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Information needs and mHealth applications for carers of people with dementia in managing behavioural and psychological symptoms of care recipients: an integrative review protocol

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ABSTRACT

Introduction This integrative review aims to synthesise, appraise and analyse the evidence on informal carers' information needs, features and functions of available mHealth applications, and informal carers' usability and engagement with mHealth applications for managing behavioural and psychological symptoms of dementia (BPSD).

Methods and analysis This integrative review will include quantitative, qualitative and mixed-methods studies and follow the 'Preferred Reporting for Systematic Reviews and Meta-Analyses 2020' guidelines. Peer-reviewed articles published in English from 2000 to 2021 will be included from Cochrane Library, CINHAL, Embase, MEDLINE, ProQuest and PsycINFO. Five broader concept categories will be included: 'dementia', 'behavioural and psychological symptoms', 'informal carers', '(information need' OR 'mHealth application)'. In title and abstract review, first, the researchers will independently screen 10% of sources for consensus, and one reviewer will screen the rest. In full-text review, two reviewers will conduct the screening process and assess the relevancy of the full-text articles using a two-point scale (high-low) and the methodological quality of included articles using the Mixed Methods Appraisal Tool. Narrative synthesis will be employed to synthesise themes. The findings may identify the need for planning interventions for carers of people with dementia concerning the management of BPSD.

Ethics and dissemination Ethics approval not required. This review will be published in a peer-review journal and be presented at national and international conferences.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This integrative review will potentially report the evidence of informal carers' information needs in managing behavioural and psychological symptoms of people with dementia to design mHealth applications.
⇒ The review will be conducted based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and the Whittemore and Knafl framework for integrative review.
⇒ The search databases will be chosen to cover a wide range of disciplines, including medicine, nursing, allied health, psychology, biomedical, and pharmacology.
⇒ This review will include only the peer-reviewed articles to ensure the quality of the findings.
⇒ The limitation of this systematic review will be including articles published only in the English language, excluding grey literature and only screening 10% of titles and abstracts of sources initially by both reviewers.

INTRODUCTION

Dementia is a significant health and social issue worldwide.[1] Most people with dementia are affected by behavioural and psychological symptoms of dementia (BPSD) over the dementia trajectory.[2 3] BPSD refer to heterogeneous clusters of non-cognitive symptoms and behaviours,[4] and these symptoms include agitation, physical or verbal aggression, depression or dysphoria, anxiety, apathy or indifference, disinhibition, irritability, sleeping problems, delusions, hallucinations, motor disturbances, perseveration, and pathological collection.[2 5] The management strategies, including the management of BPSD, include both pharmacological and non-pharmacological treatments.[6] However, there is no approved disease-modifying medication for dementia,[7 8] and literature supports that BPSD is mostly undertreated.[9] Moreover, a lack of evidence has been shown concerning medication effectiveness in managing BPSD.[6] Consequently, BPSD negatively affects people with dementia psychologically, socially, and financially.[5 10]

Caring for people with dementia is mainly performed by informal carers,[11] including spouses, children, relatives or rarely friends who do not get paid for providing care.[12 13]

Literature supports that providing BPSD related care is challenging for informal carers,[10] and they present with psychological distress, burden, depression and reduced well-being.[2 14] Conversely, the literature supports that BPSD among people with dementia is triggered or exuberated by their carers' stress, depression, communication patterns, coping abilities and mismatch of expectations.[2] Therefore, it is essential to focus on carers' needs concerning managing BPSD of their care recipients with dementia.[2 10] However, the literature indicates that informal carers of people with dementia have limited access to information and support services.[9 15] As a result, carers face challenges in identifying, responding to, and managing BPSD, and can feel frustrated, especially at the beginning of BPSD.[15 16]

With the increased use of mobile technologies, mobile health (mHealth) applications are a recent trend in healthcare.[17] Literature suggests that mHealth application-based interventions for dementia care can improve the quality of life of people with dementia and their carers.[18] However, carers of people with dementia face some barriers and limitations of using mHealth applications; for example, technology-related, literacy-related, and time-related barriers.[19] Scharett *et al*[20] highlighted that more research needs to be conducted on providing information with more user-friendly interfaces to caregivers of people with dementia.[20]

The rationale of the review

This review is a part of the doctoral study of the first author that aims to develop an mHealth application to address carers' needs related to the management of BPSD of their care recipients. Literature reports that the usefulness and utilisation of mHealth applications are increased when mHealth application developers consider users' tailored needs, barriers, and limitations of information-seeking through mHealth platforms.[21–24] The tailoring of users' needs is an important feature of mHealth,[25] and tailored information needs entail 'information on demand'[26] that allows an assessment of informal carers' information needs. However, to date, the evidence is inadequately reported in the given context. Therefore, an integrative review will be conducted to integrate the evidence to identify tailored information needs in various settings and factors regarding available mHealth applications for informal carers in managing BPSD. These factors will include features and functions of applications and usability and engagement with applications, including potential barriers and challenges faced by carers when using the applications. The integrative review approach helps to identify research gaps, combine related areas of work, and provide a broader understanding of a body of knowledge to practice and research.[27] The integrated knowledge in the current review will facilitate researchers to develop user-friendly mHealth applications. Identified information needs will help to design an in-depth interview guide to explore further the information needs of carers of people with dementia related to managing BPSD. Evidence related to mHealth applications will be used in designing and developing an mHealth application for carers.

Objectives of the review

This integrative review aims to synthesise, appraise and analyse the evidence on informal carers' information needs, features and functions of available mHealth applications, and informal carers' usability and engagement with mHealth applications for managing BPSD.

Review questions

1. What are the information needs of informal carers of people with dementia concerning BPSD?
2. What are the features and functions of available mHealth applications as an educational and supportive information source for informal carers of people with dementia in managing BPSD?
3. What are the factors that affect usability and engagement in mHealth applications among informal carers of people with dementia in managing BPSD?

METHODS AND ANALYSIS

Review design

This integrative review combines diverse methodologies, including experimental and non-experimental studies.[28] Whittemore and Knafl framework for an integrative review[28] will guide the current review that includes five steps: problem identification, literature search, data evaluation, data analysis and presentation. The authors will follow the 'Preferred Reporting for Systematic Reviews and Meta-Analyses (PRISMA) 2020' checklist in designing and reporting the review.[29] Two frameworks will be used to construct the questions of this review: the 'Population, Phenomena of interest and Context' framework for qualitative studies and the 'Problem/Patient/Population, Intervention, Comparison and Outcome' framework for quantitative studies.[30]

Eligibility criteria

Study characteristics

This review will include (1) quantitative studies, for example, randomised control trials, non-randomised control trials, case–control studies, pre–post interventions, cross-sectional studies, case studies, descriptive studies and cohort studies, (2) qualitative studies, for example, grounded theory, phenomenological studies, action research, (3) mixed-method studies, and (4) pilot and feasibility studies. The reference lists of included articles and review articles will be searched manually to identify additional studies. We will exclude books and book chapters, theses, dissertations, conference proceedings and abstracts, protocols, web articles, paper articles, expert letters, opinion pieces, notes, editorials, presentations and other types of grey literature.

Reporting characteristics

Peer-reviewed full-text articles published in English from 2000 to 2021 will be included in the current review.

The population

The population of this review will be informal carers of people with dementia, including family carers, spouses, children, partners, relatives, friends, neighbours or individuals who are caring on a non-payable basis. This review will exclude formal carers, registered nurses and nurse assistants who work in hospital settings, nursing homes, daycare facilities and paid care services.

The phenomena of interest

This review will focus on factors that will improve the development of useful and user-friendly mHealth applications as an information source for informal carers of people with dementia in managing BPSD of their care recipients. The studies that do not focus on BPSD will be excluded from the review. Informal carers' educational and supportive information needs will be analysed to identify tailored mHealth information needs from the perspectives of those managing BPSD of their care recipients. The features and functions of available mHealth applications will be analysed to identify the scope of available applications concerning BPSD. Usability will be discussed concerning perceived usefulness,[31] ease of use (e.g., application format, clear wordings, nature of guidance, and nature of interactivity),[31 32] satisfaction (likability, comfort, pleasure),[33] and content.[32] Engagement will focus on effectiveness,[32] support (eg, community support or coach),[32] and barriers and limitations of informal carers for engaging with mHealth applications (eg, time investment, affordability and technology gaps).[32 34]

The context

The context of this review will be providing care for people with dementia in their homes. The studies that focus on nursing homes, long term care facilities, daycare facilities and hospitals will be excluded.

Patient and public involvement

No patient involved.

Information sources

The following databases will be searched: Cochrane Central Register of Controlled Trials (CENTRAL), Cumulative Index to Nursing and Allied Health Literature (CINHAL), Embase, MEDLINE, ProQuest and PsycINFO.

Search strategy

Five broader concept categories will be included in the current review: "dementia", "behavioural and psychological symptoms", "informal carers", "information need" and "mHealth application". The search terms were selected based on the previous studies relevant to the aims of this study. The Boolean operators and truncations will be incorporated to strengthen the search strategy. The search will be "dementia" AND "behavioural and psychological symptoms" AND "informal carers" AND "(information need OR mHealth application)". Search strategies are displayed in table 1.

Data extraction (selection and coding)

The data screening will be reported in a flow diagram according to the PRISMA 2020 guidelines.[29] The PRISMA flow diagram is shown in figure 1. The first researcher will extract the data, and the second researcher will check the extracted data against the study articles to ensure accuracy. The discrepancies and disagreements of data extraction will be resolved at a consensus meeting among the researchers.

The first reviewer will retrieve and integrate the retrieved studies using the EndNote reference management software V.20. Duplicates will be removed. Based on the inclusion criteria, two reviewers will screen the 10% of titles and abstracts of retrieved sources, and the first reviewer will continue the screening. The full-text screening will be conducted by two reviewers independently based on the same inclusion criteria. Discrepancies, including reasons for both inclusion and exclusion will be discussed at a consensus meeting and final articles will be chosen.

Table 1

Medical Subject Headings (MeSH) and keywords

Concept category	MeSH and keywords
Dementia	Alzheimer* OR dementia*
Behavioural and psychological symptoms	"behavio?ral and psychological symptoms of dementia" OR "behavio?ral symptoms" OR "behavio?ral disturbance*" OR "neuropsychiatric problem*" OR "neuropsychiatric symptoms" OR BPSD
Informal carers	caregiver* OR carer* OR "personal assistant*" OR "informal caregiver*" OR "family carers*" OR "famil*" OR spouse* OR partner OR friend* OR relative*
Information needs	"information need*" OR "education* need*" OR "learning need*" OR "supportive need*" OR "training* preference" OR "unmet need*" OR knowledge* OR need*
mHealth application	"electronic health app*" OR "eHealth app*" OR "smartphone app*" OR "mobile health app*" OR "mobile app*" OR "mHealth app*" OR "mobile phone app*" OR "iPhone app*" OR "Android app*" OR "phone app*" OR "handheld computer*" OR "internet based application*"

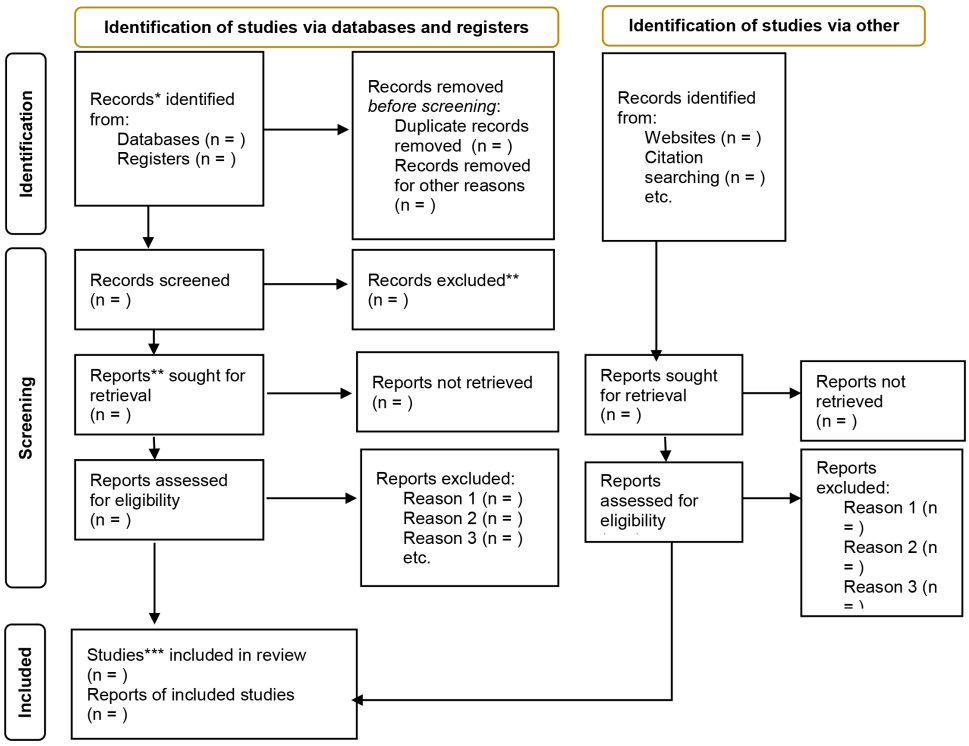

Figure 1 The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram.[29]
*Record: The title or abstract (or both) of a report indexed in a database or website.
**Report: A document (paper or electronic) supplying information about a particular study.
*** Studies: An investigation that includes a defined group of participants and one or more interventions and outcomes.

Reasons for excluding full-text studies will be recorded. Additionally, initial average kappa value will be computed to examine the agreement among two authors.[35]

Data will be entered into a prepiloted Excel datasheet. The first reviewer will extract data, and the second reviewer will check the extracted data for accuracy. The Excel data sheet will include general study information (author, publication year, country and title), study characteristics (aims/specific research questions of the study, theoretical/conceptual framework, hypothesis, design), population characteristics (population, inclusion and exclusion criteria, sample size, sample, setting), variables (educational and supportive information needs of users concerning BPSD, available mHealth applications, features of mHealth applications, functions of mHealth applications, perceived usefulness, ease of use, satisfaction, content, effectiveness, support, and barriers and limitation of use of applications), study instrument characteristics (validity, reliability, risk of bias assessment), key findings, conclusion and recommendation.

Outcomes of the review

The first outcome will be the educational and supportive information needs of informal carers in the provision of care for BPSD, and it will lead to design an in-depth qualitative inquiry that explores carers' information needs and potential content for mHealth applications. The second outcome will be available mHealth applications for informal carers in managing BPSD, including its features and functions. The third outcome will be mHealth usability and engagement factors of informal carers in managing BPSD.

Risk of bias (quality) assessment

According to Whittemore and Knafl[28] framework, the quality of the selected articles will be reported based on the methodological rigour and data relevance will be reported based on a two-point scale (high or low) (high or low). Two reviewers will assess the methodological quality of studies using the Mixed Methods Appraisal Tool (MMAT) Version 2018.[36] The discrepancies will be resolved with the discussion among three researchers. MMAT is used to assess qualitative studies, quantitative randomised trials, quantitative non-randomised studies, quantitative descriptive studies and mixed-method studies.[36] The current review will briefly describe the study criteria alone with numerical scores based on MMAT.

Data synthesis

According to Whittemore and Knafl[28] guidelines for integrative review, data will be analysed and interpreted.[28] This process involves (1) data reduction, (2) data display, (3) data comparison and (4) conclusion drawing and verification.[28] Narrative synthesis will be employed to synthesise the data of quantitative and qualitative studies. First, the findings of both qualitative and quantitative studies will be analysed thematically, based on the integrated method described by Sandelowski,[37] including the findings from randomised control trials. The themes will be synthesised to understand the concepts, and findings

will be reported in a narrative form using text and tables. Finally, the authors will report the available evidence to identify the knowledge gap and future study directions through the conclusion and recommendations. Information needs and features of mobile applications that support particular information needs will be compared using a table and a concept map.

Biases of the review

The robustness of the studies will be assured by synthesising the peer-reviewed articles, reporting the methodological quality and reporting the validity of the scales.

ETHICS AND DISSEMINATION

Ethical approval from a recognised body is not required due to retrieving the findings from available sources (ie, secondary analysis). The results will be disseminated through scientific conferences, research forums and peer-reviewed journals.

CONCLUSION

This review will identify information needs of informal carers, features and functions of available mHealth applications, and usability and engagement with mHealth applications among informal carers in managing BPSD. The findings can integrate to support the context of education and support for carers in managing BPSD. In particular, researchers will use the findings of this review to codesign an mHealth application to address the educational and supportive needs of informal carers in managing BPSD of their loved ones with dementia. Additionally, health professionals, for example, nurses in mental health or public health, can use the findings of this review in planning educational programmes, guidelines and resources. Eventually, those applications and programmes will improve the quality of life of informal carers and their care recipients.

Limitations

The limitations of this study include language bias (considering only the articles in English) and publication bias (excluding the grey literature).

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