

Views of people living with dementia and their families/care partners: helpful and unhelpful responses to behavioral changes

Claire V. Burley,¹ Anne-Nicole Casey,¹ Lynn Chenoweth,¹ and Henry Brodaty^{1,2}

¹Centre for Healthy Brain Ageing (CHeBA), UNSW Sydney, NSW, Australia

²Academic Department for Old Age Psychiatry, Prince of Wales Hospital, South Eastern Sydney Local Health District, NSW, Australia

ABSTRACT

Objectives: This study investigated the views of people living with dementia and their families/care partners on (i) what they find helpful or unhelpful regarding behavioral changes, i.e. which coping strategies they used for themselves and/or which responses from others, and (ii) what they consider to be appropriate terminology to describe behavioral changes.

Design & setting: One-on-one semi-structured interviews were conducted with people living with dementia and families/care partners face to face, online, or over the telephone.

Measurements: Data from open-ended questions were analyzed inductively. Common themes were derived from the data using an iterative approach.

Results: Twenty-one people living with dementia and 20 family members/care partners were interviewed. Four main themes were derived for helpful responses, and three main themes for unhelpful responses. Helpful responses included providing clear professional support pathways and supportive environments where people living with dementia can engage in physical, cognitive, social, and spiritual activities. Unhelpful responses included discriminatory treatment from others and use of medicalized terminology. Views toward terminology varied; people with lived experience most favored using “changed behaviors” over other terminology. Areas for improvement included targeting dementia stigma, societal education on dementia, and building confidence in people living with dementia by focusing on living well with dementia.

Conclusion: Knowledge of the views of people living with dementia may assist healthcare professionals to provide more appropriate care for people living with dementia.

Key words Biopsychosocial, behavioral changes, Dementia, Neuropsychiatric symptoms, Pharmacological, Nonpharmacological

Introduction

Most people living with dementia experience changes in self-perception and behavior, which are often reinforced by how others respond to them (Kitwood, 1993; 1997). Behavioral changes present different challenges for people living with dementia (Larsson *et al.*, 2019; van Wijngaarden, *et al.*, 2019), families and/or care partners (Braun *et al.*, 2019), and care workers (Burns *et al.*, 2012). Social and emotional challenges may manifest in the form of

diminished social integration, stigma, and strained interpersonal relationships (Birt *et al.*, 2020; Górska *et al.*, 2018). Practical challenges may include need for informal and formal support services and treatment resulting in significant financial outlay for care provision (Beeri *et al.*, 2002; Burley *et al.*, 2020).

Other peoples' responses to behavioral changes also impact enablement and autonomy in the daily life of the person living with dementia, such as in contexts that cause confusion or distress for the person (Low *et al.*, 2018). Accessibility in public spaces represents one example of this in the community context where problematic situations may relate to crowding, high tempo and noise, change of landmarks, and use of everyday technologies (Brorsson *et al.*, 2011). Infrastructure and policy decisions made by local councils affect

Correspondence should be addressed to: Professor Henry Brodaty, Centre for Healthy Brain Ageing (CHeBA), School of Clinical Medicine, UNSW Medicine & Health, Discipline of Psychiatry and Mental Health, Level 3, AGSM Building, School of Psychiatry, University of New South Wales, Sydney, NSW 2052, Australia. Email: h.brodaty@unsw.edu.au Received 12 Mar 2022; revision requested 12 Apr 2022; revised version received 08 Sep 2022; accepted 15 Sep 2022. First published online 04 November 2022.

whether community members who are living with dementia are able to access public spaces and services that meet their needs (Brorsson *et al.*, 2011).

The responses of healthcare staff and national policy-makers can also have profound effects for people living with dementia and their family/care partners. Diagnostic care and interventions for people experiencing dementia symptoms provide salient examples from diverse contexts. Research evidence (Ballard *et al.*, 2017; Brodaty *et al.*, 2018), clinical guidelines (Laver *et al.*, 2016; NHMRC Guideline Adaptation Committee, 2016), and the recent Australian Royal Commission into Aged Care Quality and Safety (Commonwealth of Australia, 2021) support the use of thorough clinical assessment and psychosocial interventions including person-centred care for people living with dementia. Although there is considerable evidence for the use of nonpharmacological approaches in residential, hospital, and community settings for people living with dementia (2021b; Ballard *et al.*, 2017; Burns *et al.*, 2012; Chenoweth *et al.*, 2014; Livingston *et al.*, 2017; 2020; Burley *et al.*, 2020; Dyer *et al.*, 2018), acceptance and implementation of these approaches and changing practice is more challenging (Chenoweth *et al.*, 2021a; Livingston *et al.*, 2014). Despite their detrimental impact, psychotropic medicines, e.g. benzodiazepines and anti-psychotics, are still frequently prescribed in response to behavioral changes, especially in residential care settings (Brimelow *et al.*, 2019; Robins *et al.*, 2021).

Effects of terminology on people living with dementia

Decisions regarding care for people living with dementia are generally made by families/carers and/or healthcare professionals and based on clinical frames of reference, such as “Behavioral and Psychological Symptoms of Dementia” (BPSD). The term BPSD is commonly used in clinical settings as a generic term to denote specific behaviors including “aggression,” “agitation,” “disinhibited behaviors,” “nocturnal disruption,” “vocally disruptive behaviors,” and “wandering”; and psychological/psychiatric symptoms such as anxiety, apathy, depression, delusions, and hallucinations. These terms represent diverse presentations of non-cognitive changes experienced by people living with dementia (Finkel *et al.*, 1998). Three main models of BPSD cited in the Australian clinical context (RACGP, 2019) are the “Unmet need,” “Lowered stress-threshold,” and “Biological” models. These causal models describe behavioral symptoms either as manifestations of unmet needs (Algase *et al.*, 1996), reactions to stressors

(Hall, 1987), or resulting from pathophysiological processes (IPA, 2010).

The nomenclature of BPSD and the framework they provide permeate current dementia-related clinical practice and research. Their purpose is to categorize and simplify the description of a complex range of changes in behaviors and psychological symptoms that are diverse and varied in their presentations. The inherent constraints of using BPSD terminology are widely acknowledged (Cohen-Mansfield *et al.*, 2015; Cunningham *et al.*, 2019), since language pertaining to dementia influences thoughts, beliefs, emotions, and actions toward people living with dementia (Wolverson *et al.*, 2019; Gilmore-Bykovski *et al.*, 2020).

Terminology used to describe these behaviors has evolved (Finkel *et al.*, 1998; Kitwood, 1993), from improved understanding of disease processes, acknowledgement of appropriate language to describe symptomology and from recommendations of dementia advocates and consumers (Cunningham *et al.*, 2019). Adopting alternative terms has been attempted, although with limited success, as common usage leads to them also becoming stigmatizing (Cunningham *et al.*, 2019). Alternative terms to BPSD proposed in the Australian context include “changed behaviors” (p.11, Dementia Australia, 2021), “behaviors and psychological symptoms associated with dementia” which retains the same acronym, BPSD, but does not label behaviors as symptoms (Cunningham *et al.*, 2019) and “responsive behaviors” (Dementia Training Australia, 2022) as well as “expressions of unmet needs” (p. 11, Dementia Australia, 2021). Additional terms have been proposed in other national contexts, including “behavioral expressions” and “symptoms of distress” (DEEP UK 2014; Alzheimer’s Society Canada, 2017; Alzheimer’s Society UK 2018). Currently, there is no universally agreed alternative term to BPSD.

What do people with lived experience of dementia and behavioral changes report about the responses of others and terminology they have encountered?

Few studies have investigated the views of people living with dementia and families/care partners on their lived experiences of behavioral changes, asked what they find helpful or unhelpful regarding behavioral changes, and what they consider to be appropriate terminology. The authors’ previous qualitative research suggests that reconceptualizing BPSD terminology, to reflect the lived experiences and perceptions of the person living with dementia and behavioral changes, would likely encourage more person-centred approaches from families/

informal carers and healthcare staff (Burley *et al.*, 2021).

In the current study, we used an inductive approach to investigate the views of people living with dementia and family/care partners regarding what they found to be helpful/unhelpful responses from others to their behavior changes and strategies they used to help themselves. We also sought the views of people living with dementia on specific terminology used by healthcare professionals and others, e.g. “BPSD.” Learning from people with lived experience will help healthcare professionals and others better respond to people who experience behavioral changes associated with dementia and inform government initiatives aimed at educating societies and reducing stigma.

Study aims

This study aimed to investigate the views of people living with dementia and families/care partners on (i) what they find helpful or unhelpful regarding behavioral changes, i.e. which coping strategies they used for themselves and/or which responses from others, and (ii) what they consider to be appropriate terminology to describe behavioral changes.

Materials and Methods

Study design

This qualitative study comprised semi-structured interviews with people living with dementia and their family members and/or care partners. Ethical approval was obtained from the South Eastern Sydney Local Health District (SESLHD) Research Strategy Office (RSO) and the University of New South Wales (UNSW) Sydney Human Research Ethics Committee (HREC): 2019/ETH09814. Qualitative research study methods adhered to the Standard for Reporting Qualitative Research (O’Brien *et al.*, 2014). The study methods, including participant recruitment and consent procedures, are summarized here and described in more detail previously (Burley *et al.*, 2021). The study team included two postdoctoral psychologists (CB and AC), Professor of Nursing and registered nurse (LC), and Scientia Professor of Ageing and Mental Health and psychogeriatrician (HB).

Participant recruitment and setting

Participants were recruited using the online platform StepUp for Dementia Research (<https://www.stepupfordementiaresearch.org.au/>). People who register with the StepUp for Dementia Research

platform as study volunteers submit a participant profile and are provided with descriptions of available studies that may be a good match for them. Volunteers express their interest in participating studies (Jeon *et al.*, 2021). A Participant Information Sheet and Consent Form was emailed to potential participants who expressed an interest. In most cases, we recruited dyads consisting of the person living with dementia and a close family member/care partner. Inclusion criteria for people living with dementia were having a formal diagnosis of dementia, capable of giving informed consent and understanding of the study. Exclusion criteria were inability to demonstrate understanding of what study participation involved, and/or Mini-Mental State Examination (MMSE; Folstein, *et al.*, 1975) score of less than 18 out of 30 (assessed by lead researcher and author CB). Family/care partners were required to be either cohabiting with a person living with dementia or seeing them ≥ 4 hours per week. Where participants were not eligible, this was communicated to them sensitively. People were signposted to additional support services where appropriate. Eligible participants were invited to complete an interview that lasted 45–90 minutes according to their needs and wishes. Author CB met participants via their preferred method, either at UNSW Sydney prior to the COVID-19 pandemic, online via Zoom/Skype, or by telephone. All participants were invited to receive a summary of results at the end of the study.

Data collection

Author CB conducted all interviews. People living with dementia and families/care partners were asked to describe any behavioral changes they experienced and were given examples following an open-ended question (results reported in Burley *et al.*, 2021). They were then asked, “*What have you found helpful/unhelpful when you experienced (behavior/symptom using participant’s wording)? What would you like to happen? What do you think should happen?*” They were asked how examples of terminology used to describe behavioral changes associated with dementia made them feel and were invited to share other concerns. The interviewer used reflective language to clarify, confirm, or explore participant responses during interviews.

Data entry and storage

Audio-recordings and electronic documents were stored on a password-protected secure university server, only accessible to the research team. Author CB transcribed all recordings, removed identifying information, and allocated unique participant identification numbers.

Data analysis

A data-driven inductive approach (Burley *et al.*, 2021; Miles and Huberman, 1994; Morgan, 1993; Whitemore *et al.*, 2001) was used for the open-ended question responses (Boyatzis, 1998). Authors CB and AC read the interview transcripts independently, developed data codes, and tabulated them in Microsoft Word. Author LC reviewed the codes alongside the supporting quotes. An iterative process took place, with meetings to discuss, compare, and document the researchers' independent and shared findings. Discrepancies in findings were discussed until consensus was achieved. Common themes arising from the agreed codes were identified and named by CB, AC, and LC (Gibbs, 2018).

Safety and risk considerations

Participants were able to end participation in the study at any time, allowed as much time as they required to answer questions, and were monitored for signs of distress, fatigue, and/or confusion. If the participant showed any signs of distress, CB paused interview questions and offered a break or to end the interview. Participants were offered contact details and resources for relevant support services and invited to contact CB if they had any concerns regarding the study.

Results

The results reported in this article focus on participants' views toward helpful and unhelpful responses of others to behavioral changes in the person living with dementia and terminology used regarding behavioral changes.

Participant characteristics

Forty-one participants were recruited and interviewed between December 2019 and February 2021. Another eight people expressed an interest in taking part though did not complete the study (four were unable to give informed consent, two declined, and two did not respond). Recruitment was temporarily paused due to physical distancing requirements during the COVID-19 pandemic from March to July 2020. Interviews recommenced online only. Twenty-one people living with dementia, mean aged 71 years, mean Mini-Mental State Examination score 25, and 20 family members/care partners were interviewed separately. Participant demographic and clinical characteristics, e.g. age, sex, geographical location, dementia subtype/severity, comorbid conditions, difficulties with mobility or communication, and medication are summarized in Table 1.

Main findings

The findings below are structured around three thematic categories that align with the study aims. Quotations from people living with dementia are marked with a "P," family/care partners with a "C," and matching numbers show where quotations came from a dyad, e.g. P07 and C07 are the person and their spouse. An overview of three main thematic categories (Tables 2, 3 & 4) and their themes are shown in Figure 1.

THEMATIC CATEGORY 1. HELPFUL RESPONSES/ COPING STRATEGIES WHEN EXPERIENCING BEHAVIORAL CHANGES

People living with dementia and families/care partners gave examples of helpful responses initiated by themselves, i.e. coping strategies, and by those around them including other family members, friends, the public and healthcare professionals. Themes of category 1 were (1.1) information seeking and support, both professional and peer, (1.2) information providing, advocacy, contributing to science, e.g. by volunteering to take part in research studies or sharing their experiences with the scientific community, (1.3) activity engagement/avoidance, e.g. physical, social, cognitive and spiritual, and (1.4) views toward medication and alternative strategies (Table 2).

1.1. Information seeking and support, professional and peer People living with dementia described the importance of support from a significant other, e.g. spouse, or the desire for the support if they felt that person was missing from their life. Examples of support included receiving reassurance, practical support in day-to-day activities and having someone to remind them about things. Many participants described the importance of family help in coping with cognitive changes occurring with dementia (see Table 2, Theme 1.1.a).

People living with dementia also described family/care partners' reaction in coping with behavioral changes, such as becoming angry. People living with dementia explained they would like others to try and understand the underlying reasons behind the behavior and to recognize that the behavior may be caused by difficulty in expressing an unmet need, e.g. being in pain. Carers said it was important to understand that people living with dementia were not always behaving in particular ways on purpose (see Table 2, Theme 1.1.b).

In terms of professional support, some people living with dementia explained they wanted to seek information so they could prepare for what might happen. Some also expressed they wanted to be treated respectfully and felt that adequate training

Table 1. Participant demographic and clinical characteristics

DEMOGRAPHIC CHARACTERISTICS		CLINICAL CHARACTERISTICS	
Sex of people living with dementia (<i>n</i> = 21)	Female (14) Male (7)	Dementia type	AD (5) FTD (4) LBD (1) Mixed/other (11)
Age (years) of people living with dementia	Mean SD: 70 ± 7 Range: 55 - 86	Dementia severity*	Mild (12) Moderate (6) Unknown (3)
Sex of family member/care partner (<i>n</i> = 20)	Female (14) Male (6)	MMSE score	Mean: 25 ± 4.55 Range: 18 - 30
Relationship to person living with dementia	Partner (13) Daughter/son (5) Carer (1) Friend (1)	Other medical conditions	>1 other (10) None (8) Mood disorders (10) Sleep disorders (9) High BP (6) Cancer (4) Other (6)
Place of residence	Private with family (17) Private alone (3) Residential care (1)	Medications	>1 medication (7) None (3) Dementia (8) Mood disorders (6) Other (11) Unknown (5)
Geographical location by State of residence	New South Wales (10) Victoria (5) Queensland (4) Western Australia (2)	Other difficulties	>1 other difficulty (3) None (11) Mobility (6) Communication (4) Hearing (3) Intellectual (1) Unknown (2)

Abbreviations: AD, Alzheimer's disease; BP, blood pressure; FTD, frontotemporal dementia; LBD, Lewy body dementia; MMSE, Mini-Mental State Examination. "Other" medical conditions included cardiac problems, diabetes, or stroke. Other medications included treatment for cancer, stroke, gastrointestinal conditions, pain, high cholesterol, and high blood pressure.

*Dementia severity was taken from the StepUp for Dementia Research platform. MMSEs were administered by author CB.

of healthcare professionals was required to achieve this (see Table 2, Theme 1.1.c).

People living with dementia expressed how important it was to feel accepted by society generally in addition to having a close family member and professional support to assist throughout the process of being diagnosed with dementia and managing the changes in their cognition and behavior they were to experience. They described positive experiences of integration where people without dementia could learn from people with dementia and become more compassionate (see Table 2, Theme 1.1.d).

1.2. Information providing, advocacy, contributing to science Participants described educating people about what it is like to live with dementia, or to care for someone living with dementia, as an activity that provided them a great level of "purpose" and satisfaction. This was described as a coping

mechanism and some described doing this in active ways such as through advocacy, where they could provide consultation to researchers, healthcare staff, and policy-makers. Others explained that participating in scientific studies to progress research and knowledge of dementia gave them relief, while acknowledging that research outcomes may benefit future generations and not themselves (see Table 2, Theme 1.2.a).

Other coping mechanisms that people living with dementia described were to challenge the perceptions of others, so that people accepted their reality and lived experience, rather than challenge them. Many family members explained that a barrier to coping was having others question the reality that the person was experiencing, as this would often cause them distress. Memory retention strategies were also described by some people living with dementia to help them with day-to-day activities (see Table 2, Theme 1.2.b).

Table 2. Thematic category 1. Helpful responses/coping strategies when experiencing behavioral changes

THEME	EXAMPLE QUOTES
1.1. Information seeking and support (professional and peer)	
1.1.a Importance of support from a significant other	<p>P02: <i>I'd like someone to come and live with me and tell me it's going to be alright.</i></p> <p>C02: <i>You have to adjust your living to fit in with them. I see a counselor now and the things I'm working on is changing my behaviors and my reactions and my expectations.</i></p> <p>P03: <i>I get support from my wife. She supports me really well. I give her a hard time at times I know that.</i></p> <p>P07: <i>I can just ring and say (to my husband), "What am I supposed to be doing? What am I supposed to be doing? I know I'm supposed to be doing something, what is it?"</i></p> <p>C04: <i>With specialist appointments for instance, it'll come under my phone and that's the number I give. Because at the end of the day it's important I know what's going on with (partner's name).</i></p>
1.1.b Importance of understanding the underlying reasons for behavioral changes	<p>P05: <i>So what I would want to do is the person around me to try and figure out why am I getting angry because, where is the impact that is changing that, not assume that I'm angry as a person but angry as a reaction to something, what am I angry about and what needs to be changed.</i></p> <p>P05: <i>These ideas of BPSD most of them have a cause, but some time it's not the easiest cause to find, but a good carer would, in the environment. Are they in pain? Are they uncomfortable? Is there too much stimulation? There's a whole lot of things that can impact.</i></p> <p>C21: <i>You (carers) have to realize that they are not doing it on purpose. They just can't control all that.</i></p>
1.1.c Information seeking and being treated respectfully	<p>P05: <i>I liked to be informed as much as I can, so I know what's going to affect me. What's going to be detrimental, what I can't do. I see how far I can go. I just got to accept it.</i></p> <p>P05: <i>I know people who are involved with the advocacy program at Dementia Australia, they really treat you well. They ask you, "Are you ok with this?" They've been well trained.</i></p>
1.1.d Feeling accepted by society	<p>P07: <i>We were at the memory café where two ladies sat down at a reserved table by accident. Then they realized they were sitting with this group of people with dementia. They apologized for sitting on the reserved table. We said, 'No you can sit here and join us', and they did. They got a better understanding of people with dementia because we talked to them, and they talked to us. They had a better view of people with dementia and their challenges. They were happy they'd sat in the wrong seat.</i></p> <p>C08: <i>I've sort of organized for her to go out with people. She's a people person. She's quite happy and looks forward to those trips because she goes out with, maybe a dozen or so other women. They go to different places and thoroughly enjoys that.</i></p>
1.2. Information providing, advocacy, contributing to science	
1.2.a Educating people about what it is like to live with dementia	<p>P02: <i>I keep busy, mostly volunteering. I'm an advocate for dementia. Create awareness and get involved in research. I sit on the board and advisory committees (for dementia advocacy organizations). It gives me purpose.</i></p> <p>C02: <i>Now with her diagnosis she has thrown herself well and truly into (lists dementia advocacy organizations),</i></p> <p>P17: <i>I liked the university environment, so the research and that kind of work, I always found good, and I enjoy doing things like that now.</i></p> <p>P18: <i>It helps me get out of bed (dementia advocacy work) you know.</i></p>
1.2.b Accepting the reality of the person living with dementia	<p>C05: <i>Just accept that they've got a different perspective (hallucinations), a different way of thinking, a different way of brain working. It's just, ok yes, they've got pink elephants that are floating through the sky then so what! Why not? Pink elephants aren't going to hurt you. If that's what they want to see, then go ahead.</i></p>
Memory strategies	<p>P04: <i>Then I use my backup calendar. I just write things down, so I do not forget to do them. I give myself clues and I think about things.</i></p>

Table 2. Continued

THEME	EXAMPLE QUOTES
1.3. Activity engagement/avoidance (physical, social, cognitive, and spiritual)	
1.3.a Taking part in activities described as both helpful and unhelpful	<p>P02: <i>I lead a very active life. But it's deliberate activity in order to keep my brain functioning. I know lack of motivation is an issue for us and I'm certainly conscious of it but I'm just really fighting it.</i></p> <p>C02: <i>I think now with her diagnosis she has thrown herself well and truly into (things), back into (lists activities, removed to protect participants' confidentiality), she looks after her grandkids every second weekend, she's very social.</i></p> <p>P01: <i>Sometimes I avoid things well in advance because there is likely to be a situation like that can be avoided. Some people I know [pause] because of the likelihood of leading to those sorts of situations, because of their [pause] narrow perspectives.</i></p> <p>P03: <i>I would just like to withdraw from the situation . . . just get away from the situation and the pressure.</i></p>
1.3.b Freedom of diverse emotional expression	<p>P04: <i>I don't get depressed very often. Because I won't let myself.</i></p> <p>P01: <i>Be able to express them, and for people to know that it's not just necessarily a feeling of sadness but it's also often a combination of joy and sadness together.</i></p>
1.3.c Benefits of social contact	<p>C15: <i>My older sister (has) gone into a care unit, but what is really interesting is, she's enjoying it there because she's getting more social contact than she did before because her family is much closer.</i></p> <p>P04: <i>How can I be lonely I've got two dogs, so when my husband used to work or go away, I always had the dogs. And you would be so surprised at the amount of people who will stop and talk to you because you have dogs, or they've got dogs.</i></p>
Appreciate being independent	<p>P11: <i>I love being independent.</i></p> <p>P04: <i>I used to meet all sorts of people down in [place names] or wherever, you meet all these lovely people to talk to because you've got dogs. But now I don't get that, because . . . people don't talk to you because you're with your husband or whatever. I used to love that when he was away (describing how the people living with dementia would meet more new people). So, I don't know if he realizes but it's quite easy to cope when he's not there. And I don't worry about getting lost because the dogs won't let me get lost.</i></p>
1.3.d Variety of reasons for engaging less in activities	<p>C08: <i>I'd love to see her get back into something, like hobbies. She used to do cross-stitch. I'd love to see her get back into that. But she's not inclined to do that either.</i></p> <p>P25: <i>I used to do a lot of craft things. I used to do, you know coloring in. Yeah, but because of the concentration thing, you know you begin to think, "Now is it worth trying to do it for a little while?" and you know you'll probably get a headache at the end of it. Or whether it's "I just cannot be bothered because I do not want to suffer the consequences."</i></p> <p>C08: <i>She's happy and enjoys those trips because she goes out with a dozen or so other women.</i></p> <p>C21: <i>He still plays golf twice a week and he loves that. We went to the beach this morning, so we exercise down there and he loves that. They are short, doable activities that he still enjoys a lot.</i></p>
1.4. Views toward medication and alternative strategies	
P01: <i>It's minor pain that keeps me awake or wakes me up. But none of the magic pain killing medication has any effect. Elastic bandages, strapping tape stuff, does work for a while. The results seem to be more predictable than medication.</i>	
P02: <i>I'd like people to not restrict me, drug me, or tie me in a chair. I'd like people to walk with me and talk to me and see if they can help me.</i>	
C02: <i>I personally think that exercise. It's a great thing for anyone to do with mental conditions. And even though, dementia is like a degenerative condition, I really believe that exercise can assist in that and just keeping those neurons, you know, nerves and everything, sort of still sparking.</i>	
P05: <i>I would like the person around me to recognize that I'm probably going into depression, and I need some help. And I'm not talking about medication [laughs] there are other ways, medication is one of the worst things you can do.</i>	

Table 2. Continued

THEME	EXAMPLE QUOTES
P05: CBT plus diet. The community program was called the “Depression and anxiety recovery program.” You choose one or two things you do every week. If you apply what you’ve heard and keep on applying what you’ve heard, you will get there eventually.	
P05: I’m pretty much anti-medication unless there’s a really good reason. I think, you go for medication when, for acute things, erm, medication for long term things if there’s no other option essentially. I don’t think adding chemicals to your system is the best way to go if there’s any alternatives that work.	
C09: The new doctor emphasized depression. I’m trying to look at it holistically. How can I handle it? Say depression, try to steer clear of drugs in the first instance, use diversional therapy. To counteract it now, we try to get off the property at least every second day. Maybe social, she has a small social group of women, she also has ex-colleagues in the (place she goes to).	

Table 3. Thematic category 2. Unhelpful responses/barriers to coping with behavioral changes

THEME	EXAMPLE QUOTES
2.1. Stigma, treatment from others	
2.1 Lack of public awareness about dementia	<p>P01: I think the real area is broadening public awareness around, what the disease is in general, if disease is the right word. It (dementia awareness) needs more mainstream coverage.</p> <p>P02: My friends are supportive as far as giving me lifts to places and things, but none of them really get it.</p> <p>C05: I think for carers they need to be reminded that it’s not the person it’s the dementia that is speaking.</p> <p>P01: With being disorientated, probably being able to take the time to really reorient rather than being told.</p>
2.2. No clear support pathway/inadequate professional support	
2.2.a Experiences with professional support varied	<p>P01: It’s really disheartening to see the standards that are involved not just in care but building design for example.</p> <p>C02: . . . doctors and professionals not believing that she has all these symptoms because she functions quite well and she presents quite well . . . because she’s fought for it (to receive medical attention) it’s a little bit easier for her.</p> <p>P05: Often it’s lack of a proper diagnosis that leads to depression. When you start thinking that the end of this trail is death, well that’s a little depressing. When you get your diagnosis, and the doctor says, ‘go home and prepare to die’.</p> <p>P01: They still have a lot of attitude issues with the staff which I think is the big issue. And you know, that’s going to require major attitudinal changes within that sort of system a little bit like the aged care system at the moment. I don’t think you can treat unless you understood. Because I suspect the most likely forms of treatment would compound problems.</p>
2.2.b Being treated differently to someone with dementia	<p>P01: The same behavior from someone in a different situation would be considered normal, maybe even to be admired.</p> <p>P02: If somebody comes in, a stranger comes up to you and says, “Oh, we’re going to take your clothes off and have a shower now.” I mean, the natural reaction, if you’ve got any stranger danger awareness, is to say, “You gotta be kidding me! I’m not taking my clothes off in front of you!” If you haven’t got the language and somebody starts to take your clothes off, you’re going to hit out. And to me, that is not a challenging behavior, that is a response to a normal situation because of the lack of, the memory of the person and the knowledge of why they’re there, the understanding of why they’re there, but the behavior itself is a perfectly normal behavior.</p>
2.3. Loss of identity and confidence/increased dependence	
2.3.a Negative self-talk because of lost abilities	<p>P03: It’s just frustrating when you cannot remember certain things.</p> <p>P04: All I would really like, and it will never happen, is somebody to take my brain out, wash it clean it and give it back to me and then I remember everything again. I get angry with myself, but it’s not anger it’s just, “Oh for God’s sake you stupid women! [laughs] . . . I do get sad with myself when I wish I’d remember these things. I just get angry with myself I say, ‘You stupid woman’”. I get angry with myself. I do not get angry with other people.</p>
2.3.b Increased energy and time required to do tasks	<p>P05: Dementia takes energy from you, so you’ve got less energy available, to do the same amount of jobs, the same amount of things you were able to do before.</p> <p>C02: I think what (she) does is she holds herself. She tries to maintain a tight control on herself, which to be quite honest, I think sometimes she finds it quite mentally exhausting.</p>

Table 4. Thematic category 3. Views toward terminology used to describe behavioral changes (umbrella terms including “BPSD,” “responsive behaviors,” “changed behaviors,” and “unmet needs”)

TERM/THEME	VIEWS	EXAMPLE QUOTES
3.1. Views toward terms		
Behavioral and Psychological Symptoms of Dementia (BPSD)	Disagree	P01: <i>It's I think a catch-all excuse category. It's grouping together things that maybe shouldn't be grouped together. And perhaps puts emphasis on the wrong area. It definitely puts emphasis on the behavior and not the cause of the behavior.</i>
		P02: <i>The terminology is wrong at the moment. The first time I heard it I couldn't believe that term was used. It's medicalizing behavior.</i>
		C09: <i>I don't think the construct necessarily reflects what is actually in the person with dementia's mind.</i>
		C21: <i>It feels like they're medicalizing a problem. They said we can have behavior modification medicine if you need. And I said that sounds a bit weird it sounds like something out of Hitler.</i>
	Agree	C01: <i>I think it's quite black and white, it's fine. I think it's just a way of describing it. I certainly do not think it's offensive.</i>
		P21: <i>I feel fine. I think it is a sort of framework for understanding.</i>
	Neutral/ other	C22: <i>It doesn't make me feel anything. I wouldn't agree with using it to enforce medication.</i>
		P08: <i>It's just one of the effects of this insidious illness!</i>
		C19: <i>It's another shortening of a terminology that we've got to wrap our heads around.</i>
Responsive behaviors	Disagree	C09: <i>I think it's too technical quite frankly. They're working on a formula that other professionals have developed as a way to understand dementia. they're all about control and discipline and achieving particular objectives. That's not the same for dementia.</i>
	Agree	P02: <i>Responsive behavior is the term I prefer. The behaviors we're displaying, are symptoms of humanity, not enough symptoms of dementia. Everybody displays behaviors and behaviors are a response to a situation.</i>
	Neutral/ other	C22: <i>I do not really have any strong feelings about it, it just seems a bit of jargon.</i>
		C01: <i>It doesn't really explain. It's kind of ambiguous.</i>
		P01: <i>It's a context, it's applicable to anything. You're going to respond to different actions, environments, everyone is.</i>
		P21: <i>If the responsive behavior means involving other people like responding to other people.</i>
		C19: <i>I hear that and I feel positive, and I think you know it's probably something we all have to adapt to. Because our lives are changing and evolving day to day week to week and, if anything, this COVID year has proven that we've all had to sort of be responsive in how we behave and often it's the only thing we are in control of.</i>
		C13: <i>I wouldn't worry about it cause that's part and parcel of it.</i>
Changed behaviors	Disagree	C21: <i>I've got no real feeling about that.</i>
		P01: <i>I'd say you need to make it changing behaviors. Changed suggests they're stable. I suppose the fear is always the simplification.</i>
		C09: <i>They're only markers from what was to what is.</i>
	Agree	P02: <i>We're behaving normally to abnormal circumstances.</i>
		C08: <i>She's not the same person I married you know. That person's gone.</i>
		C22: <i>That's exactly what it is. No, I haven't got a problem with that.</i>
		P23: <i>It says more to me than responsive behaviors, in terms of my condition.</i>
		C23: <i>That's pretty much what happens. It's easy to understand. It doesn't have any kind of connotations either. It's pretty direct.</i>
	Neutral/ other	C1b: <i>Changed behaviors is probably the biggest one because there is the whole, everything about them changes.</i>
		P02: <i>The majority of practitioners that are out there do not know whether it's a changed behavior or whether it's a behavior that you've always had.</i>
	P04: <i>I do not realize that I've changed. I do not realize that I've got changed behaviors.</i>	

Table 4. Continued

TERM/THEME	VIEWS	EXAMPLE QUOTES
Unmet needs	Disagree	P13: <i>It's very difficult to gauge a person who is, if you do not see the person regularly and see that, see the changes coming through.</i>
		P19: <i>Well, everybody has changed behaviors. That's a normal part of growing, this changed behavior, not a specific part of a disease. We all have changed behaviors.</i>
		C09: <i>Again that's a psychological term isn't it. Your psychological values. Erm not used in terms of dementia. I doubt it's something people are aware of.</i>
		C23: <i>I definitely understand what that one is about. There are definitely unmet needs. I've heard that people who have end-stage dementia who are in pain cannot explain it. You have to have other ways of determining that as an issue.</i>
		P25: <i>Oh yes, I hear that quite a bit and I believe unmet need. And I can relate wholly and solely to that because people do not understand me. Because coming into an aged care facility, probably early with dementia that so many staff, they are not trained, they have no empathy with me.</i>
Others (e.g., dementia)	Agree	P25: <i>And like with my sensory problems. I'll sit out there you know, in the little dining room there's only a couple of us out there, and we'll switch the main lights off because the lights are too bright and staff will just come along and switch it on. And I will say please do not, "Oh why?! Just get used to it." I have, because I look so good, I have many, many challenges in the staff that they just do not understand me. And like I've got a little booklet about sensory challenges and I've given it to some of this staff but It just seems to go straight over their head.</i>
		C19: <i>That doesn't really register anything. Other than. Maybe let me think about that, but again that's probably the (ageing?) process and yeah that's my only though on that.</i>
		C23: <i>("Dementia" as a term) it's almost like putting a label on someone that's not deserved. it tends to bring about negative feelings, rather than seeing that the person is still themselves.</i>
Alternatives/suggestions	Behaviors of concern	P02: <i>Maybe behaviors of concern but it depends on who's concerned, whether it's upsetting the person who's experiencing them or whether it's just upsetting the therapist.</i>
	Behavioral issues	P01: <i>"Behavioral issues" is unacceptable, has a quality judgement on behavior.</i>
	Changing behaviors	P01: <i>I think changing behaviors is better.</i>
	Changed experiences	P02: <i>I think what you've covered in your questions are changed experiences as much as behaviors.</i>
3.2. Other concerns expressed Quality and availability of support	Changed expression	P26: <i>I would prefer to call it changed expression. The expression you get on the outside doesn't always reflect what you feel on the inside, but very likely it expresses pain.</i>
	Disagree	P25: <i>There's lots of healthcare workers and they do most of the work, but they're not educated and they do not understand. I think there needs to be more education in the aged care facilities also.</i>
		P19: <i>We need to go right back to kindergarten so some of the most glorious interview things, have you seen that program where they have the kindergartens coming into the age care homes? Something as simple as that. You know, and those kids got it! They got that people are different, but they welcome the differences and they allowed for it.</i>
		C3b: <i>More support would be really good, access to support would be really good. Being able to access people who understand what they're talking about.</i>
	Agree	C3b: <i>We do not have enough general GPs with dementia training or awareness.</i>
		C11: <i>I just keep coming back to perceptions. Peoples' and society's perceptions. That's as much as an instrument of effect on somebody as anything else is sometimes.</i>

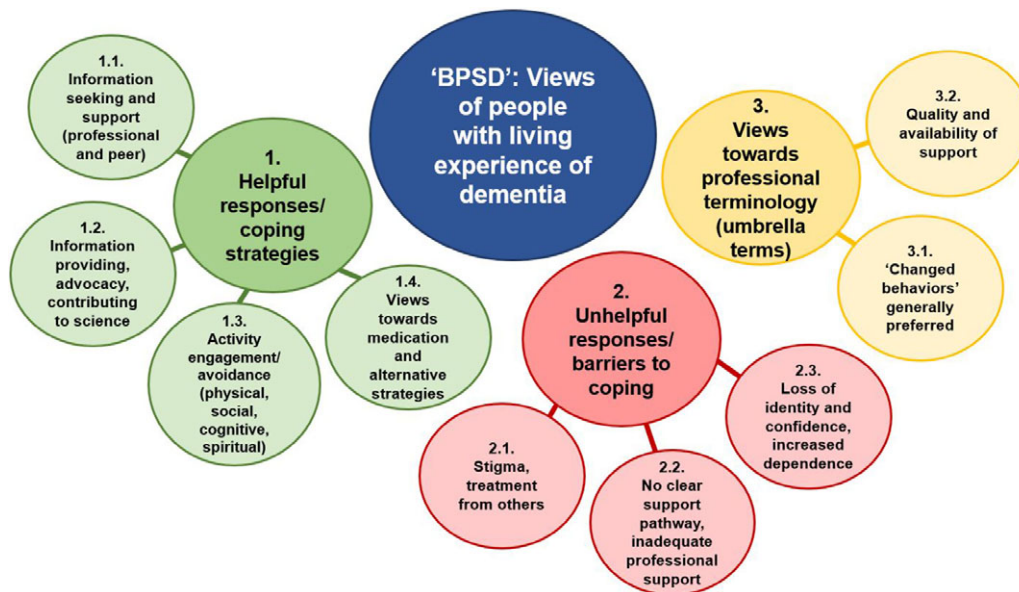


Figure 1. Summary of thematic categories and associated themes that emerged relating to the aims of this article. For category 3, “terminology” included “behavioral and psychological symptoms of dementia (BPSD),” “responsive behaviors,” “changed behaviors,” and “unmet needs.’

1.3. Activity engagement/avoidance, e.g. physical, social, cognitive, and spiritual People living with dementia described taking part in activities as being helpful. Some described many unhelpful experiences or examples of avoiding activities they previously enjoyed in order to avoid potential stress, “pressure,” or the “narrow perspectives” of others. They also described challenging unhelpful feelings and thoughts, for example loss of motivation and low mood (see Table 2, Theme 1.3.a).

Although people living with dementia sometimes described challenging feelings (e.g. feeling frustrated by something or someone when they would not have done previously), they also described wanting to be able to express themselves freely. They hoped that people around them would try to understand their expressions, and that these may be more complicated than simple binary emotions, e.g. intertwined feelings of sadness and joy (see Table 2, Theme 1.3.b).

Some participants described spirituality and engaging with animals as reducing loneliness (see Table 2, Theme 1.3.c). Others expressed their wish to remain independent. Family members often expressed that people living with dementia were less engaged in activities and described a variety of reasons including a loss of interest, increased anxiety, and finding previously enjoyed activities too difficult. Some carers described helpful approaches such as group activities with other people living with dementia and engaging in shorter, more manageable activities (see Table 2, Theme 1.3.d).

1.4. Views toward medication and alternative strategies Most of the people living with dementia described negative viewpoints toward medication for managing behavioral changes, including sleep disturbances, “wandering” and depression. Alternative suggestions to these medications included addressing underlying causes and unmet needs, by using non-pharmaceutical methods, e.g. compression bandaging to reduce pain, cognitive-behavioral therapy (CBT) for psychological factors, and dietary refinements for general health and wellbeing. Many expressed strong views against any form of restraint – chemical or physical (see Table 2, Theme 1.4).

THEMATIC CATEGORY 2. UNHELPFUL RESPONSES/BARRIERS TO COPING WITH BEHAVIORAL CHANGES

This category outlines unhelpful responses from other people and barriers to coping that were expressed by participants. Themes were (2.1) stigma, treatment from others, (2.2) no clear support pathway/inadequate professional support, and (2.3) loss of identity and confidence, increased independence (Table 3).

2.1. Stigma, treatment from others Most participants felt there was a lack of public awareness and understanding from other people about what it is like to live with dementia as well as what dementia is. Although the good intention of peers, e.g. extended family or friends, was recognized, people living with dementia felt that “none of them really get it.” Some

felt they just needed more time to process sensory information and wanted to be allowed to do this and remain independent, rather than having others try and do everything for them. Many people living with dementia suggested that increasing public awareness of dementia would be beneficial by promoting compassion, patience, and understanding (see Table 3, Theme 2.1).

2.2. No clear support pathway/inadequate professional support It was common for participants to describe feeling “disappointed” with healthcare services, although some reported “excellent” professional support. Some felt that health professionals did not believe their experiences or take their concerns seriously. Others said that when they were given an official diagnosis, they were told that there was nothing more they could do, and no follow-up support was offered. The variety of experiences reported by people living with dementia and families/care partners indicated that a nationally consistent and clear pathway of support for people through diagnosis and beyond was lacking (see Table 3, Theme 2.2.a).

People living with dementia also described feeling they were discriminated against for reacting in ways that a person without a diagnosis might not. An example was an unknown health professional entering their personal space to provide personal care without explanation and permission and doing so in a way that made the person feel threatened (see Table 3, Theme 2.2.b).

2.3. Loss of identity and confidence/increased dependence People living with dementia expressed frustration and/or sadness over loss in their abilities and loss of independence, e.g. not remembering things and no longer being able to drive. They also expressed losing confidence and their sense of identity/purpose. Often the negative self-talk they directed toward themselves further exacerbated feelings of low self-esteem. Some participants felt that other people such as family and peers shared similar views toward them (see Table 3, Theme 2.3.a).

Commonly, people living with dementia described having less physical energy than before, and they perceived this as a barrier to coping. This example mirrored previous quotes that explained how being allowed more time to process information would be helpful (see Table 3, Theme 2.3.b).

THEMATIC CATEGORY 3. VIEWS TOWARD TERMINOLOGY USED TO DESCRIBE BEHAVIORAL CHANGES (UMBRELLA TERMS) AND OTHER CONCERNS

People living with dementia and families/care partners responded to questions on knowledge of terminology used by healthcare professionals and

others to describe behavioral changes (see Table 4), and how the terms made them feel. Participants were given examples of terms, e.g. “behavioral and psychological symptoms of dementia,” “responsive behaviors,” “changed behaviors,” “unmet needs” and asked, “*Have you heard of this term before?*,” followed by “*How does this term make you feel?*”

Approximately half of people living with dementia struggled to answer more abstract questions about alternative terminology for behavioral changes and instead described experiences they thought corresponded to the terms. Themes of thematic category 3 were (3.1) “changed behaviors” generally preferred over “BPSD,” “responsive behaviors,” and “unmet needs,” and (3.2) quality and availability of support.

3.1. “Changed behaviors” generally preferred Most participants preferred the term “changed behaviors,” since this term did not carry negative connotations in contrast with “BPSD,” which was described to be “too medical,” “stigmatizing,” and “encouraged medication use.” Many participants considered that the terms were “ambiguous,” “could be applied to anyone,” “were not very useful,” or were “jargon” (Table 4). Approximately half of participants who did answer these questions felt neutral toward the terms, though some participants felt very strongly about specific terms. Those with strong views were linked with professional dementia services and/or were involved with Dementia Advocacy work, e.g. Dementia Alliance International. Those who worked with dementia organizations and Dementia Advocacy services also expressed finding this work incredibly rewarding (see Category 1).

3.2. Quality and availability of support Some participants who felt neutral toward the terms considered that quality and availability of support was more important to them than the terminology used. Those who opposed use of certain terms felt these terms had a direct impact on the quality of care and support available, e.g. encouraging medication use, as quoted above. Regarding quality and availability of support, some individuals expressed the view that more research was required specifically in this area, whereas others felt more effort should go into researching preventative strategies.

Discussion

Summary of main findings

The thematic categories were (1) helpful responses and coping strategies, (2) unhelpful responses and barriers to coping, and (3) views toward terminology used by healthcare professionals. Most participants

engaged in seeking information and professional support. Some found information provision and advocacy work rewarding. Most participants expressed they volunteered for this study because they wanted to contribute to scientific knowledge. However, participants who were concerned by how their friends now viewed them avoided peer support and were likely to avoid previously enjoyable physical, social, and cognitive activities. Experiences of professional support were mixed, from very positive to “disappointment,” reflecting known problems with existing dementia care pathways (Cations *et al.*, 2020).

Approximately half of the participants had not heard of the terms used to describe behavioral changes, required or requested explanation, and did not find their application particularly helpful. Others expressed very strong feelings against specific terms, predominantly “Behavioral and Psychological Symptoms of Dementia (BPSD)” and felt that the use of these terms encouraged chemical restraint and poor care practice. These participants considered that the term “BPSD” was “stigmatising” and that umbrella terms were inherently inadequate. This aligned with our previous published findings, suggesting a reconceptualization of “BPSD” is required (Burley *et al.*, 2021). Some participants living with dementia found it difficult to understand some of the questions posed, which was likely a reflection of their cognitive decline. Thus, they found it difficult to consider how use of particular terminology made them feel.

Progressing awareness and understanding of the study themes

Support is growing for a new paradigm for understanding behavioral changes that people living with dementia experience (Burley *et al.*, 2021; Górska *et al.*, 2018; Hammar *et al.*, 2021; James *et al.*, 2022). Momentum is increasing for a focus on improving how others treat people living with dementia, for using person-centered approaches in care and support, and for reducing stigma and discrimination (Chenoweth *et al.*, 2021a; 2021b; Bacsu *et al.*, 2022; Hung *et al.*, 2021). The sections below refer to how themes identified here relate to previous reports.

Activity engagement and support pathways

Our findings highlighted variations in the availability, consistency, and quality of support experienced by people living with dementia in their communities and in healthcare settings. Although exploration of causal factors was beyond the scope of this study, the divergent experiences of participants suggested possible variation was based on contextual factors such as living in rural/regional versus metropolitan

settings, as well as the unique needs of each person living with dementia. Similarly, a systematic review of qualitative studies found reports of dissatisfaction with the way a dementia diagnosis was communicated, and insufficient information and support being offered (Low *et al.*, 2018). Low and colleagues’ (2018) systematic review underlined the importance of addressing communication, particularly during the diagnosis process and through ongoing post-diagnostic support to ensure that people continue to engage in their usual activities. Poor quality of services has been reported by caregivers as a major barrier to finding help and accessing services (Macleod *et al.*, 2017). Barriers included mistrust and inflexibility of services. Clear communication and an “expert” point of contact were key facilitators of positive dementia support services (Macleod *et al.*, 2017). Participants in our study who described positive experiences had at least one professional they felt supported by.

Stigma and discrimination

Participants in this study described experiences and views suggesting a lack of community awareness about the lived experiences of dementia, and/or a disconnection between awareness, and compassionate and empathetic responses toward people living with dementia. These findings complement those of a qualitative study of people with mild neurocognitive disorder in Israel and Germany (Werner *et al.*, 2021) whose overarching themes included fear of developing Alzheimer’s disease and fear of stigmatization. Themes in that study specific to people living with dementia and their families indicated that different types of fear match different reasons such as fear of the impact of a diagnosis on family members, fear of becoming a caregiver, and fear of losing self-determination because of dementia (Werner *et al.*, 2021). Fear of stigmatization arising from a dementia diagnosis led our study participants to use different coping strategies depending on the emotion/behavior they experienced. Some engaged in physical, social, cognitive, and spiritual activities (Theme 1.3) to prevent further changes in behavior and/or cognition. Others “engaged in preventative measures” as a coping strategy to deal with fear of developing dementia.

Terminology

Like other reports, our findings show that people living with dementia and families/care partners do not necessarily agree with the language commonly used by healthcare staff, researchers, and other professionals to describe behavioral changes (Adekoya and Guse, 2019; Gilmore-Bykovski *et al.*, 2020; Burley *et al.*, 2021). As terminology

used by families/care partners and healthcare staff varied considerably, evaluating language use needs to be performed in partnership with people living with dementia (Gilmore-Bykovskiy *et al.*, 2020). A recent survey investigating the perspectives of people living with dementia toward the language of behavioral changes found that over a quarter of respondents preferred the term “unmet needs,” but that there was no universal agreement on terminology (Wolverson *et al.*, 2021). This study also emphasized concerns raised by people living with dementia around language use. It noted that concerns were shared with professionals regarding how language influences the perception and portrayal of dementia (Markwell, 2016), and that a process of discussion and reflection is needed for changes to occur in improving care and reducing stigma and discrimination.

Strengths

We included the perspectives of people who were living with a diagnosis of dementia, where previous studies have tended to focus on formal and informal carer perspectives. No research study has previously included the views of people living with dementia about their personal experiences, how they would like others to respond, what strategies they find helpful/unhelpful, and how they feel toward various terms used by healthcare professionals to describe the changes they experience. We avoided leading questions and instead used a data-driven inductive approach. Data were independently coded by authors CB and AC and reviewed by LC, and data codes and themes were discussed until consensus was reached.

Limitations

Variability among study participant dementia diagnoses and severity, comorbidities, medication use (see Table 1), and socioeconomic status may have affected what participants perceived to be helpful or unhelpful coping strategies for behavioral changes and/or responses from others. Selection bias may be present as participants volunteered to take part in the study, and findings may not be generalizable to all people living with dementia or to larger populations. Several participants were members of advocacy groups which may have skewed our results. The researchers had both professional and personal experiences with dementia which may have introduced bias, though their knowledge and engagement when talking to people living with dementia and families/care partners may also be considered a strength. Participants were not invited to comment on interview data post-transcription, because interviews were transcribed verbatim, and participant

review was not considered necessary in addressing the aims of this research.

Implications and conclusion

The reports of subjective experience of behaviors and psychological/psychiatric symptoms of people living with dementia are similar to those described by others (Adekoya and Guse, 2019; Gilmore-Bykovskiy *et al.*, 2020; Larsson *et al.*, 2019; van Wijngaarden *et al.*, 2019). Many people living with dementia wanted to be actively engaged in decision-making around future planning and their care, held strong views toward the use of psychotropic medicines in “behavior management,” and often provided suggestions for alternative nonpharmacological approaches. Healthcare professionals and researchers need to consider the views of people with lived experience of dementia to better understand their experiences, coping mechanisms and what they believe to be appropriate responses to their needs. This will help to ensure the most appropriate and effective support is implemented, both at the individual level in terms of improved treatment and care, and at the societal level by improving awareness and engagement. An integrated understanding of all the views involved will assist in better understanding of how to improve the quality of life for people living with dementia, through more supportive environments and systems.

Conflict of interest

HB has been a consultant to or advisory board member for Biogen, Nutricia Australia, Roche, Synapse2Neuron, Montefiore Homes, and Cranbrook Care.

Source of funding

This research was funded by the Dementia Centre for Research Collaboration (DCRC) and supported by the Australian Government, National Health and Medical Research Council. The study recruitment was assisted through StepUp for Dementia Research, which is funded by the Australian Government Department of Health and implemented by a dedicated team at the University of Sydney.

Description of author(s) roles

C. Burley designed the study, collected data, carried out and transcribed interviews, analyzed the data, and wrote the article. A. Casey assisted with data

analysis and writing the article. L. Chenoweth gave expert guidance on analysis, assisted with data analysis and writing the article. H. Brodaty conceptualized and designed the study, supervised data collection and analysis, and assisted with writing the article. All authors reviewed drafts and final version of the manuscript.

Acknowledgements

We thank the people living with dementia and their care partners and families for their generous contribution of time. This research was funded by the Dementia Centre for Research Collaboration and supported by the Australian Government, National Health and Medical Research Council. The study recruitment was assisted through StepUp for Dementia Research, which is funded by the Australian Government Department of Health and implemented by a dedicated team at the University of Sydney.

Ethics approval statement

This study received ethical approval from the South Eastern Sydney Local Health District (SESLHD) Research Strategy Office (RSO) and UNSW Sydney Human Research Ethics Committee (HREC), HREC: 2019/ETH09814.

Patient consent statement

Participants provided informed consent to participate in this study.

Permission to reproduce material from other sources

Not applicable (except previous cited work Burley *et al.*, 2021, *Frontiers in Psychiatry*).

Clinical trial registration

Not applicable.

Data availability statement

The raw de-identified data supporting conclusions of this article will be made available by authors, without undue reservation.

Contribution to the field statement

Up to 90 percent of people living with dementia experience behavioral changes and psychological/psychiatric symptoms associated with dementia (BPSD). Decisions regarding care and strategies for people living with dementia are typically guided by professional frames of reference. This study investigated the perspectives of people living with dementia who experienced behavioral changes and families/care partners regarding strategies and responses they found helpful and unhelpful, and their feelings about terminology used by healthcare professionals, e.g. “BPSD.” People living with dementia and families/care partners participated in one-on-one semi-structured interviews. Unique themes were derived for helpful responses/coping strategies and unhelpful responses/barriers to coping and views toward terminology were explored. Findings suggest that an informed, nuanced understanding of behavioral changes and symptoms and a reconceptualization of terminology are needed to engender helpful responses, improve the quality of care, and reduce stigma experienced by people living with dementia.

References

- Adekoya, A. A. and Guse, L.** (2019). Wandering behavior from the perspectives of older adults with mild to moderate dementia in long-term care. *Research in Gerontological Nursing*, 12, 239–247.
- Algase, D. L., Beck, C. and Kolanowski, A. et al.** (1996) Need-Driven dementia-compromised behavior: an alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*. 11(6), 10–19. doi: 10.1177/153331759601100603
- Alzheimer's Society Canada** (2017). Person-centred language guidelines. https://alzheimer.ca/sites/default/files/documents/Person-centred-language-guidelines_Alzheimer-Society.pdf, 7 July 2022.
- Alzheimer's Society UK** (2018). Positive language: an Alzheimer's Society guide to talking about dementia. https://www.alzheimers.org.uk/sites/default/files/2018-09/Positive%20language%20guide_0.pdf, 7 July 2022.
- Bacsu, J. et al.** (2022). Stigma reduction interventions of dementia: a scoping review. *Canadian Journal on Aging/La Revue Canadienne Du Vieillessement*, 41, 203–213.
- Ballard, C. et al.** (2017). Impact of antipsychotic review and non-pharmacological intervention on health-related quality of life in people with dementia living in care homes: WHELD—a factorial cluster randomised controlled trial. *International Journal of Geriatric Psychiatry*, 32, 1094–1103.
- Beeri, M. S., Werner, P., Davidson, M. and Noy, S.** (2002). The cost of behavioral and psychological symptoms of dementia (BPSD) in community dwelling Alzheimer's disease patients. *International Journal of Geriatric Psychiatry*, 17, 403–408.

- Birt, L. *et al.*** (2020). Maintaining social connections in dementia: a qualitative synthesis. *Qualitative Health Research*, 30, 23–42.
- Boyatzis, R. E.** (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications Inc.
- Braun, A. *et al.*** (2019). Managing behavioral and psychological symptoms in community dwelling older people with dementia. A systematic review of qualitative studies. *Dementia*, 18, 2950–2970.
- Brimelow, R., Wollin, J., Byrne, G. and Dissanayaka, N.** (2019). Prescribing of psychotropic drugs and indicators for use in residential aged care and residents with dementia. *International Psychogeriatrics*, 31, 837–847.
- Brodaty, H. *et al.*** (2018). Antipsychotic deprescription for older adults in long-term care: the HALT study. *Journal of the American Medical Directors Association*, 19, 592–600, e7.
- Brorsson, A., Öhman, A., Lundberg, S. and Nygård, L.** (2011). Accessibility in public space as perceived by people with Alzheimer's disease. *Dementia*, 10, 587–602.
- Burley, C. V., Casey, A., Chenoweth, L. and Brodaty, H.** (2021). Reconceptualising behavioral and psychological symptoms of dementia: views of people living with dementia and families/care partners. *Frontiers in Psychiatry*, 12, 710703. DOI [10.3389/fpsyt.2021.710703](https://doi.org/10.3389/fpsyt.2021.710703).
- Burley, C. V., Livingston, G., Knapp, M. R., Wimo, A., Norman, R. and Brodaty, H.** (2020). Time to invest in prevention and better care of behaviors and psychological symptoms associated with dementia. *International Psychogeriatrics*, 32, 567–572.
- Burns, K., Jayasinha, R., Tsang, R. and Brodaty, H.** (2012). *Behavior management—a guide to good practice: Managing behavioral and psychological symptoms of dementia*. Sydney: Dementia Centre for Research Collaboration.
- Cations, M. *et al.*** (2020). Health professional perspectives on rehabilitation for people with dementia. *The Gerontologist*, 60, 503–512.
- Chenoweth, L. *et al.*** (2014). PerCEN: a cluster randomized controlled trial of person-centered residential care and environment for people with dementia. *International Psychogeriatrics*, 26, 1147–1160. DOI [10.1017/S1041610214000398](https://doi.org/10.1017/S1041610214000398).
- Chenoweth, L., Cook, J. and Williams, A.** (2021a). Perceptions of care quality during an acute hospital stay for persons with dementia and families/carers. *Healthcare*, 9, 1176–1186. DOI [10.3390/healthcare9091176](https://doi.org/10.3390/healthcare9091176).
- Chenoweth, L., Williams, A., Fry, M., Endean, E. and Liu, Z.** (2021b). Outcomes of person-centered care for persons with dementia in the acute care setting: a pilot study. *Clinical Gerontologist*, 45, 1–15. DOI [10.1080/07317115.2021.1946233](https://doi.org/10.1080/07317115.2021.1946233).
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K. and Regier, N. G.** (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Research*, 228, 59–64.
- Commonwealth of Australia** (2021). Royal commission into aged care quality and safety. Final report: Care, dignity and respect, Volume 1 Summary and recommendations, (accessed 27 August 2021). <https://agedcare.royalcommission.gov.au/publications/final-report-volume-1>.
- Cunningham, C., Macfarlane, S. and Brodaty, H.** (2019). Language paradigms when behavior changes with dementia: # BanBPSD. *International Journal of Geriatric Psychiatry*, 34, 1109–1113. DOI [10.1002/gps.5122](https://doi.org/10.1002/gps.5122).
- DEEP (The Dementia Engagement and Empowerment Project)** (2014). Dementia words matter: Guidelines on language about dementia. Available at: <https://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>, 7 July 2022.
- Dementia Australia** (2021). Dementia language guidelines. <https://www.dementia.org.au/resources/dementia-language-guidelines>, 20 January 2022.
- Dementia Training Australia** (2022). Responsive behaviors quick reference cards. <https://dta.com.au/resources/responsive-behaviors-quick-reference-cards/>, 20 January 2021.
- Dyer, S. M., Harrison, S. L., Laver, K., Whitehead, C. and Crotty, M.** (2018). An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *International Psychogeriatrics*, 30, 295–309. DOI [10.1017/S1041610217002344](https://doi.org/10.1017/S1041610217002344).
- Finkel, S. I., Silva, J. C., Cohen, G. D., Miller, S. and Sartorius, N.** (1998). Behavioral and psychological symptoms of dementia: a consensus statement on current knowledge and implications for research and treatment. *The American Journal of Geriatric Psychiatry*, 6, 97–100.
- Folstein, M. F., Folstein, S. E. and McHugh, P. R.** (1975). “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198. DOI [10.1016/0022-3956\(75\)90026-6](https://doi.org/10.1016/0022-3956(75)90026-6).
- Gibbs, G. R.** (2018). *Analyzing qualitative data*. 2nd edition, Thousand Oaks, CA: Sage Publications Ltd, <https://dx.doi.org/10.4135/9781526441867>.
- Gilmore-Bykovskiy, A., Mullen, S., Block, L., Jacobs, A. and Werner, N. E.** (2020). Nomenclature used by family caregivers to describe and characterize neuropsychiatric symptoms. *The Gerontologist*, 60, 896–904.
- Górska, S., Forsyth, K. and Maciver, D.** (2018). Living with dementia: a meta-synthesis of qualitative research on the lived experience. *The Gerontologist*, 58, e180–e196.
- Hall, G. R.** (1987). Progressively lowered stress threshold: a conceptual model for care of adults with alzheimer's disease. *Archives of Psychiatric Nursing*, 1, 399–406.
- Hammar, L. M., Alam, M., Olsen, M., Swall, A. and Boström, A.** (2021). Being treated with respect and dignity?—Perceptions of home care service among persons with dementia. *Journal of the American Medical Directors Association*, 22, 656–662.
- Hung, L. *et al.*** (2021). Creating dementia-friendly communities for social inclusion: a scoping review. *Gerontology and Geriatric Medicine*, 7, 23337214211013596.
- International Psychogeriatric Association** (2010). The IPA complete guides to behavioral and psychological symptoms of dementia, Milwaukee, WI, International Psychogeriatric Association, www.ipa-online.org/publications/guides-to-bpsd, 7 July 2022.
- James, I. A., Gray, K., Moniz-Cook, E., Lee, K., Reichelt, K. and Richardson, J.** (2022). Behavioral and

- psychological symptoms of dementia: a new framework for holistic understanding and non-pharmacological management. *BjPsych Advances*, 28, 11–20. DOI [10.1192/bja.2021.12](https://doi.org/10.1192/bja.2021.12).
- Jeon, Y. et al.** (2021). Early implementation and evaluation of StepUp for Dementia Research: an Australia-wide dementia research participation and public engagement platform. *International Journal of Environmental Research and Public Health*, 18, 11353.
- Kitwood, T.** (1993). Towards a theory of dementia care: the interpersonal process. *Ageing & Society*, 13, 51–67.
- Kitwood, T. M.** (1997). *Dementia reconsidered: The person comes first*. Buckingham, England: Open University Press.
- Larsson, V., Holmbom-Larsen, A., Torisson, G., Strandberg, E. L. and Londos, E.** (2019). Living with dementia with lewy bodies: an interpretative phenomenological analysis. *BMJ Open*, 9, e024983–2018-024983.
- Laver, K. et al.** (2016). Clinical practice guidelines for dementia in Australia. *Medical Journal of Australia*, 204, 191–193. DOI [10.5694/mja15.01339](https://doi.org/10.5694/mja15.01339).
- Livingston, G. et al.** (2014). A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioral interventions for managing agitation in older adults with dementia. *Health Technology Assessment*, 18, 1–226, v–vi.
- Livingston, G. et al.** (2017). Dementia prevention, intervention, and care. *The Lancet*, 390, 2673–2734.
- Livingston, G. et al.** (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396, 413–446.
- Low, L., Swaffer, K., McGrath, M. and Brodaty, H.** (2018). Do people with early-stage dementia experience prescribed disengagement®? A systematic review of qualitative studies. *International Psychogeriatrics*, 30, 807–831.
- Macleod, A., Tatangelo, G., McCabe, M. and You, E.** (2017). “There isn’t an easy way of finding the help that’s available.” Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *International Psychogeriatrics*, 29, 765–776.
- Markwell, H.** (2016). Loaded meanings: the narrative of behavior. *Australian Journal of Dementia Care*, 5, 12–16.
- Miles, M. B. and Huberman, A. M.** (1994). *Qualitative data analysis: An expanded sourcebook*. 2nd edition, Thousand Oaks, CA: Sage Publications Inc.
- Morgan, D. L.** (1993). Qualitative content analysis: a guide to paths not taken. *Qualitative Health Research*, 3, 112–121.
- National Health and Medical Research Council (NHMRC) Guideline Adaptation Committee** (2016). Clinical practice guidelines and principles of care for people with dementia. Sydney: NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People, (accessed 7 July 2022), <https://www.clinicalguidelines.gov.au/print/10161>.
- O’Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A. and Cook, D. A.** (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine: Journal of the Association of American Medical Colleges*, 89, 1245–1251.
- Robins, L. M. et al.** (2021). Definition and measurement of physical and chemical restraint in long-term care: a systematic review. *International Journal of Environmental Research and Public Health*, 18, 3639.
- The Royal Australian College of General Practitioners** (2019, 2020). RACGP aged care clinical guide (Silver Book), 5th edition, East Melbourne, Vic: RACGP.
- van Wijngaarden, E., Alma, M. and The, A.** (2019). ‘The eyes of others’ are what really matters: the experience of living with dementia from an insider perspective. *PLoS One*, 14, e0214724.
- Werner, P., Ulitsa, N., Shepheth, D., Abojabel, H., Alpinar-Sencan, Z. and Schickltanz, S.** (2021). Fear about Alzheimer’s disease among Israeli and German laypersons, persons with Mild Neurocognitive Disorder and their relatives: a qualitative study. *International Psychogeriatrics*, 33, 1019–1034.
- Whittemore, R., Chase, S. K. and Mandle, C. L.** (2001). Validity in qualitative research. *Qualitative Health Research*, 11, 522–537.
- Wolverson, E., Birtles, H., Moniz-Cook, E., James, I., Brooker, D. and Duffy, F.** (2019). Naming and framing the behavioral and psychological symptoms of dementia (BPSD) paradigm: professional stakeholder perspectives. *OBM Geriatrics*, 3, 1–19.
- Wolverson, E., Dunn, R., Moniz-Cook, E., Gove, D. and Diaz-Ponce, A.** (2021). The language of behavior changes in dementia: a mixed methods survey exploring the perspectives of people with dementia. *Journal of Advanced Nursing*, 77, 1992–2001. DOI [10.1111/jan.14787](https://doi.org/10.1111/jan.14787).