# **Original research**

**BMJ Open** 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 Whittemore and Knafl'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

- $\Rightarrow$  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 Whittemore and Knafl's framework (2005) for integrative review, quality appraisal using

 

 guidelines and whittemore and Khafi's framework (2005) for integrative review, quality appraisal using Mixed Methods Appraisal Tool and narrative synthe-sis strengthen the quality of this scholarly work.
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 → This review is strengthened by exploring information needs based on qualitative, quantitative and mixed-method studies.
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 → Language bias and information bias are limitations of the present review.
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 → The lack of data from developing countries limits the generalisation of the findings.
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 PROSPERO registration number CRD42021238540.
 BACKGROUND

 Dementia is a progressive and chronic neuro-degenerative disorder,<sup>1 2</sup> and it is a global health issue that negatively impacts the physical, psychological, social and financial

physical, psychological, social and financial well-being of individuals with dementia and their carers.<sup>3</sup> The majority of people with dementia receive care at home from informal carers,<sup>45</sup> and they play a pivotal role in caring for people with dementia.<sup>6</sup> For example, 96% of people with dementia in low-income and middle-income countries (LMICs) live at home.<sup>7</sup> Informal carers are unpaid, and they include family members, relatives and

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friends.<sup>3 8</sup> In 2019, WHO reported that dementia carers need information, training, services and social and financial support for looking after their care recipients.<sup>39</sup>

People with dementia present with several behavioural and psychological symptoms, and managing these symptoms is challenging.<sup>10</sup> Behavioural and psychological symptoms of dementia (BPSD) includes psychotic symptoms, mood symptoms, anxiety, apathy, agitation, disinhibition and wandering.<sup>11</sup> These symptoms are highly prevalent,<sup>1012</sup> and informal carers face several difficulties in managing these symptoms in home settings.<sup>13</sup> These challenges lead to different negative consequences, for example, carer burden,<sup>14</sup> burnout,<sup>15</sup> depression,<sup>14</sup> relationship difficulties with the partner,<sup>13</sup> isolation from family and society<sup>13</sup> and difficulties in coping.<sup>13</sup>

Given the challenges in managing BPSD,<sup>101617</sup> 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.<sup>17-19</sup> 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.<sup>13</sup> 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.<sup>10</sup> 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.<sup>20 21</sup> Smartphones are commonly used in healthcare,<sup>4</sup> and smartphone-based mobile health (mHealth) applications are a widely used technology that provides multifunctional assistance for informal carers of people with dementia.<sup>22 23</sup> 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.<sup>4 22-28</sup>

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.<sup>29</sup> This integrative review was guided by Whittemore and Knafl's framework,<sup>29</sup> 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),<sup>30</sup> and it has been published.<sup>30</sup>

#### **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
- 2. What are the available mHealth applications for in-
- 3. What factors affect usability and engagement in

# Literature search

# Eligibility criteria

Eligibility criteria The eligibility criteria were based on the 'Population, a Phenomena of interest and Context' (PICo) framework for qualitative studies,<sup>31</sup> and the 'Problem/Patient/Population, Intervention, Comparison and Outcome' (PICO) framework for quantitative studies.<sup>32</sup> However, it was evident that 'Patient/ Outcome' details are enough to formulate research questions for observational studies.<sup>33</sup>

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.

<page-header>The spectra of the included if they were related to (1) educational and  $\overline{\mathbf{g}}$ 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,<sup>34</sup> proficiency gaps<sup>34</sup> or supportive processes or systems in delivering care for BPSD.<sup>35</sup> mHealth applications-related outcomes were content, features, functions, usability or engagement. Usability outcomes of mHealth applications were perceived usefulness,<sup>36</sup> ease of use (eg, application format, clear wording, nature of guidance and nature of interactivity),<sup>3637</sup> satisfaction (likability, comfort, pleasure)<sup>38</sup> and content (educational content, supportive features).<sup>26 37</sup> Engagement-related outcomes for mHealth applications included effectiveness,<sup>37</sup> support (eg, community support or coach)<sup>37</sup> and barriers and limitations of informal carers for engaging with mHealth applications (eg, time investment, affordability and technology gaps).<sup>37,3</sup>

#### 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.<sup>33</sup> 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,33 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<sup>33</sup> (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.<sup>40</sup> 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 Z year 2000.41

#### Selection processes

copyright, inc The data search was reported in the Preferred Reporting Items for Systematic Reviews and Meta-analysis-2020 (PRISMA-2020) guidelines.<sup>42</sup> 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 use for data screening.<sup>33</sup> 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  $\overline{\mathbf{a}}$ 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<sup>43</sup> to report  $\mathbf{a}$ the degree of agreement between two raters over the fulltext screening. Kappa agreement ensures inter-rater reliability, which measures the extent of assigning the same 🤅 scores for the same variable using a nominal scale.<sup>43</sup> The  $\ge$ initial kappa value was 0.93, indicating almost perfect agreement.43

Bu The total results of six database searchers 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 technologies 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 relevancy by two reviewers (TJ and SR) independently.<sup>29</sup> The methodological rigour (risk of bias) of studies was analysed using the Mixed Methods Appraisal Tool (MMAT) V.2018,<sup>44</sup> and data relevancy was rated as high and low<sup>29</sup> by two reviewers independently (online supplemental table 1). The MMAT comprised five criteria rating scales for different studies, including quantitative, qualitative



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram. Adapted from Page *et al.*<sup>42</sup> \*Record: The title or abstract (or both) of a report indexed in a database or website. \*\*Report: A document (paper or electronic) supplying information about a particular study. \*\*\* Studies: An investigation that includes a defined group of participants and one or more interventions and outcomes. BPSD, behavioural and psychological symptoms of dementia.

and mixed-method studies.<sup>44</sup> 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%).<sup>45</sup> The kappa value between the two raters over the MMAT scoring was 0.79, indicating substantial agreement.<sup>43</sup> 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.<sup>46</sup>

#### **Data analysis**

Findings from the included studies were narratively analysed due to the methodological heterogeneity of the articles<sup>47</sup> and followed four steps: data reduction, data display, data comparison and conclusion drawing and verification.<sup>29 48</sup> 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.<sup>29</sup> 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).<sup>29</sup> In the current study, data were structured into themes/subthemes and displayed in a table.

*Data comparison*: Primary source data from data **g** displays are examined to recognise themes, patterns and **r** relationships.<sup>29</sup>

*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.<sup>29</sup>

#### **Data presentation**

Data were presented narratively using text and tables.

 
 Table 1
 Themes of information needs and related mHealth
 applications

Themes	Subthemes
1. Managing BPSD	Dementia and BPSD.
	Role of the carers.
	Misconceptions about BPSD.
2. Support systems	Professional support.
	Social support.
	Institutionalised support.
	eHealth support.
	Legal support.
3. Self-care for carers	Psychological well-being of carers.
	Safety of carers.
	Family breakdown and conflict.
	Adapting and coping.
4. mHealth function	Functions of mHealth applications.
	Usability and engagement of mHealth applications.

BPSD, behavioural and psychological symptoms of dementia; mHealth. mobile health.

# 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<sup>49</sup> and European countries.<sup>50</sup> 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) selfcare for carers and (4) the role of mHealth applications in providing education and support for carers (table 1 shows themes and subthemes).

#### 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.<sup>16</sup> Carers expressed that this poor knowledge led to triggering BPSD in their care recipients,<sup>1</sup> feeling of anger toward care recipients<sup>1</sup> and  $\neg$ frustration.<sup>16</sup> Carers stated limited knowledge of how to recognise symptoms,<sup>1 16 51–53</sup> the progression of BPSD,<sup>54 55</sup> frustration.<sup>16</sup> Carers stated limited knowledge of how to recognise symptoms,<sup>116,51–53</sup> the progression of BPSD,<sup>54,55</sup> the negative impact of BPSD on care recipients<sup>50</sup> and how to delay the symptoms.<sup>55</sup> Moreover, carers stated a lack of **2** knowledge in managing BPSD.<sup>116</sup>

They highlighted that adequate knowledge of BPSD would assist them in planning care and modifying the home environment.<sup>16</sup> Therefore, carers wanted to learn about dementia,  $5^{657}$  the progression of dementia,<sup>58</sup> how to recognise the changes in care recipients,58 59 how to manage behavioural and psychological problems,<sup>1 55 57-59</sup> available treatments<sup>58</sup> and planning future care for managing BPSD.<sup>55 59</sup> Carers highlighted the most significant symptoms that require further infor-mation, such as aggression  $\frac{60}{10}$  wandering at night time  $\frac{54}{54}$  s mation, such as aggression,<sup>60</sup> wandering at night time,<sup>54</sup> elopement<sup>61</sup> and being frightened, angry or confused.<sup>62</sup> Few carers reported their concerns about sustainability and the side effects of drugs,  $^{63}$  and they wanted to know  $\overline{\mathbf{6}}$ text about appropriate medications for managing problematic behaviours.<sup>12 57 63 64</sup> and

# **Role of the carer**

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,<sup>53</sup> particularly difficulties in identifying the caring role<sup>52</sup> and delivering ≥ care; for example, feeding,<sup>65</sup> cleaning and dressing<sup>49</sup> and a urinary and faecal incontinence.<sup>66 67</sup>

Carers reported insufficient mastery in managing behaviours.<sup>68</sup> 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.<sup>69</sup> Moreover, carers stated difficulties associated with communication with their loved ones when dealing with BPSD;<sup>63 70</sup> therefore, they needed to learn how to improve communication while providing care for BPSD.<sup>12 55 71</sup>

Carers reported that their negative attitudes and behaviours increased the presence of BPSD among their care recipients,<sup>163</sup> and they wanted to learn how to control this situation.<sup>63</sup> These attitudes and behaviours included paying poor attention to BPSD, instilling fear in care recipients and ignoring care recipients' needs.<sup>1</sup> 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.<sup>1</sup> Additionally, this situation was attributed to the development of argumentative attitudes toward care recipients<sup>63</sup> and incorrect practices; for example, adjusting medication doses without consulting healthcare providers<sup>72</sup> and offering alternative medicines such as cannabidiol oil without discussing it with their physicians.<sup>73</sup>

#### 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,<sup>70</sup> and behavioural changes were attributed to the normal process of ageing<sup>54 70</sup> or physical symptoms or features of chronic medical conditions.<sup>10</sup> When care recipients with BPSD refused diabetic care, carers perceived it as personal rather than a consequence of BPSD.<sup>72</sup> This study further reported that carers felt obligated to adjust carer recipients' medications; however, they did not inform health professionals due to embarrassment.72

#### 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

Informal carers recognised the importance of available and accessible professional support systems in managing the BPSD of care recipients.<sup>57</sup><sup>62</sup> They wanted to know about available professional support services,<sup>58 62</sup> healthcare facilities<sup>57 58</sup> and training resources<sup>58</sup> in the locality. They sought professional support due to various reasons, such as acquiring information to identify the warning signs of BPSD,<sup>16</sup> acknowledging carers' challenging situations,<sup>16</sup> managing comorbidities in the presence of BPSD<sup>72</sup> and directing carers to supportive services<sup>16</sup> and support groups.<sup>57</sup>

#### 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.<sup>57 58</sup> Carers of people with dementia reported a lack of knowledge of the services provided by voluntary or religious organisations.<sup>58</sup> They highlighted that these support systems helped to solve problems related to BPSD care; however, there was inadequate support for problem-solving,<sup>74</sup> which led to the development of anger and frustration among carers.<sup>58</sup>

#### Institutionalised support

With difficulties in looking after people with dementia at home, carers must find institutionalised care, including hospitalisation.<sup>66</sup> Therefore, carers seek recent ð

text

t and

information on institutionalised care.<sup>53 74</sup> 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.<sup>53 74</sup>

# 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.<sup>12</sup> They highlighted that they wanted to know the available electronic sources for information seeking, including looking after themselves.<sup>12</sup> by copyright, Carers preferred to find online information from a single place or platform called a 'one-stop-shop'.<sup>16</sup>

# Legal support

Another information need highlighted by carers was information on legal matters.<sup>62 64</sup> For example, the carers wanted to know what legal issues they faced when admitting a person with dementia to a care facility.<sup>62</sup> When care **a** recipients had two or more behavioural problems, carers **o** recipients had two of more benavioural problems, carers greported a need for psychosocial care, including legal advice.<sup>64</sup> 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

data mi Several studies reported that providing care for BPSD in people with dementia led to the decreased psychological well-being of carers,<sup>1 16 49 51-53 56 58-60 63 66-69 74 75</sup> 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 wellbeing;<sup>53</sup> for example, they experienced physical and **9** emotional strains<sup>49 52 67 76</sup> and lack of sleep and rest.<sup>66</sup> Moreover, providing care for BPSD caused to develop carer distress, <sup>63</sup> <sup>69</sup> <sup>71</sup> <sup>76</sup> grief, <sup>59</sup> upset, <sup>60</sup> <sup>63</sup> <sup>68</sup> disappoint-ment, <sup>59</sup> irritability, <sup>63</sup> burden, <sup>49</sup> <sup>67–69</sup> <sup>74</sup> guilt, <sup>53</sup> <sup>69</sup> frustra-tion, <sup>16</sup> <sup>51</sup> <sup>52</sup> <sup>58</sup> <sup>59</sup> <sup>63</sup> <sup>75</sup> depressive symptoms, <sup>68</sup> a feeling of powerlessness,53 feeling of shame49 53 and suicidal thoughts.<sup>63</sup> They further developed negative feelings concerning providing BPSD care, for example, exhaus- & tion,<sup>1</sup> helplessness,<sup>1</sup><sup>76</sup> overwhelming,<sup>1</sup><sup>72</sup> insecurity, selfblaming, loneliness and feeling sadness.<sup>51</sup>

Moreover, studies reported limited social interactions among carers who cared for care recipients with BPSD.<sup>58 75 77</sup> Social isolation is a common problem among carers<sup>75</sup> 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.<sup>58 75</sup> Despite the threat to

This review identified that mHealth applications were mainly developed in high-income countries. Although 96% of people with dementia are cared for in their homes social care sector in dementia, including the cost of the residential, nursing home or long-term care facilities.<sup>79</sup> 40%.<sup>79</sup> In light of a paucity of community-based dementia services in LMICs,<sup>80</sup> previous studies found that informal based approaches are needed for dementia care in LMICs,<sup>82</sup> and literature suggests that digital media could be helpful for family carers of people with dementia.<sup>80</sup>

Given the complex nature of BPSD, carers' needs related to addressing BPSD are complex and multidimensional.<sup>84</sup> The present review also supports the complex nature of the information needs of informal carers of people with dementia concerning BPSD management. Consistent with the findings of the current review, previous reviews

psychological well-being, a lack of emotional support was highlighted by carers;<sup>56</sup> particularly, their stress was not addressed.<sup>52 53 55 57 63 64 77</sup> Given the negative impacts on carer well-being due to managing BPSD, carers highlighted that they needed information on available support services for carers.<sup>57 58</sup>

# Safetv

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.<sup>59 75</sup> For example, care recipients presented with physical violence, anger and aggressiveness; therefore, carers were at high risk for physical and psychological injuries.<sup>75 77</sup> This situation led to developing a feeling of fear for their physical safety.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,<sup>58</sup> particularly the breakdown of their relationships;<sup>51 63 75</sup> for example, behavioural changes such as hypersexuality affect spouse carers' love and relationship and physical intimacy.<sup>76</sup> Carers further reported a lack of emotional connection with their relatives and a feeling of abandonment by family and friends during the caregiving journey.<sup>51</sup> Moreover, carers were angry toward other family members due to a lack of support in their caring roles.<sup>59</sup> One reported that carers faced harassment by other family members or third parties.<sup>49</sup>

#### Adapting to the situation

Studies reported that carers had difficulty adapting to changing situations related to their care recipients' behaviours.<sup>59 62</sup> 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.<sup>57 58</sup>

#### 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.<sup>78</sup>

The major function of the above application was monitoring BPSD in people with moderate-to-severe dementia.<sup>7</sup>

#### Usability and engagement of mHealth applications

In usability assessment, perceived usefulness, frequency of use, limitations and improvement of the application have been used.<sup>78</sup> With reference to the content, monitoring was performed using the simplified version of the Neuro-Psychiatric Inventory.<sup>78</sup> This study reported that the mHealth application was easy to use as all carers completed the application within 5 min.<sup>78</sup> Small font sizes and readability issues were reported.<sup>78</sup> Concerning overall satisfaction, the majority (80%) indicated that g it was 'very likely to be helpful for caregiving'.<sup>78</sup> Most pyright, including carers were willing to complete the application weekly to monitor patients' BPSD.78

# DISCUSSION

This systematic integrative review synthesised data from 34 studies that focused on informal carers who provided at studies that focused on informal carers who provided care for people with dementia at home. To the authors' knowledge, this is the first reported systematic review that explored informal carers' information needs concerning managing BPSD of people with dementia to develop an mHealth application. Based on the MMAT,<sup>44</sup> we appraised the selected articles, and the majority of the articles received high MMAT scores. However, 12 studies that scored 60% or less were also included in this review to broaden the content of a potential mHealth application to facilitate informal carers through different aspects. Overall, this integrated review contributed to the body of  $\blacksquare$ knowledge on the information and educational needs of informal carers involved in BPSD management of their G care recipients and related mHealth applications.

by informal carers,<sup>7</sup> LMICs pay only 10% of the cost of the Social care costs in high-income countries are around carers of people with dementia in these countries had o shown a lack of knowledge and the need for support  $\underline{\mathbf{G}}$ systems or services.<sup>81–83</sup> Therefore, multifaceted evidencerelated 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 selfcare.<sup>35 85</sup> Information on dementia knowledge, as reported by previous reviews, included general information on dementia, symptoms, diagnosis, managing BPSD, pharmacological management and its side effects, prognosis and maintaining a safe home environment.<sup>35 85</sup> However, these previous reviews did not explore information needs focusing on BPSD. In contrast to the previous reviews that assessed carers' information needs without specifying BPSD, some information needs were not explored by carers of the current review, for example, genetic factors, stages of dementia, chances of recovery from dementia, hygiene of people with dementia, dealing with physiological issues such as nutritional problems.<sup>35 85</sup> Consequently, a lack of evidence on informal carers' knowledge seeking, particularly the management of BPSD, was identified. Therefore, special attention is needed to address this gap by identifying the special knowledge requirements of this vulnerable population who manage BPSD, particularly in developing countries.

Moreover, the present review demonstrated that carers needed to know their roles as carers. Similarly, previous reviews reported various roles of carers throughout the trajectory of care provision, for example, care provider, communicator and interpreter.<sup>35 86</sup> Therefore, informal carers should be provided with information related to their caring roles,<sup>87</sup> and it is essential to develop affordable educational resources for carers, especially in developing countries. Some methods for information seeking include radio, television, attending seminars, reading newspapers/magazines/leaflets/books, websites or forums, through family and friends, electronic sources (email, smartphones, videos, support groups, social workers) and volunteer groups.<sup>35</sup> These approaches can be incorporated into addressing the information needs of carers.

This integrative review reported a knowledge gap about misconceptions concerning BPSD. This finding was not reported in the previous reviews. These misconceptions lead to the development of negative consequences, such as overestimating a care recipient's behaviours.<sup>88</sup> If carers' expectations were not achieved by their care recipients, carers might be distressed.<sup>88</sup> Due to the limited exploration of misconceptions about managing BPSD among carers of people with dementia, further investigation is essential.

This integrative review identified the information needs of informal carers concerning the supportive systems required in managing BPSD, such as professional support, social support, institutionalised support, eHealth support and legal support. Similar results can be found in recent reviews.<sup>35 85</sup> A recent review reported that carers' highest information needs were focused on dementia-related health services.<sup>35</sup> Health professionals should provide

carers with necessary information about supportive services from the diagnosis of dementia,<sup>35</sup> giving special attention to eHealth resources as these resources are useful, supportive, cost-effective and affordable in rural and urban areas, and can be used in flexible time.<sup>89 90</sup> 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.<sup>49 51 52</sup> Not expecting information **u** 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 copy systems/agencies for financial aid in their carer journey.

Similar to the previous reviews,<sup>35 85</sup> 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.<sup>35 85</sup> Therefore, taking care of carers is essential because they feel neglected during the carer journey.<sup>13</sup>

role with minimum psychological and emotional harm to in the several function of the several functions of mHealth applications for example, family carers of children with dementia for example, family care set of informal carers of pople with dementia for example, educating the several functions of mHealth applications for informal or example, family carers of molecular to be providing enter the several functions of mHealth applications for informal or populations for example, family carers of mHealth applications for informal providing the several functions of mHealth applications for informal or populations for informal providing the several functions of mHealth applications for example, family carers of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications for informal providing the several functions of mHealth applications that focused on providing education and support for informal carers, for example, providing information about patients (eg. clinitors 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. clinitors 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. clinitors include monitoring BPSD. Literature reported the several functions of mHealth applications that focused on providing education and support for informal carers, for example, p

carer and healthcare team;<sup>23 100 101</sup> sharing checklist for assessing carer/care recipients' condition;<sup>23 101</sup> reminders for taking medications;<sup>23 26 100 101</sup> connecting to social support and services;<sup>23 100 101</sup> and sending encouragement message.<sup>100</sup> A study conducted in Sweden explored family carers' and health professionals' perspectives on mHealth applications.<sup>102</sup> 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.<sup>102</sup> 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.<sup>23</sup> 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.<sup>100</sup> Similar to the present review, the previous studies indicated that informal carers reported positive experiences with the mHealth application.<sup>26 103</sup> 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.<sup>23</sup> 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.<sup>100</sup>

#### **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  $\clubsuit$ the mHealth application to educate and support informal carers of people with dementia. Currently, mHealth appli-cations 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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