

Supplementary table 1*Study Details and Findings*

No	Author, Year, Location	Aim of the Study/ Hypothesis	Theoretical framework, Design	Population, Sampling, Sample	Informal carers' information needs on managing BPSD OR mHealth applications in supporting BPSD management	Methodological rigour; Relevance (high or low)*
1	(Armstrong et al., 2021)	To investigate the end-of-life experiences of informal carers of individuals with who died within the prior 5 years.	None reported	Family carers of individuals who died from DLB	Information needs on managing BPSD 1. Behavioural challenges of the caring role included fluctuations, hallucinations, delusions, REM sleep behaviour disorder, constipation, and urinary incontinence.	*****, 100%
	USA		Qualitative descriptive study	Purposive Sampling 30 carers	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.	High
2	(Ball et al., 2015)	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.	None reported	Family carers of people with dementia	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.	****, 80%
	Australia		Descriptive exploratory qualitative study	14 carers		Low
3	(Barton et al., 2014)	To explore issues about the behaviour (s) and to foster the	None reported	People with dementia (PWD) and their carers in	Information needs on managing BPSD 1. A discussion with carers and patients with dementia revealed five categories of interventions for managing the behavioural symptoms:	0% High

	USA	development of an individualised approach in order to implement an advanced practice nurse clinic focused on the management of dementia-related behaviours	Mixed method study (intervention)	a behaviour management clinic 66 dyads	environmental, behavioural, pharmacological, physical, and internal to the carer. Multiple interventions were recommended; for example, modification of environment or communication style (short sentences, perhaps encouraging eye contact, speaking slowly, and delivering limited information) were highlighted. Information needs on support systems in managing BPSD 1. Carers needed clarification about issues for follow-up in the clinics Self-care for carers 1. Carer distress was reported	
4	(Borson et al., 2014) USA	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	None reported Quantitative descriptive study	Family carers of older adults, whom with clinically significant cognitive impairment 215 carers	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). Information needs on support systems in managing BPSD 1. When the care recipient had 2 or more behaviour problems, nearly all caregivers reported the need for psychosocial care, even when they reported their stress as low. Self-care for carers 1. Carers perceived stress and patient behaviour problems as the primary predictors of carers' needs and gaps.	***, 60% Low
5	(Bruinsma et al., 2020) Netherlands	To explore the lived experiences and needs of spouses and other family carers of persons with Frontotemporal dementia (FTD) to facilitate the development of support strategies and interventions.	None reported Qualitative exploratory study	Dutch family carers of FTD Purposive sampling 24 carers	Information needs on managing BPSD 1. Most carers experienced difficulties with recognising and understanding early symptoms of FTD as they developed gradually over time. Self-care for carers 1. Lack of psychological well-being of carers, especially frustration, insecurity, self-blaming, loneliness and feeling sadness 2. Early symptoms of FTD make the carers feel that their relationship with the person with FTD deteriorated due to less reciprocity interaction. Carers felt that early recognition was complicated by work-related stress, marital problems, or comorbid disease.	*****, 100% High

					3. Lack of emotional connection with their relatives and a feeling of abandonment by family and friends	
6	(Chang et al., 2020) Taiwan	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.	None reported Cross-sectional study	People with dementia and their family carers Purposive sampling 97 dyads	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.	*****, 100% High
7	(Chung et al., 2011) Hong Kong	To elucidate the phenomenon of elopement occurring in community-dwelling settings	None reported Mixed method study	Community-dwellers with dementia and their carers 45 dyads	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).	**, 40% Low
8	(Feast et al., 2017) UK	To examine carer factors as predictors of BPSD-related distress and their potential mechanisms	None reported Quantitative descriptive study	Informal carers of people with dementia 157 carers	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	***, 60% High

9	(Feil et al., 2011)	To understand the impact of dementia and its BPSD on diabetes care management for carers, and potential avenues for improvement in care delivery.	None reported	Carers of patients with dementia and type 2 diabetes	Information needs on managing BPSD 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.	*****, 100%
	USA		Qualitative exploratory study	21 cares in 6 focus groups	Information needs on support systems in managing BPSD 1. Carers wanted more support from healthcare providers; for example, they did not know what to do or how to respond when care recipients refused to adhere to the diabetes care regimen. Self-care for carers 1. Carers felt overwhelmed by the care recipients' overall care demands from their dementia, BPSD, and diabetes.	High
10	(Ferri & Ames, 2004)	Hypothesis: BPSD are independent predictors of carer strain after adjusting for clinical severity of dementia in this population	None reported	People with dementia and their carers from 17 developing countries	Information needs on managing BPSD 1. Mainly, carers faced big issues when cognitive impairment interference management of behavioural symptoms.	**, 20%
	Developing countries		Mixed-method study)	555 dyads	Self-care for carers 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.	High

11	(Hansen et al., 2020)	To examine carer reactions to aggressive behaviours.	Stress process model	Persons with dementia and their family carer (person with dementia with at least one carer reported episode of aggressive behaviour in the previous week)	Information needs on managing BPSD 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.	***, 60%
	USA	Specifically, to examine carers upset with and confidence in managing three types of aggressive behaviours: verbal aggression, destroying property, and threatening to hurt others	Quantitative descriptive study (Secondary data analysis)	A convenience sample 241 dyads	Self-care for carers 1. A higher level of reported upset was correlated with lower levels of reported confidence.	High
12	(Harel et al., 2022)	To highlight the experience of an older woman living and coping with a spouse who exhibits dementia-related hypersexuality	None reported	Carer (spouse) of people with dementia	Self-care for carers 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	*****, 100%
	Israel		Narrative case-study of a single case			High
13	(Hinton et al., 2006)	To examine (1) the frequency of mild and moderate to severe dementia	None reported	Latinos family carers of people with dementia and their care	Information needs on managing BPSD 1. Carers need professional help with information about dementia or behavioural problems and assistance in managing behavioural problems.	****, 80%
	USA	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	Mixed method study	recipients from an epidemiological cohort study 38 dyads	Information needs on support systems in managing BPSD 1. 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. Self-care for carers	High

					1. A most common unmet needs were counselling for the carers' emotional needs or stress, and information from social support groups for carers	
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	None reported	Dementia family 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	***, 60%
	China		Quantitative descriptive survey study	279 carers	Self-care for carers 1. Nearly 90% of the respondents reported having experienced caregiving stress	High
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	Carers who were given a diagnosis of Alzheimer's disease for a family member with dementia	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.	*****, 100%
	USA		Qualitative exploratory study	17 carers		Low
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.	None reported	Community-residing persons with dementia (PWD) and their carers from an ethnically and economically diverse area of Baltimore	Information needs on managing BPSD 1. Dementia education was reported as an unmet need of carers.	** , 40%
	USA		Cross-sectional study (baseline data prior to randomisation)	246 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	Low

17	(Hurt et al., 2008)	To explore the relationships between quality of life and behavioural and BPSD from both patient and carer perspectives	None reported	PWD and their carers from clinics at 7 European centres	Information needs on managing BPSD 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	*****, 100%
	European countries		Mixed method study	167 dyads		Low
18	(Ivey et al., 2013)	To examine participants' daily life experiences as informal carers to individuals with dementia, and explore how experiences and concerns may differ by ethnicity.	None reported	Carers of community-dwelling people with dementia from two ethnic groups; Filipino and non-Hispanic White	Information needs on managing BPSD 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.	*****, 80%
	USA		Qualitative phenomenological study	A convenience sample 75 carers in nine focus groups	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.	Low
19	(Kales et al., 2017)	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).	None reported	Family carers of persons with dementia	Information needs on managing BPSD 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	*****, 100%
	USA	(The tool: WeCareAdvisor facilitate family carers to assess, manage, and track BPSD using nonpharmacologic strategies. It is a web-	Mixed method study	4 focus groups (n=26) and a technology survey (n=26), and individual semi-structured interviews (n=12)	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	High

		based tailored carer - support tool.)			issues that they wish to discuss with other members of the health care team 2. Carers wanted to know the available electronic sources for information seeking	
20	(Leszko & Meenrajan, 2021) Poland	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 professionals	None reported Cross-sectional online survey	Carers of individuals with AD 73 carers	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.	****, 80% Low
21	(Leung et al., 2021) Hong Kong	To explore self-initiated strategies in managing BPSD adopted by Chinese carers	None reported Descriptive qualitative study	Chinese dementia carers in Hong Kong Purposive sampling 16 carers	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.	*****, 100% High

					4. Family conflicts with the breakdown of relationships with care recipients	
22	(Onishi et al., 2005)	To investigate the relative contributions of BPSD of care recipients, carer's background and the care environment to carer's burden assessed by using Zarit burden interview (ZBI)	Network model	Carers of elderly patients	Information needs on managing BPSD 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.	***, 60%
	Japan		Quantitative descriptive study	116 carers	Self-care for carers 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. 2. Factors contributing to ZBI included severity of dementia, the BPSD of disturbing conversation, appearing unhappy or depressed and urinary incontinence.	Low
23	(Paton et al., 2004)	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	None reported	Carers for people with AD [The carers were family and friends or, if none existed, formal carers; (12% were paid carers)].	Information needs on managing BPSD 1. Carers stated difficulties associated with aggression, apathy, communication, repetitive behaviours, dangerous behaviours, anxiety/agitation/irritability, hallucination, delusion, poor personal hygiene/ incontinence, and wandering 2. Carers believed that care recipients could control their behaviours and behavioural changes were attributed to the normal process of ageing. 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. Explanations of hallucinations and delusions by individual carers were sexual frustration, denial, physical illness and premorbid personality. 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	***, 60%
	UK		Exploratory qualitative study	205 carers		High
24	(Peeters et al., 2010)	To address the needs of informal carers for additional professional support, while also discussing the professional support they already receive.	None reported	Informal carers of persons with dementia	Information needs on managing BPSD 1. Carers wanted to learn about being frightened, angry, or confused by people with dementia	***, 60%
	Netherlands		Quantitative descriptive study	984 carers [Persons with dementia: Living	Information needs on support systems in managing BPSD 1. Information from professionals focusing on available professional support services	Low

		To describe the relationship between the needs for professional support and the specific background characteristics of the informal carers and of persons with dementia.		at home 631 (69.0%) Living in a nursing home or in a home for the elderly 299 (31.0%)]	2. The need for information on legal matters, e.g., when carers admit a person with dementia to a care facility 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)	
25	(Polenick et al., 2018) USA	To examine causal attributions about BPSD among individuals caring for a family member with dementia (part of a project to design a web-based tool for assessing and managing BPSD by carers).	None reported Descriptive qualitative study	Family carers of older adults with dementia 26 carers, 4 focus groups	Information needs on managing BPSD 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	*****, 100% High
26	(Ramirez et al., 2021) USA	To understand the needs of family carers for improving BPSD management and the extent to which carers perceived that STAR-carers Virtual Training and Follow-up (STAR-VTF) could address those needs	None reported Descriptive qualitative study (a human-centred design approach)	Family carers of Alzheimer's disease and related dementias 15 carers	Information needs on managing BPSD 1. A limited understanding of BPSD at the time of diagnosis and how to recognise BPSD and manage BPSD 2. Adequate knowledge of BPSD would assist in planning care and modifying the home environment Information needs on support systems in managing BPSD 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 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	*****, 100% High

					1. 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.	
27	(Rangseekajee et al., 2021) Thailand	To develop and validate a mobile application for carers to use in monitoring BPSD	None reported Cross-sectional study	Carers and patients with moderate- to severe dementia 104 dyads	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 readability. Relatively small text size was reported. 3. Engagement: Most carers (77.8%) were willing to use the application weekly to monitor patients’ BPSD.	***, 60% High
28	(Regier & Gitlin, 2018) USA	To examine demographic characteristics, cognitive and physical functioning of persons with dementia, and carer well-being to derive a profile of families managing restlessness	None reported Quantitative exploratory study (Secondary data analysis)	Carers of community-dwelling persons with dementia (persons with moderate-stage dementia with one or more behavioural disturbances) 569 dyads	Information needs on managing BPSD 1. Carers reported insufficient mastery in managing behaviours. 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.	****, 80% Low
29	(Rognstad et al., 2020) Norway	To explore the challenges of family carers of people with frontotemporal dementia and other forms of dementia affecting the frontal and temporal lobes causing behavioural disturbances	None reported A qualitative explorative design	Family carers of patients with bv-FTD and other dementias with degeneration of frontotemporal lobes and behavioural disturbances	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. Support systems in managing BPSD 1. Carers emphasised that they lacked information about nursing homes and daycare centres.	*****, 100% High

				11 carers	<p>Self-care for carers</p> <ol style="list-style-type: none"> 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. 	
30	(Samia et al., 2012) USA	To capture the emerging learning needs and preferences of dementia family carers who had previously completed the Maine Savvy Caregiver Program	Stress theory A multi-stage qualitative descriptive study	Dementia family carers Purposive sample 26 carers, 5 focus groups	<p>Information needs on managing BPSD</p> <ol style="list-style-type: none"> 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. 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. 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. 4. Carers sought emotional challenges and decisions faced at the end of life. <p>Self-care for carers</p> <ol style="list-style-type: none"> 1. Carers sought validation of their cumulative losses and grief and the emotional challenges and decisions faced at the end of life. 2. Carers feared for their own physical or emotional safety. They worried about safety due to dangerous behaviours. 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. 4. It was difficult for them to move on from one hope to another with the changing situation. 5. Carers expressed frustration about their lack of knowledge in finding available resources before it was too late. 	****, 80% High

					6. Some carers struggled with self-care. Carers desired knowledge and skills to anticipate and plan for their emotional responses	
31	(Song et al., 2018) South Korea	To identify family carers' experiences in managing BPSD with particular focus on their interpersonal interactions with patients with dementia	None reported Qualitative exploratory study	Family carers of dementia Purposive sample 15 carers	<p>Information needs on managing BPSD</p> <p>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.</p> <p>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.</p> <p>3. Carers ignore the needs of the care recipients when carers lack emotions, attention and failed empathy for the care recipients.</p> <p>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.</p> <p>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.</p> <p>Self-care for carers</p> <p>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.</p>	*****, 100% Low
32	(Teel et al., 2003) USA	To describe the experience of families in seeking diagnosis and treatment for a	None reported	Family carers for loved ones with dementia from 11 communities across Kansas	<p>Information needs on managing BPSD</p> <p>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.</p>	*****, 100% Low

		<p>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</p>	<p>Descriptive qualitative study</p>	<p>14 carers</p>	<p>2. They became increasingly uneasy about the symptoms and eventually sought medical assistance from their physicians.</p> <p>3. Understanding the caring role was challenging due to difficulties in personal limits and accessing necessary information about caring.</p> <p>Support systems in managing BPSD</p> <p>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.</p> <p>Self-care for carers</p> <p>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.</p>	
33	<p>(Tyrrell et al., 2019)</p> <p>Sweeden</p>	<p>To describe spouses' experiences of living with partners who have developed neuropsychiatric symptoms related to dementia in a community setting.</p>	<p>None reported</p> <p>Descriptive qualitative study</p>	<p>Spouses to older adults with dementia, a diagnosis of Alzheimer's Disease, Vascular Dementia or combined diagnosis</p> <p>A purposeful sample of 14 carers</p>	<p>Information needs on managing BPSD</p> <p>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</p> <p>Support systems in managing BPSD</p> <p>1. Feeling vulnerable and facing domestic violence were experienced by cares 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.</p> <p>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.</p> <p>Self-care for carers</p> <p>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.</p>	<p>*****, 100%</p> <p>High</p>

					<p>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.</p> <p>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.</p>	
34	(Vaingankar et al., 2013) Singapore	To explore the experiences and challenges of informal carers in Singapore with the intent of identifying the multi-dimensional unmet needs from their perspective and generating carers' needs checklist based on the findings	None reported Explorative qualitative study	Informal carers of relatives of people with dementia 63 carers	<p>Information needs on managing BPSD</p> <p>1. Managing care recipients' emotions and behaviours was a challenge due to distraction from routine activities and personal life.</p> <p>2. Carers wanted to learn about early recognition of dementia, the progress of dementia, managing BPSD, and treatments</p> <p>Support systems in managing BPSD</p> <p>1. Carer wanted to know about professional support services, health care facilities and training resources in their area.</p> <p>2. Carers wanted social support in managing BPSD, for example, support groups, and voluntary or religious organisations</p> <p>Self-care for carers</p> <p>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.</p> <p>2. The real and perceived lack of social support and understanding led to anger and frustration.</p> <p>3. Family conflict was raised from their relative's behaviour.</p> <p>4. Information on counselling services for adapting to caring associated emotional issues were noted</p>	*****, 100%, low

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 Amerika; ZBI, Zarit Burden Interview

