore, while some relevant information was available, it was often dispersed among numerous credible sources. This dispersion not only made it difficult to combine and create concise information, but also raised concerns about consistency when integrating information from different origins. The fragmented nature of the information required extensive literature reviews and consultations with experts to ensure the content's reliability and applicability to the target audience of caregivers. Moving forward, the content will be subjected to a validation process prior to its release or public availability.

Secondly, the content development process was sequential, necessitating that every sub-module content be fully developed and approved by its respective expert panel. This sequential approval process enabled the researcher to focus on refining each sub-modules' content and ensuring its accuracy before moving on to develop the next sub-module with a different expert panel's input. This step often experienced delays due to the panels' clinical duties, impacting the overall project timeline. Moreover, translating these resources directly from English to Bahasa Malaysia, while simplifying medical jargon was a demanding task, despite the researcher's proficiency in both languages. To enhance clarity and comprehension, a Bahasa Malaysia educator reviewed the translations.

Thirdly, regarding the technical aspects, our initial plan was to create a fully offline app featuring embedded videos, nonetheless, posed storage and performance issues, potentially leading to lagging and uninstalls. As a solution, we opted to embed external video content and website using links within the app, yet the disadvantage would be the continued availability of these original resources, as their removal would render them inaccessible to app users. This dependency necessitates regular monitoring and updates to ensure content remains accessible, including the replacement of these resources with suitable alternatives. Furthermore, sourcing educational content in Bahasa Malaysia posed another challenge due to the prevalence of English-language videos. To overcome this, we selected videos that offered subtitles in Bahasa Malaysia. Nonetheless, Demensia KITA stands as the first-of-its-kind prototype dedicated to bridging the psychoeducational, psychosocial, and caregiving skill gaps for Malaysian PLwD caregivers. We anticipate that future project will investigate the integration of additional features to enhance the app's functionality, including interactive elements like games, caregiver support chatrooms, and embedded videos, while also seeking methods to reduce the app's data storage requirements on smartphones.

Conclusions

This study highlights the practicability of using online qualitative methods in developing mobile app content, which encourage further digital health research in a similar way. Our findings reveal a significant need for an improved understanding of dementia caregiving skills, and greater availability of PLwD caregiver support in Malaysia. Future efforts should examine the app's impact on reducing caregiver burden in both urban and rural settings, assess caregivers' knowledge, attitudes, and practices, and determine their acceptance. The app will also undergo scheduled updates to meet the evolving needs of Malaysian dementia caregivers. "Demensia KITA" contributes to the Sustainable Development Goals by promoting better awareness on health and reducing inequalities, demonstrating how focused technological solutions can aid in achieving these global goals.

Data availability

All data generated or analysed during this study are included in this published article.

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Conceptualization, N.S.A.R., X.W.C., M.F.M.M. and R.M.Y.; data curation, investigation, and methodology, N.S.A.R.; funding acquisition, X.W.C., R.M.Y. and A.A.T.; project administration, N.S.A.R., X.W.C. and R.M.Y.; first draft write-up, N.S.A.R.; supervision and offered substantial revisions, X.W.C., M.F.M.M., N.N.A., M.M., A.A.T., and R.M.Y.; validation, X.W.C., M.F.M.M., N.N.A., M.M., A.A.T., and R.M.Y.; All authors have read and approved the final manuscript.

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Competing interests

The authors declare no competing interests.

Additional information

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