Informal carers' information needs in managing behavioural and psychological symptoms of people with dementia and related mHealth applications: a systematic integrative review to inform the design of an mHealth application

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ABSTRACT

Objective To review and synthesise the evidence on informal carers’ information needs in managing behavioural and psychological symptoms of dementia (BPSD) of their care recipients and related mobile health (mHealth) applications to inform the design of an mHealth application.

Design This is a systematic integrative review guided by Whitemore and Knaff’s five-stages framework. Six databases were searched: Cochrane, CINAHL, Embase, MEDLINE, ProQuest and PsycINFO. The key concepts included ‘dementia’, ‘behavioural and psychological symptoms’, ‘informal carers’ and (‘information need’ or ‘mHealth application’). Peer-reviewed full-text articles published in English from 2000 to 2022 were included. The methodological rigour of studies was analysed using the Mixed Methods Appraisal Tool V.2018. Preferred Reporting Items for Systematic Reviews and Meta-Analyses-2020 reporting guidelines were followed.

Results This review included 34 studies, including quantitative (n=13), qualitative (n=17) and mixed-method (n=4) studies. Four major themes emerged from the reported studies: the need for addressing information needs on managing BPSD, the role of support systems in managing BPSD, self-care for carers and the role of mHealth applications in providing education and support for carers. In managing BPSD, carers seek knowledge about dementia and BPSD, the roles of the carers and misconceptions about BPSD. One study reported an mHealth application to monitor the behavioural issues of people with dementia.

Conclusion Informal carers of people with dementia face a number of challenges when providing care for BPSD of their care recipients. The lack of knowledge on managing BPSD is a significant challenge. Support systems such as professional, social, residential, legal and eHealth have a significant role in managing the BPSD of people with dementia in the community. mHealth interventions are sparse to support BPSD management. These findings can be used in designing an mHealth application that addresses needs related to managing BPSD of informal carers of people with dementia.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ To the best of our knowledge, this is the first reported integrative review that understands gaps in the information needs of informal carers of people with dementia and related mobile health (mHealth) applications that guide the designing of an mHealth application focusing on behavioural and psychological symptoms of dementia (BPSD).
⇒ Registering on PROSPERO, publishing the protocol in a peer-review journal, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and Whitemore and Knaff’s framework (2005) for integrative review, quality appraisal using Mixed Methods Appraisal Tool and narrative synthesis strengthen the quality of this scholarly work.
⇒ This review is strengthened by exploring information needs based on qualitative, quantitative and mixed-method studies.
⇒ Language bias and information bias are limitations of the present review.
⇒ The lack of data from developing countries limits the generalisation of the findings.

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BACKGROUND

Dementia is a progressive and chronic neurodegenerative disorder, and it is a global health issue that negatively impacts the physical, psychological, social and financial well-being of individuals with dementia and their carers. The majority of people with dementia receive care at home from informal carers, and they play a pivotal role in caring for people with dementia. For example, 96% of people with dementia in low-income and middle-income countries (LMICs) live at home. Informal carers are unpaid, and they include family members, relatives and
friends. In 2019, WHO reported that dementia carers need information, training, services and social and financial support for looking after their care recipients.

People with dementia present with several behavioural and psychological symptoms, and managing these symptoms is challenging. Behavioural and psychological symptoms of dementia (BPSD) include psychotic symptoms, mood symptoms, anxiety, apathy, agitation, disinhibition and wandering. These symptoms are highly prevalent, and informal carers face several difficulties in managing these symptoms in home settings. These challenges lead to different negative consequences, for example, carer burden, burnout, depression, relationship difficulties with the partner, isolation from family and society, and difficulties in coping.

Given the challenges in managing BPSD, informal carers require multidimensional strategies in managing BPSD; for example, modifying relationships with their care recipients, the modification of the care environment, active engagement, humour, self-care and social support. Literature suggests that the early recognition of BPSD and the use of support and external services are beneficial for informal carers in managing the BPSD of their care recipients. Moreover, researchers highlighted that it was essential to address the unmet educational needs of family carers concerning the management of BPSD to reduce their stresses. Consequently, addressing informal carers’ educational and supportive information needs is paramount for dementia care in the community.

Health information technologies are innovative strategies for supporting people with cognitive impairments, including people with dementia and their carers. Smartphones are commonly used in healthcare, and smartphone-based mobile health (mHealth) applications are a widely used technology that provides multifunctional assistance for informal carers of people with dementia. These supports include providing information and support services, linking health professionals to community services, monitoring the health and wellness of care recipients and carers, delivering messages and notifications and maintaining social contacts.

To the authors’ knowledge, review studies that integrate the evidence on educational and supporting information needs on managing BPSD of people with dementia with a particular focus on designing mHealth applications are not available. Consequently, this integrative review synthesised, appraised and analysed the evidence on informal carers’ information needs in managing the BPSD of their care recipients. Moreover, the current review analysed mHealth applications as information and supportive resource, including applications’ features, usability and the engagement of informal carers.

METHOD
Design
This review is part of a larger project to co-design an mHealth application for informal carers of people with dementia to address managing BPSD in the home setting. We used a systematic integrative review design that combines studies with diverse methodologies, including experimental and non-experimental studies. This integrative review was guided by Whittemore and Knaff’s framework, which includes five steps: (1) problem identification, (2) literature search, (3) data evaluation, (4) data analysis and (5) presentation. The protocol of this review has been registered on the International Prospective Register on Systematic Reviews (CRD42021238540), and it has been published.

Problem identification
This review focused on the evidence required for designing mHealth applications to be used by informal carers in managing the BPSD of their care recipients with dementia. The research questions underpinning this review were:

1. What are the information needs of informal carers of people with dementia concerning managing BPSD in their care recipients?
2. What are the available mHealth applications for informal carers that address educational and supportive information needs related to managing BPSD in their care recipients?
3. What factors affect usability and engagement in mHealth applications among informal carers of people with dementia concerning the management of BPSD in their care recipients?

Literature search
Eligibility criteria
The eligibility criteria were based on the ‘Population, Phenomena of interest and Context’ (PICo) framework for qualitative studies, and the ‘Problem/Patient/Population, Intervention, Comparison and Outcome’ (PICO) framework for quantitative studies. However, it was evident that ‘Patient/ Outcome’ details are enough to formulate research questions for observational studies.

Population: The population of interest was informal carers of people with dementia who delivered care for home-dwelling people with dementia on a non-paid basis, including (1) family carers, such as spouses, children and relatives; (2) friends; or (3) neighbours. This review excluded formal carers, registered nurses and nurse assistants who worked in hospital settings, nursing homes, daycare facilities and paid care services.

Intervention or phenomena of interest: Articles were included if they were related to (1) educational and supportive information needs of informal carers of people with dementia in managing BPSD and/or (2) mHealth applications designed for informal carers of people with dementia in managing BPSD. Studies concerning information needs were included if carers (1) recognised/expressed their knowledge gaps or proficiency gaps or (2) showed the desire for information to resolve issues or problems experienced by both care recipients and carers concerning the management of BPSD or (3) showed their...
unmet needs in managing BPSD. Studies on mHealth applications were included if they reported the content, features, functions, usability or engagement concerning the management of BPSD by carers.

Studies were excluded if they did not focus on BPSD or if carers did not recognise, desire, express or expect information, information needs or unmet needs. Studies were further excluded if they only reported the quantitative measurements of negative impacts of caring, for example, care burden, depression or quality of life.

Comparison: Not applicable.

Context: The context for this review included providing care for people with dementia in their homes. The articles concerning nursing homes, long-term care facilities, daycare facilities and hospitals were excluded.

Outcomes: Information needs-related outcomes were knowledge gaps, proficiency gaps or supportive processes or systems in delivering care for BPSD. mHealth applications-related outcomes were content, features, functions, usability or engagement. Usability outcomes of mHealth applications were perceived usefulness, ease of use (eg, application format, clear wording, nature of guidance and nature of interaction), satisfaction (likability, comfort, pleasure) and content (educational content, supportive features). Engagement-related outcomes for mHealth applications included effectiveness, support (eg, community support or coach) and barriers and limitations of informal carers for engaging with mHealth applications (eg, time investment, affordability and technology gaps).

Information sources
A systematic search was conducted across six databases to cover published articles in health-related fields: Cochrane Central Register of Controlled Trials (CENTRAL), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, MEDLINE, ProQuest and PsyCINFO. Additional studies were manually identified through the reference lists of included articles and review articles.

Search strategy
The preliminary search helped to identify relevant articles, maintain the validity of the context of reviewing and ensure the availability of enough articles. In this review, we conducted a preliminary search in PubMed before commencing the search in the six aforementioned databases. The key concepts underpinning the search strategy were based on PICO/PICO, including ‘dementia’, ‘behavioural and psychological symptoms’, ‘informal carers’ and ‘(information need or mHealth application)’. The combination of keywords and individual database subject headings (eg, MeSH (Medical Subject Headings) in MEDLINE; Emtree in Embase; CINAHL subject headings; American Psychological Association index in PsyCINFO) were applied using Boolean operators, while truncations were used where necessary. The search strategy used in PubMed was modified for other databases (online supplemental material 1). The search was limited to peer-reviewed full-text articles published in English from September 2000 to September 2022. We excluded books and book chapters, theses and dissertations, conference proceedings, abstracts, protocols, web articles, newspaper articles, expert letters, opinion pieces, notes, editorials, presentations and other types of grey literature. The grey literature was excluded in the absence of the peer-review process. In this systematic review, researchers were interested in identifying all mHealth applications available for family carers of people with dementia to address their needs related to managing the BPSD of care recipients. Therefore, the starting point of the literature search was limited to the year 2000 onwards, as the word ‘mobile health’ was defined in the year 2000.

Selection processes
The data search was reported in the Preferred Reporting Items for Systematic Reviews and Meta-analysis-2020 (PRISMA-2020) guidelines. The PRISMA flow diagram is shown in figure 1. Retrieved sources were entered into EndNote-20 reference management software, then removed duplicates and transformed into an Excel sheet for data screening. One reviewer (TJ) checked the Excel sheet manually to identify duplications again. Two reviewers (TJ and SR) independently screened 10% of titles/abstracts (n=169), and the rest was completed by one researcher (TJ). Full texts were assessed by the two reviewers (TJ and SR) individually according to the eligibility criteria to determine their suitability and relevancy. Reasons for exclusion are recorded in figure 1. Disagreements were resolved in consensus meetings. The Cohen’s kappa inter-rater agreement was calculated to report the degree of agreement between two raters over the full-text screening. Kappa agreement ensures inter-rater reliability, which measures the extent of assigning the same scores for the same variable using a nominal scale. The initial kappa value was 0.93, indicating almost perfect agreement.

The total results of six database searches were 3731 records. After eliminating 1890 duplicate records, there were 1841 records left for the review of titles/abstracts. A total of 374 records were eligible for full-text screening. Thirty-four articles that met the eligibility criteria were included, including six articles through manual searching of the reference lists of selected articles and review articles. Figure 1 shows the process of screening and identification of the studies.

Data evaluation
Data were evaluated for methodological rigour and data relevance by two reviewers (TJ and SR) independently. The methodological rigour (risk of bias) of studies was analysed using the Mixed Methods Appraisal Tool (MMAT) V.2018, and data relevance was rated as high and low by two reviewers independently (online supplemental table 1). The MMAT comprised five criteria rating scales for different studies, including quantitative, qualitative...
and mixed-method studies. If five criteria were met for a research study, it was scored as ***** (100%) (meeting five criteria *****100%; meeting four criteria ****80%; meeting three criteria *** 60%; meeting two criteria **40%; meeting one criterion * 20%; meeting zero criteria 0%). The kappa value between the two raters over the MMAT scoring was 0.79, indicating substantial agreement. In this review, we included all articles due to their information values, even though some studies were not rated as high on quality due to their research designs.

**Data analysis**

Findings from the included studies were narratively analysed due to the methodological heterogeneity of the articles and followed four steps: data reduction, data display, data comparison and conclusion drawing and verification. The first researcher (TJ) performed the analysis, and the other researchers (SR and SD) checked and supervised for accuracy. Discrepancies were discussed to reach a consensus.

**Data reduction**: Data reduction involves classifying data to facilitate data analysis. In the current review, the studies were classified into two broader categories: information needs and mHealth.

**Data display**: Data display involves assembling data extracted from multiple primary sources for particular variables/subgroups through various visualisation methods (eg, matrices, graphs, charts). In the current study, data were structured into themes/subthemes and displayed in a table.

**Data comparison**: Primary source data from data displays are examined to recognise themes, patterns and relationships.

**Conclusion drawing and verification**: Finally, conclusions of the findings were made based on the review objectives. The findings in the current review were compared with the primary sources to maintain accuracy and conformability.

**Data presentation**

Data were presented narratively using text and tables.
RESULTS

Study characteristic and quality assessment

This review included 34 studies (figure 1) published between 2003 and 2022, including 13 descriptive quantitative studies, 17 qualitative studies and 4 mixed-method studies. Qualitative studies included descriptive studies (n=5), a phenomenological study (n=1), a case study (n=1) and exploratory studies (n=10). Based on the MMAT results, 16 studies scored 100%, 6 scored 80% and others scored 0–60% (online supplemental table 1).

Most of the studies were from the USA (n=15), followed by The Netherlands (n=2), Hong Kong (n=2) and the UK (n=2). One article was found from each country, including Australia, Taiwan, China, Korea, Poland, Japan, Thailand, Norway, Sweden, Israel and Singapore. There were two multinational studies: participants from developing countries and European countries. The reported mean age of carers ranged from 51.18±10.7 years to 83 years. Online supplemental table 1 shows the characteristics of the included studies.

This review emerged four major themes: (1) the need for addressing information needs on managing BPSD, (2) the role of support systems in managing BPSD, (3) self-care for carers and (4) the role of mHealth applications in providing education and support for carers (table 1 shows themes and subthemes).

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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<tr>
<td>1. Managing BPSD</td>
<td>Dementia and BPSD.</td>
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<td>Role of the carers.</td>
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<td>Misconceptions about BPSD.</td>
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<td>2. Support systems</td>
<td>Professional support.</td>
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<td>Social support.</td>
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<td>Institutionalised support.</td>
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<td>Safety of carers.</td>
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<td>Family breakdown and conflict.</td>
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<td>Adapting and coping.</td>
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<td>4. mHealth function</td>
<td>Functions of mHealth applications.</td>
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<td></td>
<td>Usability and engagement of mHealth applications.</td>
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BPSD, behavioural and psychological symptoms of dementia; mHealth, mobile health.

Theme 1: the need for addressing information needs on managing BPSD

Theme one discusses the information required by carers to improve the quality of life and well-being of care recipients presented with BPSD, and it includes three subthemes: (1) dementia and BPSD, (2) role of the carers and (3) misconceptions about BPSD.

Dementia and BPSD

This subtheme discusses informal carers’ information needs to enhance knowledge about dementia or BPSD. Carers showed a limited understanding of BPSD at the time of the diagnosis of dementia. Carers expressed that this poor knowledge led to triggering BPSD in their care recipients, feeling of anger toward care recipients and frustration. Carers stated limited knowledge of how to recognise symptoms, the progression of BPSD, the negative impact of BPSD on care recipients and how to delay the symptoms. Moreover, carers stated a lack of knowledge in managing BPSD.

They highlighted that adequate knowledge of BPSD would assist them in planning care and modifying the home environment. Therefore, carers wanted to learn about dementia, the progression of dementia, how to recognise the changes in care recipients, how to manage behavioural and psychological problems, available treatments and planning future care for managing BPSD. Carers highlighted the most significant symptoms that require further information, such as aggression, wandering at night time, elopement and being frightened, angry or confused.

Few carers reported their concerns about sustainability and the side effects of drugs, and they wanted to know about appropriate medications for managing problematic behaviours.

Role of the carer

Under this subtheme, the information needed to enhance the carer’s performance, attitudes and behaviours was explored. Informal carers experienced significant difficulties associated with caring for BPSD, particularly difficulties in identifying the caring role and delivering care; for example, feeding, cleaning and dressing and urinary and faecal incontinence.

Carers reported insufficient mastery in managing behaviours. This situation negatively affected the caring role. For example, carers stated that they were stressed and experienced a burden due to their current role, and insufficient mastery negatively affected BPSD care for their care recipients. Moreover, carers stated difficulties associated with communication with their loved ones when dealing with BPSD; therefore, they needed to learn how to improve communication while providing care for BPSD.

Carers reported that their negative attitudes and behaviours increased the presence of BPSD among their care recipients, and they wanted to learn how to control this situation. These attitudes and behaviours included paying poor attention to BPSD, instilling fear in care recipients and ignoring care recipients’ needs. Moreover, carers ignored the needs of care recipients due to a lack of empathy, attention and emotions toward care recipients and sometimes they felt angry with their...
care recipients. Additionally, this situation was attributed to the development of argumentative attitudes toward care recipients and incorrect practices; for example, adjusting medication doses without consulting healthcare providers and offering alternative medicines such as cannabidiol oil without discussing it with their physicians.

**Misconceptions about BPSD**

This subtheme reported on carers’ wrong interpretations or incorrect beliefs concerning BPSD, which showed a knowledge gap among carers in managing BPSD in their loved ones. Carers believed that care recipients could control their behaviours, and behavioural changes were attributed to the normal process of ageing or physical symptoms or features of chronic medical conditions. When care recipients with BPSD refused diabetic care, carers perceived it as personal rather than a consequence of BPSD. This study further reported that carers felt obligated to adjust carer recipients’ medications; however, they did not inform health professionals due to embarrassment.

**Theme 2: role of the support systems in managing BPSD**

Theme two discusses the role of the support systems, focusing on the information needs of carers in managing BPSD. This theme includes five subthemes: professional support, social support, institutionalised support, eHealth support and legal support.

**Professional support**

In informal carers recognised the importance of available and accessible professional support systems in managing the BPSD of care recipients. They wanted to know about available professional support services, health-care facilities and training resources in the locality. They sought professional support due to various reasons, such as acquiring information to identify the warning signs of BPSD, acknowledging carers’ challenging situations, managing comorbidities in the presence of BPSD and directing carers to supportive services and support groups.

**Social support for caring**

Social support includes the support received from social systems or services, for example, support centres for dementia and support groups for carers. Carers of people with dementia reported a lack of knowledge of the services provided by voluntary or religious organisations. They highlighted that these support systems helped to solve problems related to BPSD care; however, there was inadequate support for problem-solving, which led to the development of anger and frustration among carers.

**Institutionalised support**

With difficulties in looking after people with dementia at home, carers must find institutionalised care, including hospitalisation. Therefore, carers seek recent information on institutionalised care. Moreover, studies reported limited use of institutionalised care due to a lack of information and awareness on the availability of care facilities, including available resources within those facilities.

**eHealth support**

Another information need identified by carers was electronic support. Carers reported internet and web-based platforms could support caring, for example, by sending daily emails or messages encouraging them and strengthening the caring process. They highlighted that they wanted to know the available electronic sources for information seeking, including looking after themselves. Carers preferred to find online information from a single place or platform called a ‘one-stop-shop’.

**Legal support**

Another information need highlighted by carers was information on legal matters. For example, the carers wanted to know what legal issues they faced when admitting a person with dementia to a care facility. When care recipients had two or more behavioural problems, carers reported a need for psychosocial care, including legal advice.

**Theme 3: self-care for carers**

Theme three discusses the information needs concerning how to manage the well-being of carers while providing care for people with dementia and consists of four subthemes: psychological well-being, safety, family conflict and breakdown and adapting to the situation.

**Psychological well-being**

Several studies reported that providing care for BPSD in people with dementia led to the decreased psychological well-being of carers, indicating the need for support in improving their psychological well-being. Changes in the behaviours and personalities of care recipients had a negative impact on carer well-being, for example, they experienced physical and emotional strains and lack of sleep and rest. Moreover, providing care for BPSD caused to development carer distress, grief, upset, disappointment, irritability, burden, guilt, frustration, depressive symptoms, a feeling of powerlessness, feeling of shame and suicidal thoughts. They further developed negative feelings concerning providing BPSD care, for example, exhaustion, helplessness, overwhelming, insecurity, self-blaming, loneliness and feeling sadness.

Moreover, studies reported limited social interactions among carers who cared for care recipients with BPSD. Social isolation is a common problem among carers and is caused by the inability to keep the care recipients alone at home, antisocial behaviours of care recipients, an embarrassment in the community due to care recipients’ behaviours and the need to maintain a dark environment at home. Despite the threat to
psychological well-being, a lack of emotional support was highlighted by carers, \textsuperscript{56} particularly, their stress was not addressed. \textsuperscript{52} 53 55 57 64 77 Given the negative impacts on carer well-being due to managing BPSD, carers highlighted that they needed information on available support services for carers. \textsuperscript{37} 38

Safety
Carers’ own safety was challenged due to the provision of care for BPSD of people with dementia, revealing the information needed to ensure their safety. \textsuperscript{59} 75 For example, care recipients presented with physical violence, anger and aggressiveness; therefore, carers were at high risk for physical and psychological injuries. \textsuperscript{75} 77 This situation led to developing a feeling of fear for their physical safety. \textsuperscript{59}

Family conflicts and breakdown
This review identified carers’ unmet needs regarding achieving harmony within the family. Carers experienced conflicts within the family due to behavioural changes in care recipients, \textsuperscript{58} particularly the breakdown of their relationships. \textsuperscript{51} 63 75 for example, behavioural changes such as hypersexuality affect spouse carers’ love and relationship and physical intimacy. \textsuperscript{76} Carers further reported a lack of emotional connection with their relatives and a feeling of abandonment by family and friends during the caregiving journey. \textsuperscript{51} Moreover, carers were angry toward other family members due to a lack of support in their caring roles. \textsuperscript{59} One reported that carers faced harassment by other family members or third parties. \textsuperscript{49}

Adapting to the situation
Studies reported that carers had difficulty adapting to changing situations related to their care recipients’ behaviours. \textsuperscript{59} 62 According to Ramirez et al (2021), healthcare providers did not support the carers in coping with frustration. Carers reported that they needed information on available counselling services to adapt to the situation associated with the BPSD of their care recipients. \textsuperscript{37} 38

Theme 4: role of the mHealth applications in providing education and support for carers
This theme focuses on mHealth application in supporting informal carers of people with dementia in managing BPSD and consists of three subthemes: supportive mHealth applications, functions of mHealth applications, and usability and engagement of mHealth applications.

Supportive mHealth applications
Only one mHealth application was identified in the current review that supported informal carers in managing the BPSD of their care recipients. The main aim of this study was to develop and validate an mHealth application that monitors the BPSD of people with dementia. \textsuperscript{78}

Functions of mHealth applications
The major function of the above application was monitoring BPSD in people with moderate-to-severe dementia. \textsuperscript{28}

Usability and engagement of mHealth applications
In usability assessment, perceived usefulness, frequency of use, limitations and improvement of the application have been used. \textsuperscript{78} With reference to the content, monitoring was performed using the simplified version of the Neuro-Psychiatric Inventory. \textsuperscript{78} This study reported that the mHealth application was easy to use as all carers completed the application within 5 min. \textsuperscript{78} Small font sizes and readability issues were reported. \textsuperscript{78} Concerning overall satisfaction, the majority (80%) indicated that it was ‘very likely to be helpful for caregiving’. \textsuperscript{78} Most carers were willing to complete the application weekly to monitor patients’ BPSD. \textsuperscript{78}
related to the information needs of informal carers of dementia reported the greater need for information to manage BPSD, for example, knowledge on disease and care provision; care skills, supportive health services; the impact of dementia on both care dyads; and carer self-care. Moreover, a gap between what they need and what they need to know was identified in the current review. For example, information on financial aid was not reported by informal carers even though they had financial issues associated with caring.

Not expecting information on some needs might be attributed to not being aware of these needs and facilities. Therefore, health professionals should provide education to enhance awareness about potential information needs, for example, available systems/agents for financial aid in their carer journey.

Similarly, the present review identified carers’ information needs related to managing their self-care. Carers face safety issues during the carer role. They need to maintain a balance between their caring and personal lives while coping with the caring role with minimum psychological and emotional harm to themselves. Therefore, taking care of carers is essential because they feel neglected during the carer journey. Specifically, this review found that carers needed information about family counselling to maintain strong relationships between carers and people with dementia or other family members. Consequently, carers need to be provided with information on coping techniques, counselling services, psychosocial and psychoeducational interventions, cognitive behavioural therapy, relaxation therapy, and peer-support groups.

The present review identified only one mHealth application that addressed needs related to the management of BPSD in people with dementia, showing limited use of mHealth in addressing the BPSD needs of informal carers of people with dementia. The major function of this application is monitoring the BPSD of people with moderate-to-severe dementia. Recent literature indicates that mHealth applications have been used for informal carers of people with dementia, for example, educating the management of functional disabilities, increasing positive mental health, and receiving professional help through interactive mHealth applications. Moreover, recent studies revealed that mHealth applications were designed for educating and supporting other carer populations, for example, family carers of children with cancer and asthma. Consequently, it is essential to expand the use of mHealth applications for informal carers of people with dementia in managing the BPSD symptoms of their care recipients.

Based on the current review, functions of mHealth applications include monitoring BPSD. Literature reported the several functions of mHealth applications that focused on providing education and support for informal carers, for example, providing information about patients (eg, clinical information, daily activities), linking to useful websites, sharing experience among carers, providing digital calendars; communication between
mHealth applications. A study conducted in Sweden explored family carers’ and health professionals’ perspectives on mHealth applications. It revealed that mHealth applications would be helpful in receiving information to structure their own life, caring for themselves and accessing contact information needed to deliver care for their loved ones with dementia. Therefore, the abovementioned multifunctions may be used in designing and developing mHealth applications.

Usability assessment of mHealth applications is paramount to ensure that the application caters for the needs of the target population. The present review identified positive aspects of the usability of the mHealth application in terms of ease of use, satisfaction and readiness to engage on a weekly basis while reporting negative aspects of the usability, such as small font size. Similarly, a previous systematic review identified the usability and acceptability of mHealth applications in terms of ease of use, ease of navigating technical challenges and mHealth content tailored for carers of older adults. Similar to the present review, the previous studies indicated that informal carers reported positive experiences with the mHealth application. Even though mHealth applications address the multidimensional information needs of informal carers of people with dementia, there is no value if applications are not adapted to use and engaged by carers. However, compared with previous reviews about mHealth interventions for other disease conditions, a limited usability and acceptability assessment was demonstrated in the study of the present review, while the literature reported that mHealth interventions should assess the economic feasibility and availability of quality internet connectivity.

Recommendations for future research
Based on the findings of this review, the following suggestions are recommended for future research. Informal carers’ information needs must be explored in developing countries concerning the management of BPSD. This review highlights the necessity to explore more tailored information needs, including educational and supportive information needs concerning the management of BPSD at home. Particularly, carers’ misconceptions about dementia and/or BPSD should be explored and addressed. With the availability of a limited number of mHealth applications that address needs related to the management of BPSD of informal carers of people with dementia, researchers can use mHealth applications to address the above needs. Moreover, studies are essential to assess the economic feasibility, usability and engagement with mHealth interventions.

CONCLUSION
Caring for BPSD is challenging for informal carers of people with dementia; therefore, they need adequate education and support in their carer role. Carers need to enhance their knowledge of dementia and BPSD, the roles of the carers and misconceptions about BPSD. The support systems have an essential role in managing the BPSD needs of informal carers; therefore, they need information on available support systems, including professional, non-professional and eHealth support. Caring for carers is essential; they need information about psychological well-being, safety, family conflict and breakdown and adapting to the situation. Given the broad information needs concerning BPSD, there is great potential for the mHealth application to educate and support informal carers of people with dementia. Currently, mHealth applications are limited to educating and supporting informal carers who manage the BPSD of their family members with dementia; however, emerging evidence shows that informal carers accept mHealth applications. These findings can be used in designing an mHealth application for informal carers to manage BPSD of their care recipients with dementia.

Limitations
This study has some limitations. Reviewing studies published only in English may limit the retrieving of potential studies, leading to language bias. Studies published only in peer-review journals were included, which leads to information bias due to excluding grey literature. Since most studies were from developed countries, the findings may not be generalisable to developing countries. Even though the current search was limited from 2000 to date, starting the searches from the inception would be better to avoid missing any vital information.

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Contributors TJ: Conceptualisation, designing the study, data extraction, analysis, interpretation, writing and editing and final approval of the manuscript. SR: Guarantor, conceptualisation, designing the study, analysis, interpretation, critical review and editing, final approval of the manuscript and supervising. SD: Designing the study, critical review, final approval of the manuscript and supervising.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Ethics approval for the integrative review, which is a part of a large study that can be designing an mHealth application, was obtained from
REFERENCES


27. Kabir ZN, Leung AYM, Grundberg Å, et al. Care of family caregivers of persons with dementia (CaFCa) through a tailor-made mobile APP: study protocol of a complex intervention study. BMC Geriatr 2020;20:


100 Garnett A, Northwood M, Ting J, et al. Mhealth interventions to support caregivers of older adults: equity-focused systematic review. JMIR Aging 2022;5:e33085.
Supplementary material 1

Concept Categories and Search Strategies used in MEDLINE

<table>
<thead>
<tr>
<th>Dementia</th>
<th>Behavioral and psychological symptoms</th>
<th>Caregiver</th>
<th>Information needs</th>
<th>mHealth application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key words</td>
<td>Alzheimer* dement*</td>
<td>“behavioral and psychological symptoms of dementia” “behavioral symptoms” “behavioral disturbance*” “neuropsychiatric problem*” “neuropsychiatric symptoms” BPSD</td>
<td>Key words</td>
<td>“information need*” “education* need*” “learning need*” “supportive need*” “unmet need*” knowledge* need*</td>
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<tr>
<td>Mesh terms</td>
<td>alzheimer disease dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Search strategy

1. Medline

1 alzheimer disease (MeSH)
2 dementia (MeSH)
3 Alzheimer* (ti/ab)
4 dement* (ti/ab)
Behavioral and psychological symptoms of dementia (ti/ab)
“behavioral symptoms” (ti/ab)
“behavioral disturbance*” (ti/ab)
“neuropsychiatric problem*” (ti/ab)
“neuropsychiatric symptoms” (ti/ab)
BPSD (ti/ab)

6 OR 7 OR 8 OR 9 OR 10 OR 11

caregivers (MeSH)
spouses (MeSH)
family (MeSH)
caregiver* (ti/ab)
carer* (ti/ab)
“personal assistant*” (ti/ab)
“informal caregiver*” (ti/ab)
“family caregiver*” (ti/ab)
famil* (ti/ab)
spouse* (ti/ab)
partner (ti/ab)
friend* (ti/ab)
relative* (ti/ab)

13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25

Education (MeSH)
“information need*” (ti/ab)
“education* need*” (ti/ab)
“learning need*” (ti/ab)
“supportive need*” (ti/ab)
“unmet need*” (ti/ab)
knowledge* (ti/ab)
need* (ti/ab)
27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34

Computers, Handheld (MeSH)
Mobile applications (MeSH)
Smartphone (MeSH)
“electronic health app*” (ti/ab)
“eHealth app*” (ti/ab)
“smartphone app*” (ti/ab)
“mobile health app*” (ti/ab)
“mobile app*” (ti/ab)
“mHealth app*” (ti/ab)
“mobile phone app*” (ti/ab)
“iPhone app*” (ti/ab)
“Android app*” (ti/ab)
“phone app*” (ti/ab)
“handheld computer*” (ti/ab)
“internet based application*” (ti/ab)

36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 50
5 AND 12 AND 26
35 OR 51
52 AND 53
2. CINAHL

S1  (MH “Alzheimer’s Disease”)
S2  (MH “Dementia+”)
S3  Alzheimer*
S4  dement*
S5  1 OR 2 OR 3 OR 4

S6  “behavioral and psychological symptoms of dementia”
S7  “behavioral symptoms”
S8  “behavioral disturbance*”
S9  “neuropsychiatric problem*”
S10 “neuropsychiatric symptoms”
S11 BPSD
S12 6 OR 7 OR 8 OR 9 OR 10 OR 11

S13 (MH “Caregivers”)
S14 (MH “Spouses”
S15 (MH “Family+”)
S16 caregiver*
S17 carer*
S18 “personal assistant*”
S19 “informal caregiver*”
S20 “family caregiver*”
S21 famil*
S22 spouse*
S23 partner*
S24 friend*
S25 relative*
S26 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25
S27 (MH “Education+”)
S28 “information need*”
S29 “education* need*”
S30 “learning need*”
S31 “supportive need*”
S32 “unmet need*”
S33 knowledge*
S34 need*
S35 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34

S36 (MH “Computers, Handheld+”)
S37 (MH “Mobile Applications”)
S38 (MH “Smartphone”)
S39 “electronic health app*”
S40 “eHealth app*”
S41 “smartphone app*”
S42 “mobile health app*”
S43 “mobile app*”
S44 “mhealth app*”
S45 “mobile phone app*”
S46 “iPhone app*”
S47 “Android app*”
S48 “phone app*”
S49 “handheld computer”
S50 “internet based application*”
S51 36 OR 37 OR 38 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 50

S52 S35 OR S51

S53 S5 AND S12 AND S26 AND S52
3. PsycInfo

1 Alzheimer disease.mp. or exp Alzheimer's Disease
2 exp Dementia/ or dementia.mp.
3 Alzheimer*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
4 dement*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
5 1 or 2 or 3 or 4
6 "behavioral and psychological symptoms of dementia".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
7 "behavioral symptoms".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
8 "behavioral disturbance*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
9 "neuropsychiatric problem*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
10 "neuropsychiatric symptoms*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
11 BPSD.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
12 6 or 7 or 8 or 9 or 10 or 11
13 caregiver.mp. or exp Caregivers
14 spouse.mp. or exp Spouses
15 exp Family
16 caregiver*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
17 carer.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
18 "personal assistant*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
19 "informal caregiver*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
20  "family caregiver*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
21  famil*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
22  spouse*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
23  partner*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
24  friend*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
25  relative*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
26  13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27  exp Education
28  "information need*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
29  "education* need*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
30  "learning need*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
31  "supportive need*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
32  "unmet need*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
33  knowledge*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
34  need*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]
35  27 or 28 or 29 or 30 or 31 or 32 or 33 or 34
36  exp Computers/ or Computers, Handheld.mp.
37  exp Mobile Applications/ or Mobile applications.mp.
38  exp Smartphones/ or Smartphone.mp.
"electronic health app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"eHealth app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"smartphone app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"mobile health app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"mobile app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"mHealth app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"mobile phone app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"iPhone app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"Android app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"phone app*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"handheld computer*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

"internet based application*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]

36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50

35 or 51

5 and 12 and 26 and 52

4. EMBASE

#1 ‘dementia’/exp

#2 ‘alzheimer disease’/exp

#3 alzheimer*

#4 dement*
#5  #1 OR #2 OR# 3 OR #4

#6  ‘behavioral and psychological symptoms of dementia’
#7  ‘behavioral symptoms’
#8  ‘behavioral disturbance*’
#9  ‘neuropsychiatric problem*’
#10 ‘neuropsychiatric symptoms’
#11 bpsd

#12  #6 OR #7 OR #8 OR #9 OR #10 OR #11
#13  ‘caregivers’/exp
#14  ‘spouse’/exp
#15  ‘family’/exp
#16  caregiver*
#17  carer*
#18  ‘personal assistant*’
#19  ‘informal caregiver*’
#20  ‘family caregiver*’
#21  famil*
#22  spouse*
#23  partner*
#24  friend*
#25  relative*
#26  #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25

#27  ‘education’/exp
#28  ‘information need*’
#29  ‘education* need*’
#30  ‘learning need*’
#31  ‘supportive need*’
5. Cochrane

#1 (dementia OR alzheimer disease):ti,ab,kw AND (“behavioral and psychological symptoms of dementia” OR “behavioral symptoms” OR “behavioral disturbance*” OR “neuropsychiatric problem*” OR “neuropsychiatric symptoms” OR BPSD):ti,ab,kw AND (caregiver* OR carer* OR “personal assistant*” OR “informal caregiver*” OR “family caregiver*” OR famil* OR spouse* OR partner* OR friend* OR relative*):ti,ab,kw AND (“information need*” OR “education* OR need*” OR “learning need*” OR “supportive need*” OR “unmet need*” OR knowledge* OR need*) OR (“electronic health app*” OR

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“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*”):ti,ab,kw, in Trials (Word variations have been searched)

6. ProQuest

S1 mainsubject(alzheimer s disease)
S2 mainsubject(dementia)
S3 ab(alzheimer*)
S4 ab(dement*)
S5 ab(“behavioral and psychological symptoms of dementia”)
S6 ab(“behavioral symptoms
S7 ab(“behavioral disturbance*”)
S8 ab(“neuropsychiatric problem*”)
S9 ab(“neuropsychiatric symptoms”)
S10 ab(BPSD)

S11 mainsubject(caregivers)
S12 mainsubject(spouses)
S13 mainsubject(family)
S14 ab(caregiver*)
S15 ab(carer*)
S16 ab(“personal assistant*”)
S17 ab(“informal caregiver*”)
S18 ab(“family caregiver*”)
S19 ab(famil*)
S20 ab(spouse*)
S21 ab(partner*)
S22 ab(friend*)
S23 ab(relative*)
S24 mainsubject(education)
S25 ab("information need*")
S26 ab("education* need*")
S27 ab("learning need*")
S28 ab("supportive need*")
S29 ab("unmet need*")
S30 ab(knowledge*)
S31 ab(need*)

S32 mainsubject(Computers, Handheld)
S33 mainsubject(Mobile applications)
S34 mainsubject(Smartphone)
S35 ab("electronic health app*")
S36 ab("eHealth app")
S37 ab("smartphone app")
S38 ab("mobile health app")
S39 ab("mobile app")
S40 ab("mHealth app")
S41 ab("mobile phone app")
S42 ab("iPhone app")
S43 ab("Android app")
S44 ab("phone app")
S45 ab("handheld computer")
S46 ab("internet based application")

S47 (mainsubject(alzheimer s disease)) OR (mainsubject(dementia)) OR (ab(alzheimer*))
OR (ab(dement*))

S48 (ab("behavioral and psychological symptoms of dementia")) OR (ab("behavioral symptoms")) OR (ab("behavioral disturbance")) OR (ab("neuropsychiatric problem")) OR (ab("neuropsychiatric symptoms")) OR (ab(BPSD))

S49 (mainsubject(caregivers)) OR ((mainsubject(spouses)) OR (mainsubject(family)) OR
(ab(caregiver*)) OR (ab(carer*)) OR (ab("personal assistant")) OR (ab("informal

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Supplemental material

caregiver* OR (ab("family caregiver*")) OR (ab(famil*)) OR (ab(spouse*)) OR (ab(partner*)) OR (ab(friend*)) OR (ab(relative*))

S50 (mainsubject(education)) OR (ab("information need*")) OR (ab("education* need*")) OR (ab("learning need*")) OR (ab("supportive need*")) OR (ab("unmet need*")) OR (ab(knowledge*)) OR (ab(need*))

S51 (mainsubject(Computers, Handheld)) OR (mainsubject(Mobile applications) AND PEER(yes)) OR (mainsubject(Smartphone)) OR (ab("electronic health app*")) OR (ab("eHealth app*")) OR (ab("smartphone app*")) OR (ab("mobile app*")) OR (ab("mHealth app*")) OR (ab("mobile phone app*")) OR (ab("iPhone app*")) OR (ab("Android app*")) OR (ab("phone app*")) OR (ab("handheld computer*")) OR (ab("internet based application*"))

S52 ((mainsubject(education)) OR (ab("information need*")) OR (ab("education* need*")) OR (ab("learning need*")) OR (ab("supportive need*")) OR (ab("unmet need*")) OR (ab(knowledge*)) OR (ab(need*))) OR ((mainsubject(Computers, Handheld)) OR (mainsubject(Mobile applications)) OR (mainsubject(Smartphone)) OR (ab("electronic health app*")) OR (ab("eHealth app*")) OR (ab("smartphone app*")) OR (ab("mobile app*")) OR (ab("mHealth app*")) OR (ab("mobile phone app*")) OR (ab("iPhone app*")) OR (ab("Android app*")) OR (ab("phone app*")) OR (ab("handheld computer*")) OR (ab("internet based application*"))

S53 ((mainsubject(alzheimer s disease)) OR (mainsubject(dementia)) OR (ab(alzheimer*)) OR (ab(dement*)) AND ((ab("behavioral and psychological symptoms of dementia")) OR (ab("behavioral symptoms")) OR (ab("behavioral disturbance*")) OR (ab("neuropsychiatric problem*")) OR (ab("neuropsychiatric symptoms")) OR (ab(BPSD)) AND ((mainsubject(caregivers)) OR (mainsubject(spouses) AND (mainsubject(family))) OR (ab(carer*)) OR (ab("personal assistant*")) OR (ab("informal caregiver*")) OR (ab("family caregiver*")) OR (ab(famil*)) OR (ab(spouse*)) OR (ab(partner*)) OR (ab(friend*)) OR (ab(relative*)) AND ((mainsubject(education)) OR (ab("information need*")) OR (ab("education* need*")) OR (ab("learning need*")) OR (ab("supportive need*")) OR (ab("unmet need*")) OR (ab(knowledge*)) OR (ab(need*))) OR ((mainsubject(Computers, Handheld)) OR (mainsubject(Mobile applications)) OR (mainsubject(Smartphone)) OR (ab("electronic health app*")) OR (ab("eHealth app*")) OR (ab("smartphone app*")) OR (ab("mobile app*")) OR (ab("mHealth app*")) OR (ab("mobile phone app*")) OR (ab("iPhone app*")) OR (ab("Android app*")) OR (ab("phone app*")) OR (ab("handheld computer*")) OR (ab("internet based application*"))

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### Supplementary table 1

**Study Details and Findings**

<table>
<thead>
<tr>
<th>No</th>
<th>Author, Year, Location</th>
<th>Aim of the Study/ Hypothesis</th>
<th>Theoretical framework, Design</th>
<th>Population, Sampling, Sample</th>
<th>Informal carers’ information needs on managing BPSD OR mHealth applications in supporting BPSD management</th>
<th>Methodological rigour; Relevance (high or low)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Armstrong et al., 2021) USA</td>
<td>To investigate the end-of-life experiences of informal carers of individuals with who died within the prior 5 years.</td>
<td>None reported Qualitative descriptive study</td>
<td>Family carers of individuals who died from DLB Purposive Sampling 30 carers</td>
<td>Information needs on managing BPSD 1. Behavioural challenges of the caring role included fluctuations, hallucinations, delusions, REM sleep behaviour disorder, constipation, and urinary incontinence. Information needs on support systems in managing BPSD 1. Several carers reported that behavioural symptoms prompted the need for institutional care/hospital care 2. Numerous carers reported challenges regarding finding a nursing facility due to the inability to safely keep care recipients at home. Self-care for carers 1. Several carers reported lack of sleep and rest due to behavioural problems.</td>
<td>100% High</td>
</tr>
<tr>
<td>2</td>
<td>(Ball et al., 2015) Australia</td>
<td>To explore the perceptions of family carers of people with dementia, with emphasis on feeding-related challenges, burden of care attributable to nutrition support and practical strategies developed to address these challenges.</td>
<td>None reported Descriptive exploratory qualitative study</td>
<td>Family carers of people with dementia 14 carers</td>
<td>Information needs on managing BPSD 1. Family carers reported feeding-related challenges experienced during caring for people with dementia. 2. Behavioral challenges included anger and aggression or hoarding food and cutlery.</td>
<td>80% Low</td>
</tr>
<tr>
<td>3</td>
<td>(Barton et al., 2014)</td>
<td>To explore issues about the behaviour(s) and to foster the</td>
<td>None reported People with dementia (PWD) and their carers in</td>
<td>Information needs on managing BPSD 1. A discussion with carers and patients with dementia revealed five categories of interventions for managing the behavioural symptoms:</td>
<td></td>
<td>0% High</td>
</tr>
<tr>
<td>Country</td>
<td>Description</td>
<td>Method</td>
<td>Study Type</td>
<td>Sample Size</td>
<td>Intervention Details</td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
<td>--------</td>
<td>------------</td>
<td>-------------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>Development of an individualised approach in order to implement an advanced practice nurse clinic focused on the management of dementia-related behaviours</td>
<td>Mixed method study (intervention)</td>
<td>66 dyads</td>
<td>Information needs on support systems in managing BPSD 1. Carers needed clarification about issues for follow-up in the clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>USA</td>
<td>To explore whether dementia specific service needs and gaps could be predicted from simple information that can be readily acquired in routine medical care settings</td>
<td>None reported</td>
<td>Quantitative descriptive study</td>
<td>215 carers</td>
<td>Information needs on managing BPSD 1. Major medical care gaps (the difference between service needs and service usage) were reported only when high-stress levels of carers were coupled with care recipients’ highly problematic behaviours, and these gaps were mainly related to dementia care interventions (counselling, medications to manage patient behaviour problems and/or carer stress).</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td>To explore the lived experiences and needs of spouses and other family carers of persons with Fronto-temporal dementia (FTD) to facilitate the development of support strategies and interventions.</td>
<td>None reported</td>
<td>Dutch family carers of FTD</td>
<td>24 carers</td>
<td>Information needs on managing BPSD 1. Most carers experienced difficulties with recognising and understanding early symptoms of FTD as they developed gradually over time. ** ** <strong>,</strong> 100%</td>
<td></td>
</tr>
<tr>
<td><strong>4</strong> (Borson et al., 2014)</td>
<td>USA</td>
<td></td>
<td></td>
<td></td>
<td><strong>,</strong> 60%</td>
<td></td>
</tr>
<tr>
<td><strong>5</strong> (Bruinsma et al., 2020)</td>
<td>Netherlands</td>
<td></td>
<td></td>
<td></td>
<td>** ** ** <strong>,</strong> 100%</td>
<td></td>
</tr>
</tbody>
</table>
3. Lack of emotional connection with their relatives and a feeling of abandonment by family and friends

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Objective</th>
<th>Design</th>
<th>Sample Size</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Taiwan</td>
<td>To evaluate the utilisation of long-term care service resources for carers of PWD; to identify the relationship between the characteristics of patients and carers, and to explore the factors affecting carers in using long-term care service resources.</td>
<td>Cross-sectional study</td>
<td>None reported</td>
<td>People with dementia and their family carers</td>
<td>Information needs on support systems in managing BPSD 1. Using the Functional Social Support Scale, the social support score for carers was averaged, with the lowest score in the information support. Informational support assesses providing guidance, advice, messages, or feedback information for problem-solving. 2. 40% of caregivers had never used long-term care service resources due to “not sure whether they fulfil the criteria to use those service resources” (38.2%), “never heard of the resources” (20.8%), and “not required” (19.4%). Self-care for carers 1. Carer burden was reported, with the highest score in time burden and the lowest score in emotional burden. The more frequent the BPSD, the greater the burden was found.</td>
</tr>
<tr>
<td>7</td>
<td>Hong Kong</td>
<td>To elucidate the phenomenon of elopement occurring in community-dwelling settings</td>
<td>Mixed method study</td>
<td>None reported</td>
<td>Community-dwellers with dementia and their carers</td>
<td>Information needs on managing BPSD 1. Only one subject showed obvious emotional and/or behavioural symptoms prior to elopement. This subject presented delusional behaviour and thought that someone asked her out for meals. All family informants expressed they introduced preventive strategies to avoid future elopement. Family informants noted that some strategies were not practical while some would provoke undesirable consequences (e.g., becoming agitated and restless when putting on physical restraints).</td>
</tr>
<tr>
<td>8</td>
<td>UK</td>
<td>To examine carer factors as predictors of BPSD-related distress and their potential mechanisms</td>
<td>Quantitative descriptive study</td>
<td>None reported</td>
<td>Informal carers of people with dementia</td>
<td>Information needs on managing BPSD 1. Path analysis shows that a significant negative moderate association was identified between competence and reactivity to BPSD Self-care for carers 1. Large significant correlations were seen between BPSD-related distress, reactivity to BPSD, frequency of BPSD and burden. 2. Variables which significantly predicted BPSD-related distress were competence, guilt, quality of life of the person with dementia, reactivity to BPSD and burden</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Objective</td>
<td>Design</td>
<td>Participants</td>
<td>Information needs on managing BPSD</td>
<td>Self-care for carers</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>-----------</td>
<td>--------</td>
<td>--------------</td>
<td>-----------------------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>9</td>
<td>USA</td>
<td>To understand the impact of dementia and its BPSD on diabetes care management for carers, and potential avenues for improvement in care delivery.</td>
<td>Qualitative exploratory study</td>
<td>21 cares in 6 focus groups</td>
<td>1. BPSD interfere with diabetes caregiving. For example, cussing and raging, agitation, impatience, patients making unreasonable comments and demands of them, hitting, wandering, blaming to carers, and ‘denial’ of diabetes or dementia. Carers tended to interpret their family members’ refusal as personal rather than as a symptom of their dementia. 2. Carers often felt obligated to adjust medications on their own and then would feel embarrassed to report this back to the care recipients’ healthcare providers.</td>
<td>1. Carers felt overwhelmed by the care recipients’ overall care demands from their dementia, BPSD, and diabetes.</td>
</tr>
<tr>
<td>10</td>
<td>Developing countries</td>
<td>Hypothesis: BPSD are independent predictors of carer strain after adjusting for clinical severity of dementia in this population</td>
<td>Mixed-method study</td>
<td>People with dementia and their carers from 17 developing countries (555 dyads)</td>
<td>1. Mainly, carers faced big issues when cognitive impairment interference management of behavioural symptoms.</td>
<td>1. BPSD are identified as the main focus of concern of carers, and it was overwhelming 2. One or more BPSD exhibited by the person with dementia were associated with higher caregiver ZBI scores. 3. Carers reported strain associated with managing BPSD from various sources: the physical and emotional strain of providing care, often with inadequate support from other family members, and the financial strain due to the inability to go to work. 4. Many carers felt shame about the changed behaviour of their relatives. 5. On occasion, family and people blames carers. Because they considered that carer was responsible for the alterations of behaviours.</td>
</tr>
<tr>
<td></td>
<td>Authors</td>
<td>Country</td>
<td>Study Objectives</td>
<td>Study Design</td>
<td>Sample Size</td>
<td>Information Needs on Managing BPSD</td>
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<tr>
<td>11</td>
<td>Hansen et al.</td>
<td>USA</td>
<td>To examine carer reactions to aggressive behaviours. Specifically, to examine carers upset with and confidence in managing three types of aggressive behaviours: verbal aggression, destroying property, and threatening to hurt others.</td>
<td>Stress process model Quantitative descriptive study (Secondary data analysis)</td>
<td>241 dyads</td>
<td>Persons with dementia and their family carer (person with dementia at least one carer reported episode of aggressive behaviour in the previous week) 1. The majority 2/3 of carers were upset with all aggressive behaviours, and more than 3/4 were upset with destroying property and threatening to hurt others, while a slightly lower percentage were upset with verbal aggression. 2. A little over 1/2 of carers reported confident in managing aggressive behaviours of any type, with more carers reporting being confident in managing threatening to hurt others and verbal aggression, but less than 1/2 reporting being confident in managing destroying property.</td>
</tr>
<tr>
<td>12</td>
<td>Harel et al.</td>
<td>Israel</td>
<td>To highlight the experience of an older woman living and coping with a spouse who exhibits dementia-related hypersexuality</td>
<td>None reported Narrative case-study of a single case</td>
<td>241 dyads</td>
<td>Carer (spouse) of people with dementia 1. Carer explained feelings of helplessness 2. Distress was experienced following spouse's hypersexual behaviors 3. Hypersexuality affect to ongoing love and relationship, and loss of her physical intimacy with spouse</td>
</tr>
<tr>
<td>13</td>
<td>Hinton et al.</td>
<td>USA</td>
<td>To examine (1) the frequency of mild and moderate to severe dementia neuropsychiatric symptoms in demented elderly, (2) the patterns of help-seeking by carers, and (3) carer’s unmet need for professional help coping with these symptoms</td>
<td>None reported Mixed method study</td>
<td>38 dyads</td>
<td>Latinos family carers of people with dementia and their care recipients from an epidemiological cohort study 1. Carers need professional help with information about dementia or behavioural problems and assistance in managing behavioural problems. 2. Many carers expressed unmet needs for professional help in managing neuropsychiatric symptoms, for example, information about referrals to support groups; assistance from a home health aide or other paid care providers; and improved access to health care, for example, finding acceptable services, overcoming transportation problems, and overcoming the care recipient’s resistance to going to see a doctor.</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Objective</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Key Findings</td>
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</table>
| 14 | Ho et al., 2015 | To evaluate dementia family carers’ demographic background, stressfulness as well as their willingness, preferences, and expectations on online dementia-related education (dementia E-learning) programme | Quantitative descriptive survey study | 279 carers | Information needs on managing BPSD:
1. Around 80% of the respondents were interested in taking part in dementia e-learning programme: handling BPSD (25.7%), improving understanding and communication with care recipient (18.8%), delaying dementia progression (17.8%) and setting up long-term caring plan (16.2%).
2. Carers need to improve communication with their care recipients |
| 15 | Hughes et al., 2009 | To retrospectively examine the experiences of African American carers that led them to seek a formal diagnosis for a family member with chronic memory loss and their initial awareness and recognition of Alzheimer’s disease | Health Belief Model Qualitative exploratory study | 17 carers | Information needs on managing BPSD:
1. Carers expressed a lack of knowledge about AD, for example, one participant reported wandering behaviours of her care recipient at nighttime.
2. Beyond a general label of AD, carers were not familiar with the symptoms, progression, or behavioural outcomes of the disease.
3. A gradual loss of intellectual abilities and changes in personality and behaviour were seen as a natural ageing process.
4. Behavioural changes deviated their relationship with family members. |
| 16 | Hughes et al., 2014 | To examine the relationship of unmet dementia-related care needs of community-dwelling persons, and their carers to measures of carer burden. | Cross-sectional study (baseline data prior to randomisation) | 246 carers | Information needs on managing BPSD:
1. Dementia education was reported as an unmet need of carers. Self-care for carers:
1. There was a significant correlation between patients’ neuropsychiatric symptoms and carer unmet need for emotional support (13.2% of the variance).
2. The average ZBI score was 15.1 (SD: 8.5), and the total mean hours carer spent for and with participants in a week was 91.1 (SD: 77.5).
3. Carers reported a lack of emotional support for them. |
<table>
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<tr>
<th></th>
<th>Study</th>
<th>Region</th>
<th>Objective</th>
<th>Research Design</th>
<th>Sample Size</th>
<th>Information Needs on Managing BPSD</th>
<th>Support Needs in Managing BPSD</th>
</tr>
</thead>
</table>
| 17 | Hurt et al., 2008 | European countries | To explore the relationships between quality of life and behavioural and BPSD from both patient and carer perspectives | Mixed method study | 167 dyads | 1. The majority could not find triggers for the behaviour.  
2. Few carers reported problematic behaviours when the patient was tired.  
3. Few carers were unable to identify the negative impact of BPSD |  |
| 18 | Ivey et al., 2013 | USA | To examine participants’ daily life experiences as informal carers to individuals with dementia, and explore how experiences and concerns may differ by ethnicity. | Qualitative phenomenological study | Carers of community-dwelling people with dementia from two ethnic groups; Filipino and non-Hispanic White | 1. Carers expressed their fears and concerns about care recipients wandering, getting lost, and getting hurt.  
2. They needed information or support to learn how to provide better care for the care recipient and themselves.  
Self-care for carers  
1. Due to care recipients’ repeating questions or statements, many carers spoke of experiencing stress and having their patience tested due to care recipient repeating questions or statements.  
2. Carers commented that caring for someone with dementia reduces social interaction time. A carer mentioned that she limits interacting with other couples because it is no longer fun due to her spouse’s behaviour.  
3. Carers described demanding or aggressive behaviour by care recipients and the potential dangers for the carers. |  |
| 19 | Kales et al., 2017 | USA | To meet the needs of end-users (style of approach and “look and feel”) of the tool, and the types of psycho education most needed by carers (end users). | Mixed method study | Family carers of persons with dementia | 1. Carers have expressed educational needs they prefer to include in the proposed tool: strategies on how to speak with someone who is confused and upset, an understanding of how medical problems like urinary tract infections cause behaviours, medication side effects and a horizontal graded pain scale over a face scale  
Information needs on support systems in managing BPSD  
1. Carers have expressed supportive needs they prefer to include in the proposed tool: getting an email each day with some words of encouragement, strength and energy to keep doing what they are doing, having a little search engine to put in whatever they are dealing with and popping up some strategies, ideas for taking care of the carer, and a notes section where carers can write notes to themselves about care |  |
<table>
<thead>
<tr>
<th>Study (Ref.)</th>
<th>Country</th>
<th>Methodology</th>
<th>Sample</th>
<th>Objectives</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leszko &amp; Meenrajan, 2021</td>
<td>Poland</td>
<td>Cross-sectional online survey</td>
<td>73 carers</td>
<td>To identify the attitudes and beliefs of carers of individuals with AD toward CBD oil in Poland, to identify factors that might be associated with the decision to use CBD oil among carers, and to explore whether such a decision was discussed with a healthcare professional</td>
<td>Information needs on managing BPSD 1. The most common reasons carers offered for using CBD oil were to slow memory loss and manage certain AD symptoms such as agitation, anxiety, and insomnia. 37% disclosed that they had not discussed the CBD oil usage with their physician, and 37% administered CBD without their physician's knowledge. The majority reported positive effects of the CBD oil. It said that CBD improved their care recipient's quality of life (84%), and five caregivers reported that CBD turned out to be ineffective in managing AD symptoms. Carers felt that CBD oil was helpful for treating the symptoms of the disease. A few carers (n = 7) pointed that people often confuse CBD with medical cannabis.</td>
</tr>
<tr>
<td>Leung et al., 2021</td>
<td>Hong Kong</td>
<td>Descriptive qualitative study</td>
<td>16 carers</td>
<td>To explore self-initiated strategies in managing BPSD adopted by Chinese carers</td>
<td>Information needs on managing BPSD 1. Carers thought that addressing unmet needs or external stimulation (thirst, hunger, and discomfort) could reduce BPSD. One carer reported the necessity of spending more time to figure out the needs of care recipient due to his deteriorating communication ability. 2. A few carers were concerned about the sustainability and side effects of taking medicine. 3. Carers mentioned confronting the care recipients would only induce further argument and agitation, and distress in carers. Carers felt frustration due to a lack of understanding of dementia, which led them to take a confrontational attitude towards the care recipients' behaviours. Self-care for carers 1. Carers mentioned having upsetting thoughts and irritability at the beginning of the caring journey. 2. A carer expressed suicidal thoughts and gave up due to caring stresses. 3. Carers demonstrated frustration and distress in monitoring care recipients around the clock.</td>
</tr>
<tr>
<td>REFERENCE</td>
<td>DESIGN</td>
<td>OBJECTIVE</td>
<td>CONTEXT</td>
<td>OUTCOME</td>
<td>NATURE</td>
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<tr>
<td><strong>22</strong> (Onishi et al., 2005)</td>
<td><strong>Network model</strong></td>
<td>To investigate the relative contributions of BPSD of care recipients, carers’ background and the care environment to carers’ burden assessed by using Zarit burden interview (ZBI)</td>
<td>Japan</td>
<td>Information needs on managing BPSD</td>
<td>***, 60%</td>
</tr>
<tr>
<td></td>
<td><strong>Quantitative descriptive study</strong></td>
<td></td>
<td></td>
<td>1. Carers experienced major difficulties in coping with some BPSD, including care recipients’ inability to find the way home, the inability to manage money and faecal incontinence.</td>
<td>Low</td>
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<tr>
<td></td>
<td></td>
<td>Self-care for carers</td>
<td></td>
<td>1. The ZBI and the burden score were significantly associated with the duration of care, the presence of an intimate counsellor, and the frequency of physical pain in the carers.</td>
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<td>2. Factors contributing to ZBI included severity of dementia, the BPSD of disturbing conversation, appearing unhappy or depressed and urinary incontinence.</td>
<td></td>
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<tr>
<td><strong>23</strong> (Paton et al., 2004)</td>
<td><strong>Exploratory qualitative study</strong></td>
<td>To gain insight into carers’ understanding of the causes of behaviours they find problematic in people with Alzheimer’s disease in order to inform the development of educational strategies</td>
<td>UK</td>
<td>Information needs on managing BPSD</td>
<td>***, 60%</td>
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<td>1. Carers stated difficulties associated with aggression, apathy, communication, repetitive behaviours, dangerous behaviours, anxiety/agitation/irritability, hallucination, delusion, poor personal hygiene/ incontinence, and wandering</td>
<td>High</td>
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<td>2. Carers believed that care recipients could control their behaviours and behavioural changes were attributed to the normal process of ageing.</td>
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<td>3. They thought aggression was due to premorbid personality factors, frustration or an unknown cause. Apathy was considered part of normal ageing or due to depression, physical illness and medication.</td>
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<td>4. Many carers felt that the person with dementia was acting in a particular way because of either negative experience, particularly loss, or earlier difficulties, for example, in childhood issues</td>
<td></td>
</tr>
<tr>
<td><strong>24</strong> (Peeters et al., 2010)</td>
<td><strong>Quantitative descriptive study</strong></td>
<td>To address the needs of informal carers for additional professional support, while also discussing the professional support they already receive.</td>
<td>Netherlands</td>
<td>Information needs on managing BPSD</td>
<td>***, 60%</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>1. Carers wanted to learn about being frightened, angry, or confused by people with dementia</td>
<td>Low</td>
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<td></td>
<td></td>
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<td></td>
<td>2. Information needs on support systems in managing BPSD</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1. Information from professionals focusing on available professional support services</td>
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</tbody>
</table>
To describe the relationship between the needs for professional support and the specific background characteristics of the informal carers and of persons with dementia.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Design</th>
<th>Sample</th>
<th>Needs for Information on Managing BPSD</th>
<th>Needs for Information on Support Systems in Managing BPSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>25 (Polenick et al., 2018)</td>
<td>USA</td>
<td>Descriptive qualitative study</td>
<td>26 carers, 4 focus groups</td>
<td>Information needs on managing BPSD</td>
<td>Information needs on support systems in managing BPSD</td>
</tr>
<tr>
<td>26 (Ramirez et al., 2021)</td>
<td>USA</td>
<td>Descriptive qualitative study</td>
<td>15 carers</td>
<td>Information needs on managing BPSD</td>
<td>Information needs on support systems in managing BPSD</td>
</tr>
</tbody>
</table>

| | | | | 1. BPSD was attributed to physical symptoms (such as fatigue or features of chronic medical conditions), care recipient’s adverse psychological reactions to dementia (such as fear), care recipient’s feelings of anger or frustration over diminished communication abilities, care recipient’s loss of personal control or independence, adverse social consequences of dementia (including social isolation, social exclusion, and loss of meaningful social roles), and changes in routine | 1. Health care providers did not offer support to identify warning of the personality and behavioural changes and to help carers cope with the frustration of BPSD. Carers wanted health care providers to acknowledge their challenging situation and direct them to supportive services. |

| | | | | 2. The need for information on legal matters, e.g., when carers admit a person with dementia to a care facility | 2. The internet was a major source of information for most carers. However, they often found the amount of information online to be overwhelming. Carers desired a single source (“one-stop shop”) of comprehensive and high-quality information. |

Self-care for carers

1. Difficulties in adapting to the caring situation (how to cope with changes in the behaviour of the person with dementia)
<table>
<thead>
<tr>
<th>Study</th>
<th>Data Collection</th>
<th>Data Analysis</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>27</td>
<td>Thailand</td>
<td>Cross-sectional</td>
<td>104 dyads</td>
<td>Carers described their frustration with not understanding why the BPSD were happening and how they could handle them. BPSD-related changes were deep frustration for carers.</td>
<td>***</td>
</tr>
<tr>
<td></td>
<td>Rangseekajee et al., 2021</td>
<td>None reported</td>
<td>Carers and patients with moderate–to-severe dementia</td>
<td>1. This study developed a mobile application for monitoring BPSD in patients with moderate-severe dementia. 2. Usability of the application: This application contained a simplified version of NPI scoring to better suit mobile phones and tablets. All carers completed the application within 5 minutes by themselves. Overall satisfaction was 80%, indicating “very likely to be helpful for caregiving”. Most complaints were about the readable. Relatively small text size was reported. 3. Engagement: Most carers (77.8%) were willing to use the application weekly to monitor patients’ BPSD.</td>
<td>High</td>
</tr>
<tr>
<td>28</td>
<td>USA</td>
<td>Quantitative exploratory study (Secondary data analysis)</td>
<td>569 dyads</td>
<td>Information needs on managing BPSD 1. Carers reported insufficient mastery in managing behaviours. 2. Self-care for carers 1. The carers reported burden, a higher degree of upset with dementia behaviours and greater depressive symptomatology than their counterparts not reporting restlessness.</td>
<td>****</td>
</tr>
<tr>
<td></td>
<td>Regier &amp; Gitlin, 2018</td>
<td>None reported</td>
<td>Carers of community-dwelling persons with dementia (persons with moderate-stage dementia with one or more behavioural disturbances)</td>
<td>569 dyads</td>
<td>**</td>
</tr>
<tr>
<td>29</td>
<td>Norway</td>
<td>A qualitative explorative design</td>
<td>Family carers of patients with bv-FTD and other dementias with degeneration of frontotemporal lobes and behavioural disturbances</td>
<td>Information needs on managing BPSD 1. It took a long time for family members to realise that their care recipient needed help for their behavioural symptoms. 2. The behavioural changes were gradual, and carers were unable to recognise these symptoms in the early period. Therefore, the diagnosis was delayed.</td>
<td>****</td>
</tr>
<tr>
<td></td>
<td>Rognstad et al., 2020</td>
<td>None reported</td>
<td>Family carers of patients with bv-FTD and other forms of dementia affecting the frontal and temporal lobes causing behavioural disturbances</td>
<td>Support systems in managing BPSD 1. Carers emphasised that they lacked information about nursing homes and daycare centres.</td>
<td>High</td>
</tr>
</tbody>
</table>
11 carers

Self-care for carers
1. Behavioural changes created great difficulties for carers, and these changes were perceived as incomprehensible and frightening.
2. BPSD led to a feeling of powerlessness, loneliness, sadness and embarrassment in the carer and the family.
3. Often, family carers felt stress and guilt related to the need to look after their family member.
4. The decision to move family members, often against their will, to a long-term care facility was described as a difficult process for each family.
5. Carers’ well-being was reduced due to the changes in behaviour and personality.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Participants</th>
<th>Methodology</th>
<th>Focus</th>
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</thead>
<tbody>
<tr>
<td>Samia et al., 2012</td>
<td>USA</td>
<td>26 carers, 5 focus groups</td>
<td>A multi-stage qualitative descriptive study</td>
<td>Information needs on managing BPSD</td>
</tr>
<tr>
<td></td>
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<td>Dementia family carers</td>
<td>1. Carers needed to enhance their skills to assess unmet needs, the meaning of behaviours, and to fit activities and expectations to the person’s abilities as the dementia progressed.</td>
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<td>2. Carers expressed the desire to shift from reacting to or correcting behaviour, assessing the situation, and using nonverbal communication to prevent discomfort and troubling behaviour.</td>
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<td>3. Carers desired knowledge and skills to anticipate and plan for the impending decline in the care receiver’s ability, behaviour changes, emotional responses, and dependence.</td>
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<td>4. Carers sought emotional challenges and decisions faced at the end of life.</td>
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<td>Self-care for carers</td>
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<td>1. Carers sought validation of their cumulative losses and grief and the emotional challenges and decisions faced at the end of life.</td>
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<td>2. Carers feared for their own physical or emotional safety. They worried about safety due to dangerous behaviours.</td>
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<td>3. Carers expressed disappointment, frustration, grief, or anger regarding family members who were not helped. Carers recognised that family members were not always to help them.</td>
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<td>4. It was difficult for them to move on from one hope to another with the changing situation.</td>
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<td>5. Carers expressed frustration about their lack of knowledge in finding available resources before it was too late.</td>
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</tbody>
</table>
6. Some carers struggled with self-care. Carers desired knowledge and skills to anticipate and plan for their emotional responses.

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Study Objective</th>
<th>Recruitment Method</th>
<th>Sample Size</th>
<th>Information Needs on Managing BPSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Song et al., 2018</td>
<td>South Korea</td>
<td>To identify family carers' experiences in managing BPSD with particular focus on their interpersonal interactions with patients with dementia</td>
<td>Purposive sample</td>
<td>15 carers</td>
<td>1. Carer-related triggers of BPSD were reported by carers, including lack of knowledge of patterns of BPSD, lack of consideration, instilling fear in care recipients to stop behaviours, and ignoring the needs of people with dementia. 2. Carers stated that care recipients felt a loss of power and become angry when family members attempted to stop them from problematic behaviours. The inability to communicate resulted in care recipients expressing their needs in their own manners, which family carers consequently viewed as BPSD. 3. Carers ignore the needs of the care recipients when carers lack emotions, attention and failed empathy for the care recipients. 4. Family carer's actions in response to BPSD have been reported, including, confronting patient’s behaviour, calming, preventing the cause of the behaviour, letting patients do what they want, persuading, distracting, asking others for help, bursting out in anger and giving a response. 5. Carers indicated a lack of understanding of how to manage BPSD. A carer reported that he/she was unaware of the BPSD pattern and would become irritated and yell. If carers knew about the needs of care recipients, carers could change their negative reactions.</td>
</tr>
<tr>
<td>Teel et al., 2003</td>
<td>USA</td>
<td>To describe the experience of families in seeking diagnosis and treatment for a loved one with dementia from 11 communities across Kansas</td>
<td>None reported</td>
<td>Family carers for loved ones with dementia from 11 communities across Kansas</td>
<td>Information needs on managing BPSD 1. There was uncertainty in how to interpret changes in a loved one’s behaviours during the diagnostic period. Carers identified specific, gradual deterioration in their loved one’s function.</td>
</tr>
</tbody>
</table>

Self-care for carers
1. Effects of BPSD on family carer have been reported, including: exhaustion, helplessness, sadness, and being overwhelmed. Carers were angry and felt that the patient was intentionally increasing their burden at first.
loved one with dementia and to identify any challenges or barriers encountered in the experience that might contribute to delay in recognition and treatment of AD

2. They became increasingly uneasy about the symptoms and eventually sought medical assistance from their physicians.
3. Understanding the caring role was challenging due to difficulties in personal limits and accessing necessary information about caring.

Support systems in managing BPSD
1. Carers were frustrated by the lack of services available to support care, including the virtual absence of qualified individuals to help support in-home care in small communities.

Self-care for carers
1. Stresses/worries of caring included physical and emotional stressors, financial worries (e.g., medicine, clothing, and dental bills) related to providing care, and limited education from physicians or nurses.

33 (Tyrrell et al., 2019) Sweden
To describe spouses’ experiences of living with partners who have developed neuropsychiatric symptoms related to dementia in a community setting.

Information needs on managing BPSD
1. Unpredictable behaviours were seen as a challenge. The challenging behaviours included mood swings, hallucinations or suddenly becoming violent and threatening without any obvious reason

Support systems in managing BPSD
1. Feeling vulnerable and facing domestic violence were experienced by carers due to physical violence, getting angry and aggressive, and throwing the carers out of home. Therefore, immediate help was required, including contacting the police, a neighbour or a family member.
2. Some carers expressed a lack of supportive care. For example, planning social care for care recipients was not optimal or not productive because social care planners neglected medical information, such as dementia diagnosis. Social care planning was not focused on the needs of carers.

Self-care for carers
1. The balance of carer-care recipient relationships was changed due to behaviours of care recipients: becoming passive and not interested in their surroundings, personality changes (abusive and violent), and a sense of lost identity of the person they once met and shared their lives with.
2. Carers expressed a threat to the safety of dyads due to challenging behaviours, for example, leaving the home middle of the night and being very active in the nighttime.
3. Carers felt isolated and restricted at home due to the inability to keep care recipients alone, anti-social behaviours of care recipients (humiliating and embarrassing) and keeping them home dark as requested by carers. Caring throughout the day and weeks was frustrating for carers.

| 34 | (Vaingankar et al., 2013) | To explore the experiences and challenges of informal carers in Singapore with the intent of identifying the multidimensional unmet needs from their perspective and generating carers’ needs checklist based on the findings | None reported | Informal carers of relatives of people with dementia | Information needs on managing BPSD
1. Managing care recipients’ emotions and behaviours was a challenge due to distraction from routine activities and personal life.
2. Carers wanted to learn about early recognition of dementia, the progress of dementia, managing BPSD, and treatments
Support systems in managing BPSD
1. Carer wanted to know about professional support services, health care facilities and training resources in their area.
2. Carers wanted social support in managing BPSD, for example, support groups, and voluntary or religious organisations
Self-care for carers
1. Carers were restricted to home to avoid embarrassment, stigma, or safety issues related to unexpected and unmanageable behaviour of care recipients who often caused strife with neighbours and embarrassment in the community.
2. The real and perceived lack of social support and understanding led to anger and frustration.
3. Family conflict was raised from their relative’s behaviour.
4. Information on counselling services for adapting to caring associated emotional issues were noted

Note

*MMAT criteria: *****, 100% for five criteria; ****, 80% for four criteria; ***, 60% for three criteria; **, 40% for two criteria; *, 20% for two criteria; 0% for zero criteria)

AD, Alzheimer’s disease; BPSD, Behavioural and psychological symptoms of dementia; bv-FTD, behavioural variant frontotemporal dementia; CBD, Cannabidiol oil; DLB, Dementia with Lewy bodies; FTD, Frontotemporal dementia; UK, United Kingdom; USA, United Estate of America; ZBI, Zarit Burden Interview