


# BMJ Open Ecopsychosocial strategies for the self-exploration of professional family caregivers to manage the behavioural and psychological symptoms of Alzheimer patients in Iran: a qualitative study

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## ABSTRACT

**Objective** The aim of the present study was to explore the experiences and viewpoints of professional family caregivers in the management of behavioural and psychological symptoms of dementia (BPSDs) to identify the ecopsychosocial strategies applied by them.

**Design** Qualitative study.

**Setting** Kerman, Iran.

**Participants** Stories were collected from 40 professional family caregivers of dementia patients.

**Measurement** The guidelines of the National Consensus Project (NCP) of the USA served as the conceptual framework for the deductive thematic analysis of our qualitative data. A schematic of the entire process was performed in five steps.

**Results** 30 stories relevant to the aim of this study were included in the analysis from April to June 2021. A majority of the stories were written by female caregivers. We identified 19 ecopsychosocial interventions, which covered the NCP dimensions except 'Care of the patient nearing the end of life'. More than half of these interventions were classified into psychological/psychiatric and physical aspects of care (57.8%). In addition to the care/support provided by special care units or home care, some caregivers believe that support from the government, various care organisations, social media and even other family members/friends is necessary to better manage BPSDs.

**Conclusion** Despite limitations, such as having a small sample size and analysing only one story from each caregiver, our results indicate that dementia caregivers need more educational and cultural support in their ecopsychosocial strategies. Government involvement would yield more positive outcomes in managing BPSDs.

## INTRODUCTION

One of the most common disorders associated with severe and progressive disability in adults is dementia.<sup>1,2</sup> Dementia is a broad term that encompasses a decline in memory, language, problem-solving skills and other cognitive abilities to a degree that significantly

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our exemplary stories by professional caregivers provided a rich basis for analysis of the strategies applied for the management of behavioural and psychological symptoms of dementia (BPSDs).
- ⇒ The participants were a selected group of family caregivers as they were recruited from a support group.
- ⇒ The present study does not reveal much information about the experiences and viewpoints of those who did not participate in such a virtual group.
- ⇒ We could have had richer data if we had asked participants for more stories rather than just one story.
- ⇒ We relied on the information provided by caregivers regarding the BPSDs mentioned in the stories and their management strategies.

disrupts daily life.<sup>3</sup> The number of people with dementia is estimated to increase from 4.57 million cases worldwide in 2019 to 152.8 million cases in 2050.<sup>4</sup> In 2019, the age-standardised point prevalence of dementia in the Middle East and North Africa was 777.6 cases per 100 000 people, representing a 3.0% increase compared with 1990.<sup>5</sup> According to the Global Burden of Disease study, the incidence rate of dementia in Iran from 1990 to 2017 was 75.81 cases per 100 000 individuals, totalling 62 298 people across all age groups.<sup>6</sup>

There is no ultimate cure for this disease. This disease has various stages.<sup>7</sup> The needs of each stage are completely different from those of the other stages. In the advanced stages of the disease, people suffering from dementia may lose control of their lives and require constant care.<sup>8,9</sup> A majority of dementia patients' caregivers are their family members.<sup>10</sup> In addition to the common symptom of memory loss, these patients may present with behavioural and psychological



symptoms of dementia (BPSD), such as delusions, hallucinations, screaming, restlessness, wandering, depression, anxiety and aggression.<sup>11</sup> The term BPSD is defined as 'symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia'.<sup>12 13</sup> These symptoms reveal the real and sometimes scary aspects of the disease. Since observing BPSDs is stressful for caregivers,<sup>14</sup> caregivers use different methods to address or control them.<sup>11</sup> Pharmacological interventions alone are not sufficient to control and manage BPSDs.<sup>15</sup> Therefore, patients should benefit from non-pharmacological interventions as well.<sup>16</sup>

In the UK, the National Institute for Health and Care Excellence considers non-pharmacological treatments as one of the main methods used to manage BPSDs,<sup>17</sup> among which are ecopsychosocial and ecobiopsychosocial therapies.<sup>17 18</sup> Zeisel *et al*<sup>19</sup> suggested that ecopsychosocial therapy is a cost-effective method to support the psychological needs of dementia patients and reduce their behavioural symptoms. On the other hand, Gerlach and Kales<sup>18</sup> suggested that ecobiopsychosocial therapy should target patients with dementia factors, caregiver factors and environmental factors. The only difference is that ecopsychosocial therapy includes approaches and interventions (such as environmental and contextual interventions) in dementia care that affect human experience and behaviour. Additionally, this method includes psychosocial interventions conceptually and in a broader way to be able to examine the environmental and contextual effects of interventions in the lives of dementia patients. For this reason, it is preferred to other non-pharmacological treatments.<sup>19</sup> Without realising this, caregivers initiate and use diverse ecopsychosocial therapies, including music therapy, animal-assisted therapy and play therapy, to manage BPSDs. However, there are gaps in the understanding of the experiences of caregivers in dealing with the BPSDs of their patients.<sup>20</sup>

Evidence-based clinical guidelines and theoretical frameworks, such as the Need-driven Dementia-compromised Behavior model and the Progressively Lowered Stress Threshold model, have thus far been in place to guide caregivers in managing BPSDs.<sup>21–23</sup> As mentioned earlier, non-pharmacological and ecopsychosocial care are considered almost identical; hence, non-pharmacological strategies were mostly mentioned in previous studies. To our knowledge, only a few qualitative studies have scrutinised the non-pharmacological strategies applied by family caregivers for managing BPSDs.<sup>24–28</sup> As such, there is still limited information regarding caregivers' applied strategies to manage BPSDs, especially in the context of Asian and developing countries.

According to Iranian Dementia & Alzheimer's Association statistics from 2018, every 11.5 min, one person is diagnosed with this disease.<sup>20</sup> In addition, in Iranian culture, respect for sick family members, caring for elderly family members and mutual support of family members are part of the value system of families.<sup>29</sup> The high prevalence of Alzheimer's disease in Iran and the cultural/religious

differences may make the attitudes and understanding of Iranian family caregivers about how to manage BPSDs different from those of other countries. Caring for the elderly is traditionally seen as the duty of family members. While this is changing due to work culture, many Iranian families still support and care for their elders at home.<sup>30</sup> The National Consensus Project (NCP) considers quality care to be related to the nature of spirituality.<sup>31</sup> In 2018, this project published updated clinical guidelines for providing high-quality non-pharmacological/palliative care.<sup>32 33</sup> To comply with this, we considered the conceptual framework of this study on the basis of the NCP guidelines. Since qualitative research is the prime method for scrutinising people's viewpoints,<sup>34</sup> the present study was conducted via a qualitative method to analyse the viewpoints and experiences of professional family caregivers, who have extensive experience in managing BPSDs, on the basis of NCP. We aimed to understand how a group of professional family caregivers respond to current BPSDs in dementia patients. This knowledge provides insight into ways to strengthen support systems for non-professional caregivers in managing BPSDs more effectively.

## METHODS

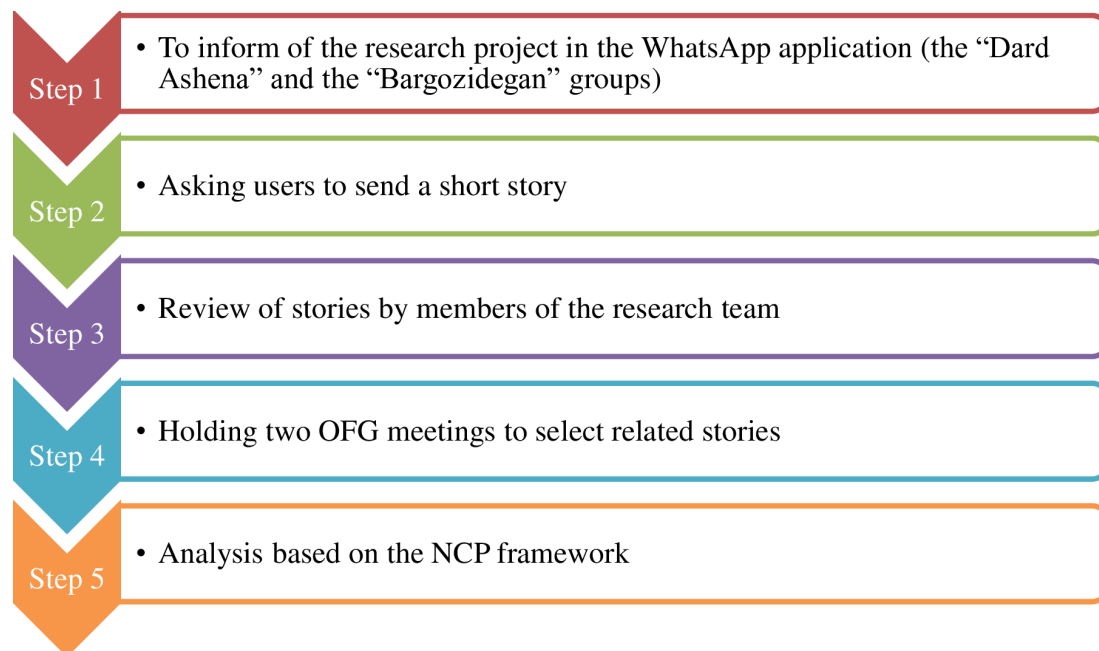
This study follows the Standards for Reporting Qualitative Research (see online supplemental file 1). In this study, BPSD included agitation, aberrant motor behaviour, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations and sleep or appetite changes. More details are given in Cerejeira *et al*.<sup>35</sup> The term self-explored strategies refers to those strategies in which the participating caregivers have previously not received any prior education or training to apply them. The term ecopsychosocial is a practical and conceptually elegant term that replaces the term non-pharmacological. Ecopsychosocial factors include the broad range of subject matter and research interests actually included in the overall term, especially contextual issues and environmental design.

## Study design and setting

This was an exploratory study conducted to determine self-explored ecopsychosocial strategies for the self-exploration of professional family caregivers in the management of BPSDs from the beginning of April to the end of June 2021 in Kerman, Iran.

## Participants

The participants in the study were caregivers of dementia patients. The criteria for selecting caregivers included being a family member of a currently living dementia patient, having at least 5 years of experience in caregiving, being over 30 years old and voluntarily agreeing to participate in the study. Participation was completely voluntary, with individuals freely choosing to share their experiences without any coercion, and they were informed that



**Figure 1** Schematic diagram of the entire process. NCP, National Consensus Project; OFG, online focus group.

they could withdraw from the study at any point without any negative consequences.

### Study procedure

A schematic of the entire process was generated in five steps (figure 1).

### Data collection procedure

In our study setting, dementia patients and their caregivers are currently being supported online in the WhatsApp application by two active groups, called the ‘Dard Ashena’ (in Persian, it means ‘those who are familiar or acquainted with pain’) and the ‘Bargozidegan’ (in Persian, it means ‘those who have been selected’). These two groups work under the supervision of a group of neurologists in Kerman and three caregivers (two men and one woman) who have more than 10 years of care experience. In these groups, patients and caregivers receive informational support through sharing their daily life problems/challenges with care providers and other experienced people. In partnership with the managers of these groups, our research team asked professional family caregivers to write or record audio just one of their ecopsychosocial strategies that they thought was most effective in managing their patients’ BPSDs as a short story and send it to the research team. The audio-recorded stories were transcribed verbatim and converted into text via Microsoft Word 2019. To preserve confidentiality, they were asked not to mention their names. After receiving each story, the demographic information of the caregivers, such as their age, gender/sex (male, female), caregiver-patient kinship (spouse, child, grandchild, etc), level of education and years of dementia care experience was obtained.

### Research framework

The conceptual framework for the thematic analysis of the data was based on the NCP.<sup>32</sup> In 2018, the project published updated clinical guidelines to provide high-quality non-pharmacological care. Considering the long and complex course of Alzheimer’s disease and the variety of symptoms, managing this disease is difficult and expensive. Hence, Alzheimer’s patients need palliative care, similar to AIDS patients and cancer patients. Palliative care aims to help relieve patients and their families from stress and related symptoms to improve their quality of life (QoL).<sup>36</sup>

According to the NCP, palliative care is defined as activities to manage pain and other symptoms, meet the needs of caregivers and coordinate care; as a result, it can lead to effective mental, functional, practical, physical and spiritual outcomes in patients. As such, in the present study, ecopsychosocial strategies were classified on the basis of the NCP dimensions as follows:

1. The ecopsychosocial strategies related to the structure and processes of care.
2. The ecopsychosocial strategies related to the psychological and psychiatric aspects of care.
3. The ecopsychosocial strategies related to the physical aspects of care.
4. The ecopsychosocial strategies related to the social aspects of care.
5. The ecopsychosocial strategies related to the cultural aspects of care.
6. The ecopsychosocial strategies related to the spiritual aspects of care.
7. The ecopsychosocial strategies related to the ethical and legal aspects of care.



## Data analysis

In total, we received 40 stories from the caregivers. Some of the stories were written, and some were recorded audio. Two online focus group (OFG) sessions in Zoom due to the COVID-19 pandemic, each lasting 60 to 80 min, with a time interval of 10 days, were subsequently held in May 2021. The OFGs were considered a complementary tool to make the research project engaging and easier.<sup>37</sup> Two research members (PA and KB) and selected participants from the previous phase (ie, three managers of the two above-mentioned groups) took part in these sessions. The managers of the two groups were invited via email. The OFGs were moderated by two researchers (PA and KB): one researcher (a physician with a medical informatics background) led the conversations, and another assisted and took notes during the OFGs. The gender of the moderators was one man and one woman with an MD, PhD or master's degree. All OFGs started with a short presentation of the aim of the study and the researchers' background and research interests. These OFGs aimed to determine the stories related to the purpose of the current study; hence, four stories that were not relevant to our study aim were excluded (three stories related to drug therapy and one story related to nutritional issues). The criteria for choosing the stories were the following: stories should be related to ecopsychosocial strategies, not other strategies such as pharmaceutical and nutritional. By reviewing the inclusion criteria, six other stories were also excluded (because the age of the caregivers in the four stories was less than 30 years, and in two of the stories, they had less than 5 years of caregiver experience). Moreover, stories including several ecopsychosocial strategies were discussed in these sessions so that the research members would be able to choose only one of the strategies. The purpose was to facilitate the management of the collected data and perform a comprehensive and sufficient analysis of this information. Our study used 'voluntary response' or 'self-selection' sampling,<sup>38</sup> with an invitation to participate shared in a WhatsApp group comprising approximately 800 members. Participation was entirely dependent on individual willingness to share their experiences. Out of this group, 40 individuals chose to contribute, providing detailed narratives about their approach to psychosocial issues in Alzheimer's care. This voluntary sampling method introduced limitations in controlling participant diversity or guaranteeing thematic exhaustiveness. However, consistent patterns and recurring themes emerged in the data provided by these 40 participants.

In qualitative research, a 'predetermined sample size' or 'stopping criteria' is not always relevant, as data collection is typically guided by the emergence of new insights. In this context, we achieved what we describe as 'relative thematic saturation'. While recognising that the voluntary nature of participation might limit generalisability, the richness and depth of the shared stories allowed us to identify repeated themes and key patterns. This consistency suggested that we had reached a point of analytical

completeness within the scope of our methodological constraints, reinforcing the validity of our findings.

In the present study, qualitative analysis of the stories was performed via the deductive thematic analysis method.<sup>39</sup> By reading the stories several times, the members of the research team gained a general understanding of their content. The content of the 30 stories was subsequently entered into ATLAS.ti8 software for coding via thematic categories from the NCP.<sup>32</sup> The NCP includes eight dimensions: (1) structure and processes of care; (2) physical aspects of care; (3) psychological and psychiatric aspects of care; (4) social aspects of care; (5) spiritual, religious and existential aspects of care; (6) cultural aspects of care; (7) ethical and legal aspects of care and (8) care of the patient near the end of life. The data analysis process involved the following steps. A detailed overview of this process is described elsewhere:<sup>40</sup>

- ▶ Preparation: all the researchers reviewed all the stories to obtain a logical connection to the overall purpose.
- ▶ Initial coding: PA and KB read all the stories. They recorded our initial thoughts via two headings: (1) Which BPSD did the story refer to? (2) What was the strategy used to address a BPSD? The codes were compared and discussed to develop themes, which were grouped into categories.
- ▶ Identification of themes: the researchers identified the most prominent or important elements in the stories before engaging in collaborative analysis to produce an initial set of codes. The findings were placed in the form of themes and subthemes of the NCP.

## Trustworthiness (rigour)

The stories were manually transcribed verbatim by the first author. The data were treated anonymously to preserve confidentiality. All identification data in the paraphrases were removed to ensure anonymization. To assess qualitative data analysis, Lincoln and Guba established the criteria of credibility, transferability, dependability and confirmability.<sup>41</sup> These criteria are useful for researchers who are concerned about the acceptability and effectiveness of their research for a variety of stakeholders. Credibility was implemented through triangulation of analysis by involving an external observer, who examined all the data analysis steps, coding and the formation of themes, and by member checking. To align with qualitative research standards for transferability, we provided detailed participant descriptions, including demographics (caregivers aged 30+), caregiving relationships (caring for dementia patients for at least 5 years) and their shared use of a WhatsApp support group. Participants were recruited from a specific WhatsApp group, which serves as a virtual support community for dementia caregivers. Eligibility criteria ensured relevance to the research focus, with only those meeting the outlined conditions able to volunteer. This comprehensive description enhances transferability by offering sufficient contextual background on recruitment and the study setting. To observe dependability in the study, we provided exemplary quotes from

**Table 1** Demographic characteristics of the study participants

Characteristics	Frequency
Gender	
Male	11
Female	19
Average age (years)	55 (range 30–80)
Level of education	Diplomas: 5 Associate degree: 7 Bachelor's degrees: 12 Master's degree: 6
Average years of caregiving	15 (range 5–25)
Kin relationship and gender	Female offspring: 9 Male offspring: 3 Female spouse: 7 Male spouse: 5 Sister: 4 Brother: 2

the participants. Finally, confirmability was achieved by having a trained research assistant review all the transcriptions by listening to the audio and reading the transcript prior to data coding. All the participants were asked to review their own transcripts, which resulted in no change. Additionally, research members reviewed the emerged themes multiple times until the entire team was satisfied with the final findings.

### Patient and public involvement

The participants in the study were family caregivers of patients with dementia. Caregivers who had at least 5 years of caregiving experience and were members of online groups to provide information about this disease were invited. Patients and the public were not involved in the design or conduct of the research procedures, but to foster collaborative research and gather insights from individuals beyond just patients, this study included the participation of caregivers of patients.

## RESULTS

In total, 40 caregivers participated in the study, most of whom were women (25 out of 40). Among the 40 stories submitted by caregivers, 30 stories (75%) were entered into the final analysis. The majority of these stories were written by female caregivers. The average age of the caregivers was 55 years. Details of the caregivers who participated in this study are presented in [table 1](#).

In total, 156 initial codes were extracted from the stories. By integrating similar codes and removing repetitive codes, 112 extracted codes included 19 ecopsychosocial interventions. Those patients were classified into seven main subgroups of the NCP framework, except for the 'Care of the patient near the end of life' category (online supplemental file 2). In addition, some exemplary quotes based on these factors, indicated with (Q#)

within the text, are available in online supplemental file 2.

### Making the most of the available structure and process of care

Our analysis revealed the willingness of caregivers to manage some BPSDs through the services of special care units or home care. Using the services of these centres was considered a part of the ecopsychosocial strategies for self-exploration by caregivers in the process and structure of care. Our participants believed that these centres could improve care processes to manage BPSDs by providing specialised care programmes by professional staff.

#### Benefiting from the services of special care centres

Special care centres such as rehabilitation centres can often be safe and appropriate environments for taking care of dementia patients. This is due to their trained and professional staff. Two caregivers declared that they had sent their patients to special centres on specific days of the week to prevent BPSDs (Q1, Q2). For example, Q1 in online supplemental file 2 clearly shows how effective these centres are in controlling and managing BPSDs.

#### Using home care services

Although providing comprehensive care for these patients at home is a very difficult task, some of our participants stated that they were willing to take care of their patients at home despite facing mental and physical problems. However, they highlighted that good home services were needed to help them deal with burdensome care. Q3 in online supplemental file 2, as part of the story of one caregiver, highlights the need for these centres to manage BPSDs.

#### Psychological and psychiatric aspects of care

An analysis of the stories revealed that many caregivers used psychological and psychiatric care strategies to manage many BPSDs. The severity of some BPSDs (such as day-to-day variations in restlessness and depression occurrence) that are related to some of the needs/compromised needs of patients is managed by employing methods such as doll therapy, animal-assisted therapy, dance therapy and music therapy to prevent the occurrence of BPSDs.

#### Doll therapy

One of the common complications of dementia patients mentioned in our study was unusual restlessness and nit-picking. Two caregivers reported choosing doll therapy to overcome these complications (Q4, Q5). Q5 in online supplemental file 2 clearly demonstrates the effectiveness of this method in controlling the BPSDs.

#### Animal-assisted therapy

Dealing with a depressed dementia patient requires appropriate information and professional behaviour from caregivers. Two caregivers used a pet to overcome their patients' depression and to improve their mental

and physical functioning. In fact, they chose this treatment method on the basis of the knowledge they had of their patients. Q6 in online supplemental file 2 is indicative of the role of animal-assisted therapy in improving patient QoL.

#### Music therapy

Although formal music therapy is commonly performed by music therapists under appropriate conditions, one caregiver stated that he had used music to overcome his patient's depression. This caregiver believed that informal music therapy effectively affected his patient's mood. Q7 in online supplemental file 2 demonstrates the effectiveness of informal music therapy in controlling and managing BPSDs and their own spirit.

#### Dance/movement therapy

Dance therapy was considered a useful intervention by one of the caregivers. This caregiver stated that dancing was a suitable way to cheer up her bored dementia patient (Q8).

#### Play therapy

Three caregivers stated that activities such as colouring, painting and poetry were appropriate ways to prevent BPSDs in their dementia patients, particularly in special conditions such as the COVID-19 pandemic. Q9 in online supplemental file 2 clearly indicates the effectiveness of play therapy in controlling BPSDs.

#### Therapeutic lying

Some of our caregivers noted that therapeutic lying was a suitable way to prevent BPSDs by allowing them to cheer dementia patients. A caregiver's story clearly shows this point (Q10).

#### Bringing back memories

According to our stories, some caregivers planned regular daily and weekly entertainment and activities for their patients. They believed that having such a plan prevented their patients from becoming bored. Caregivers said that they accompanied their patients in these activities. They also reported that reviewing personal narratives and memoirs was one of the best ways to address patient depression and boredom (Q11).

#### Routine adherence

Confusion and disorientation due to memory loss are very common in Alzheimer's disease and other types of dementia. Spatial and temporal disorientation are considered causes of patient confusion; therefore, some participants reported that they could manage it by providing structured and consistent care by regulating the time, order and delivery of tasks. Q12 in online supplemental file 2 reported it very well.

#### Supportive pretending to balance reality and patient comfort

Two caregivers mentioned in their stories that they sometimes gave in to the BPSDs of their patients and inevitably

accompanied them in their beliefs or requests out of necessity. They pretended to agree with the patients' requests, offering companionship to avoid distress but without fully endorsing them in reality (Q13, Q14).

#### Physical aspects of care

According to our participants, physical aspects of care should also be the focus of attention to manage some BPSDs. They believed that the inability to perform daily activities, changing the patient's accommodations and unemployment were among the cases in which ignoring them would exacerbate the BPSDs and decrease the patient's QoL.

#### Performing daily routines

The progression of dementia causes problems in daily routines such as eating, drinking, walking, taking showers, going to the bathroom and even talking; ultimately, functional autonomy decreases. The inability to perform such daily activities often has a negative effect on patients' mood and leads to BPSDs. Three caregivers mentioned this issue in their stories (Q15, Q16 and Q17), but one reported it very well (Q15).

#### Keeping the same place of living and care

A caregiver considered changing the place of living as a source of confusion and anxiety in patients. Q18, as part of his story, explains the relevance of this issue.

#### Entertainment

In some dementia patients who had been employed before the disease, employment and financial independence had positive emotional outcomes. Entertaining patients with their favourite job would give them a sense of employment and reduce some BPSDs. This issue has been mentioned in Q19 in online supplemental file 2. In Q19, to overcome the patient's violence, the caregiver involved the patient in a safe job, which was performed under his supervision.

#### Social aspects of care

Our participants highlighted that taking care of dementia patients is not restricted to home and that these patients should be present in the community. Their presence in the community needs the support of the government, various organisations and social networks so that patients and their families can live an easier and happier life.

#### Need to benefit from government support

One of the caregivers considered some of the government rules, such as the illegality of keeping a pet dog, as a barrier for taking care of these patients and even sometimes a source for the emergence of BPSDs. Q20 in online supplemental file 2, as part of this caregiver's story, highlights the importance of this issue. For example, dancing in public places such as parks and streets is prohibited by government laws and cultural norms in China. However, many of these patients start dancing when they hear music.

### Need to have support from public places

Wandering in dementia patients was regarded as one of the BPSDs. Handling this problem, especially outside the home and during trips, was one of the issues that caregivers experienced repeatedly. Therefore, they requested more support from public places in safer civil engineering for these patients. Q21 in online supplemental file 2, as part of a caregiver's story, illustrates the importance of support from public places such as hotels to reduce the burden of care for caregivers.

### Need to promote disease awareness through online platforms and other publicly available resources

Caregivers of dementia patients carry a heavy responsibility for several years. Our participants believed that providing support from social media to develop a supportive culture about this disease in the general public would not only reduce the psychological burden on caregivers but also prevent the occurrence of some BPSDs (Q22). In contrast, the behaviour caused by family caregivers' lack of knowledge about the Educational Psychology Service intervention would despair a patient and caregivers in life.

### Cultural aspects of care

#### Addressing cultural values in social connectedness by family members, relatives and friends towards patient care

The behaviours and beliefs of family members and friends play a crucial role in managing complex diseases such as dementia. In many cultures, socialisation and communal bonds are vital to overall well-being, especially for the mental health of older adults. In contrast, social isolation can exacerbate cognitive and emotional decline, contributing to conditions such as depression. In the context of informal care, the stigma surrounding Alzheimer's can sometimes cause friends and relatives to distance themselves. This cultural shift during illness may partly be explained by discomfort or a lack of understanding. Regardless of the reasons, such distancing can lead to increased isolation for both patients and their family caregivers. To counteract this, public education and cultural sensitivity regarding this disease and associated BPSDs are essential in fostering a supportive social network. Q23 in online supplemental file 2 highlights the significance of such cultural norms and the important role family members as well as friends can play, especially when formal social support systems are lacking.

#### Complying with the spiritual and religious aspects of care

Complying with religious concerns in care was evident in caregivers' stories, particularly from the part of patients themselves. Caregivers should pay attention to the spiritual and religious needs of their patients to prevent or control some BPSDs (Q24).

#### Addressing ethical and legal issues while providing daily care

Our participants highlighted that the lack of a safe environment facilitated some BPSDs in their patients. Therefore, they believed that it would be better to organise

financial and legal issues (such as managing bank accounts and handling the buying and selling of properties and vehicles) at the early stages of the disease while patients still have sufficient logical reasoning and comprehension to prevent stressful events afterwards. In this context, it is necessary that dementia patients are assisted and not left alone when they need to make critical decisions, particularly if the decision-making and problem-solving processes require the assessment of various aspects of an issue (Q25).

## DISCUSSION

We studied the strategies applied by experienced Alzheimer's caregivers and identified various types of ecopsychosocial interventions that they used to manage patients' BPSDs. An analysis of the stories shared by the participants indicated that the participants in this study believed that the applied interventions and strategies played effective roles in managing BPSDs and improving patients' QoL for patients and their caregivers. On the basis of the NCP framework, the majority of the identified ecopsychosocial interventions were classified into psychological and psychiatric aspects of dementia care (9 subthemes out of 18 total subthemes). Our results indicate that a considerable subset of BPSDs in dementia patients can safely be managed by caregivers in home or family environments. Yet, it was also evident that managing all BPSDs alone can be daunting and burdensome, especially when caregivers are not properly educated on management strategies and do not receive needed professional support. Indeed, satisfying other aspects of care on the basis of the NCP framework would require wider cooperation from the community and government.

Currently, the increase in the number of dementia patients and their increasing life expectancy have led to the prolongation of, on average, 10 years in the required care period.<sup>42</sup> As a result, the burnout of these patients' caregivers has become an important challenge in public health.<sup>43</sup> Managing BPSDs as one of the most challenging aspects of dementia care for caregivers has caused them much distress, stress and even burnout.<sup>43 44</sup> To prevent or mitigate the occurrence of such conditions for caregivers while managing BPSDs, our caregiver participants called for the support of healthcare services and other organisations to launch more appropriate home care services and dementia special care centres in our healthcare context. Previous studies have emphasised the need for these centres,<sup>45–47</sup> and some have denied it.<sup>48 49</sup> For example, the Taiwan Alzheimer's Association considered the need for these centres unnecessary and reported that the rate of using home care services by patients with Alzheimer's was 4.8%.<sup>48</sup> Given that the use of available services is related to the severity of the disease and its problematic behaviours in various stages,<sup>50</sup> it is likely that not all Alzheimer's patients would need such centres all the time; hence, the caregivers in our study requested



home care services and special care centres for special occasions.

In the present study, almost half of all ecopsychosocial interventions performed by caregivers (42%) were related to psychological and psychiatric methods (including doll therapy and animal-assisted therapy). Santagata *et al*<sup>51</sup> reported that doll therapy is more effective than standard treatment in the control of BPSDs in patients affected by moderate to severe dementia. Wesenberg *et al*<sup>52</sup> reported that the presence of a dog appears to have beneficial effects on psychosocial intervention for people with dementia. However, in the present study, none of the participating caregivers mentioned interventions such as group dance,<sup>48</sup> aroma therapy,<sup>53</sup> touch therapy,<sup>54</sup> light therapy<sup>55</sup> or physical exercise<sup>56</sup> to manage BPSDs, as other studies reported. One of the reasons for this issue is the small number of participants, with limited stories per participant, in our study. Increasing the number of participants and their stories in such studies would increase the number of strategies; therefore, it is likely that more ecopsychosocial interventions can be identified. The other reason might be associated with the lack of caregivers' knowledge of the use of other psychological and psychiatric treatment methods, such as aroma or light therapies. By educating professional family caregivers about other proven effective methods, physicians, psychiatrists and other health professionals can encourage them to use them, as well.

Prevention and management of BPSDs are sometimes very difficult for caregivers.<sup>57</sup> For this reason, in the present study, a number of caregivers actively engaged their patients in daily activities (such as bathing, eating and walking) or social activities (such as entertainment) to prevent some BPSDs. In line with the results of the present study, a systematic review revealed the effects of exercise and daily activities on reducing BPSDs.<sup>58</sup> A meta-analysis also revealed that occupational therapy interventions are effective in improving the QoL of dementia patients.<sup>59</sup> Moreover, several studies have shown that changes in patient living conditions contribute to the development of BPSDs.<sup>60–62</sup> Because a majority of dementia people receive care in their homes, our participants also emphasised that keeping the same place of living and care is another important issue that caregivers should take into account.

The perspectives of various ethnic groups with different socio-cultural backgrounds (such as embedded cultural stigma and shame) are connected with the occurrence and management of BPSDs.<sup>63</sup> In Persian culture, people value old people, particularly if they are member of their family.<sup>64</sup> However, changes in the behaviour and personality of an elderly family member, especially parents, due to dementia may threaten and challenge the atmosphere of honour and respect in that family. For example, it is not common to apply dance therapy (as a proven comprehensive intervention in other studies), mainly because it is not in line with the common culture of elderly individuals. Some researchers have also indicated that some aspects

of culture and religion, for example, in Asian countries, may pose challenges to the treatment of mental disorders such as dementia, such as belief in mental control by evil spirits in dementia patients.<sup>65,66</sup> Iranian dementia patients living in Sweden declared that they felt more confident and secure in Sweden than in their own country.<sup>67</sup> For example, Mazaheri *et al*<sup>66</sup> showed that Iranian people with dementia in Iran depend on others to get out of the house to avoid being lost, being hurt in traffic, being disturbed by people, etc. The reasons for such findings should be studied further to better align with the various social, cultural, religious and ethical factors important in a country. For example, in Iran, new policies and social practices might be needed to implement at the healthcare system and community organisationsto support dementia patients and their caregivers appropriately.

Finally, the diversity and frequency of BPSDs reported in previous studies indicate that the physical and psychological burdens of dementia caregivers are disproportionately greater than those of other caregivers.<sup>68</sup> To reduce this burden, some measures should be taken into account to support these caregivers. Several studies have reported that despite their effectiveness, drug therapies for the management of BPSDs have various serious side effects,<sup>69</sup> whereas non-pharmacological or ecopsychosocial therapies are considered safer alternatives.<sup>70</sup> Aligned with this notion, our results imply that, for example, socially, spiritually or culturally appropriate ecopsychosocial therapies can be helpful, acting as promising alternatives for drug therapies in managing some BPSDs. Our study is the first in the Iranian healthcare system to explore how professional family caregivers in Persian families respond to current BPSDs in dementia patients. This knowledge can be used to plan educational sessions on strategies for ecopsychosocial therapies and strengthen support systems for non-professional caregivers who have recently joined the dementia caregiver workforce.

### Strengths and Limitations

Using stories as a basis for analysis is a strength of this study. When we tell stories, we use language available and familiar to us and to our audience.<sup>71</sup> While caregivers' understanding of and experience with BPSDs have been investigated through qualitative interviews, few, if any, studies have used therapeutic lying as a research tool to explore their insights. Compared with other qualitative research methods, stories can generate more nuanced, contextualised and culturally reflective information.<sup>72</sup> The present study has several limitations. This study, like other qualitative studies, had a small sample size. The participants were asked to write one story about a single strategy they found important and relevant to our study aim. This approach was chosen to manage the collected data effectively and to facilitate a thorough analysis



within the study's scope. However, we acknowledge that limiting participants to reporting just one strategy may have constrained the breadth of experiences shared, particularly for family carers employing multiple strategies to address different challenges. As a result, our findings may not fully capture the diversity of caregiving approaches used for an individual with dementia. This limitation should be considered when interpreting the generalizability of the reported strategies. Future studies could explore multiple strategies per participant to provide a broader understanding of caregiving practices. There was no further exploration of these stories with the participants. If this was not the case, we could have collected richer data. The participants were a selected group of family caregivers as they were recruited from a support group. Hence, the present study does not reveal much about those who did not participate in such a group. Next, we relied on the information provided by caregivers regarding the BPSDs mentioned in the stories and their management strategies. Whether the strategies applied are effective can be related to their interpretation of the situation and the causal links they make themselves. Therefore, no causality can be 'shown' or 'proven' in their stories. In fact, their experience can be exposed to the interference of variables such as the caregiver's burden and personality and even their ability to understand (or comprehend) alterations in patients' behaviour, which should be considered when interpreting our results. To address some of these limitations, in future studies, researchers can examine and compare the views and experiences of other caregiver types (eg, professional and non-professional and family or nonfamily caregivers). Additionally, further studies may be needed on caregivers with a lower education level because they may have different management strategies, which will require the design of other adequate interventions to support them.

## CONCLUSIONS

Our results show that to effectively manage BPSDs through ecopsychosocial interventions, the compatibility of family caregivers with patients' needs and conditions while providing care is necessary. However, it would not be sufficient, alone. Managing most BPSDs can be facilitated through ecopsychosocial interventions under the cooperation of people and the government beyond the immediate context of families. Furthermore, our results indicate that the ecopsychosocial interventions mentioned were limited to a few types of common strategies and did not include other therapy options. However, Iranian caregivers need to be encouraged and trained to use other types as well. To this end, support from the government should be received to better prepare

the community and facilitate the use of ecopsychosocial interventions as effective interventions in the management of BPSDs. Future researchers can use the insights gained through sharing the experiences of professional caregivers in managing BPSDs to design better support systems for non-professional caregivers.

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## REFERENCES

- Craik FI, Salthouse TA. *The Handbook of Aging and Cognition*. Psychology press, 2011.
- Berendonk C, Caine V. Insights Into Care Providers' Understandings of Life Story Work With Persons With Dementia: Findings From a Qualitative Study. *Res Theory Nurs Pract* 2017;31:272–94.
- Cummings JL. Dementia: Definition, Classification, and Differential Diagnosis. *Psychiatr Ann* 1984;14:85–9.
- Nichols E, Steinmetz JD, Vollset SE, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* 2022;7:e105–25.
- Safiri S, Noori M, Nejadghaderi SA, et al. The burden of Alzheimer's disease and other types of dementia in the Middle East and North Africa region, 1990–2019. *Age Ageing* 2023;52:afad042.
- Nichols E, Szeoke CEI, Vollset SE, et al. Global, regional, and national burden of Alzheimer's disease and other dementias, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol* 2019;18:88–106.
- Rafii MS, Aisen PS. Recent developments in Alzheimer's disease therapeutics. *BMC Med* 2009;7:1–4.
- Dewing J. Participatory research: a method for process consent with persons who have dementia. *Dementia (London)* 2007;6:11–25.
- Hubbard G, Downs M, Tester S. Including the perspectives of older people in institutional care during the consent process. The perspectives of people with dementia. *Res methods and motiv* 2002;63–81.
- World Health Organization. Dementia: a public health priority. 2012.
- Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. *BMJ* 2015;350:h369.
- Finkel SI, Costa e Silva J, Cohen G, et al. Behavioral and Psychological Signs and Symptoms of Dementia: A Consensus Statement on Current Knowledge and Implications for Research and Treatment. *Int Psychogeriatr* 1997;8:497–500.
- Finkel SI. Behavioral and psychologic symptoms of dementia. *Clin Geriatr Med* 2003;19:799–824.
- Bradshaw LE, Goldberg SE, Schneider JM, et al. Carers for older people with co-morbid cognitive impairment in general hospital: characteristics and psychological well-being. *Int J Geriatr Psychiatry* 2013;28:681–90.
- O'Neil ME. A systematic evidence review of non-pharmacological interventions for behavioral symptoms of dementia. 2011.
- Gitlin LN, Kales HC, Lyketsos CG. Nonpharmacologic management of behavioral symptoms in dementia. *JAMA* 2012;308:2020–9.
- de Vugt ME, Stevens F, Aalten P, et al. Do caregiver management strategies influence patient behaviour in dementia? *Int J Geriatr Psychiatry* 2004;19:85–92.
- Gerlach LB, Kales HC. Managing Behavioral and Psychological Symptoms of Dementia. *Psychiatr Clin North Am* 2018;41:127–39.
- Zeisel J, Reisberg B, Whitehouse P, et al. Ecopsychosocial Interventions in Cognitive Decline and Dementia: A New Terminology and a New Paradigm. *Am J Alzheimers Dis Other Demen* 2016;31:502–7.
- Wolverson E, Dunn R, Moniz-Cook E, et al. The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia. *J Adv Nurs* 2021;77:1992–2001.
- Laver K, Cumming RG, Dyer SM, et al. Clinical practice guidelines for dementia in Australia. *Med J Aust* 2016;204:191–3.
- Algase DL, Beck C, Kolanowski A, et al. Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *Am J Alzheimers Dis (Columbia)* 1996;11:10–9.
- GR H. Progressively lowered stress threshold; a conceptual model for care of adults with Alzheimer's disease. *Arch Psychiatr Nurs* 1987;1:399–406.
- Polenick CA, Struble LM, Stanislawski B, et al. "I've learned to just go with the flow": Family caregivers' strategies for managing behavioral and psychological symptoms of dementia. *Dementia (London)* 2020;19:590–605.
- Turner RM, Hinton L, Gallagher-Thompson D, et al. Using an Emic lens to understand how Latino families cope with dementia behavioral problems. *Am J Alzheimers Dis Other Demen* 2015;30:454–62.
- Moore K, Ozanne E, Ames D, et al. How do family carers respond to behavioral and psychological symptoms of dementia? *Int Psychogeriatr* 2013;25:743–53.
- Huis In Het Veld J, Verkaik R, van Meijel B, et al. Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia: an online focus group study. *BMC Geriatr* 2016;16:95.
- Leung DKY, Wong KKY, Spector A, et al. Exploring dementia family carers' self-initiated strategies in managing behavioural and psychological symptoms in dementia: a qualitative study. *BMJ Open* 2021;11:e048761.
- Knight BG, Sayegh P. Cultural values and caregiving: the updated sociocultural stress and coping model. *J Gerontol B Psychol Sci Soc* 2010;65B:5–13.
- Cheraghi MA, Payne S, Salsali M. Spiritual aspects of end-of-life care for Muslim patients: experiences from Iran. *Int J Palliat Nurs* 2005;11:468–74.
- Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009;12:885–904.
- Ferrell BR, Twaddle ML, Melnick A, et al. National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition. *J Palliat Med* 2018;21:1684–9.
- Meier DE. Accountability for Quality in the Care of People Living with a Serious Illness: The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care. Health Affairs Forefront, 2018.
- LoBiondo-Wood G, Haber J. *Nursing Research E-Book: Methods and Critical Appraisal for Evidence-Based Practice*. Elsevier Health Sciences, 2021.
- Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. *Front Neurol* 2012;3:73.
- Warth M, Kessler J, Koehler F, et al. Brief psychosocial interventions improve quality of life of patients receiving palliative care: A systematic review and meta-analysis. *Palliat Med* 2019;33:332–45.
- Rivaz M, Shokrollahi P, Ebadi A. Online focus group discussions: An attractive approach to data collection for qualitative health research. *NPT* 2019;6:1–3.
- Available: <https://www.sciencedirect.com/science/article/abs/pii/S0123693985003820>
- Pearse N. An illustration of deductive analysis in qualitative research. 18th European Conference on Research Methodology for Business and Management Studies; June 20, 2019
- Lenette C, Vaughan P, Boydell K. *Reflexive Thematic Analysis in Story Completion Research*. 2022.
- Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: *Handbook of qualitative research*. 1994; 2: 105.
- Lee M, Chodosh J. Dementia and Life Expectancy: What Do We Know? *J Am Med Dir Assoc* 2009;10:466–71.
- Chan CY, Cheung G, Martinez-Ruiz A, et al. Caregiving burnout of community-dwelling people with dementia in Hong Kong and New Zealand: a cross-sectional study. *BMC Geriatr* 2021;21:261.
- Van Den Wijngaert MAG, Vernooij-Dassen M, Felling AJA. The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging Ment Health* 2007;11:626–36.
- Rokstad AMM, Engedal K, Kirkevold Ø, et al. The association between attending specialized day care centers and the quality of life of people with dementia. *Int Psychogeriatr* 2017;29:627–36.
- Rokstad AMM, McCabe L, Robertson JM, et al. Day Care for People with Dementia: A Qualitative Study Comparing Experiences from Norway and Scotland. *Dementia (London)* 2019;18:1393–409.
- Reinar LM. Effect of day care centers for people with dementia. 2018.
- Ho RT, et al. Psychophysiological effects of dance movement therapy and physical exercise on older adults with mild dementia: a randomized controlled trial. *J Gerontol Ser B* 2020;75:560–70.
- Shih PY, et al. Long-term care services use and reasons for non-use by elders with dementia and their families. *Taiwan J Public Health* 2017;36:375–85.
- Robinson KM, Buckwalter K, Reed D. Differences between dementia caregivers who are users and nonusers of community services. *Public Health Nurs* 2013;30:501–10.
- Santagata F, Massaia M, D'Amelio P. The doll therapy as a first line treatment for behavioral and psychologic symptoms of dementia in nursing homes residents: a randomized, controlled study. *BMC Geriatr* 2021;21:545.
- Wesenberg S, Mueller C, Nestmann F, et al. Effects of an animal-assisted intervention on social behaviour, emotions, and behavioural

- and psychological symptoms in nursing home residents with dementia. *Psychogeriatrics* 2019;19:219–27.
- 53 Yang M-H, Lin L-C, Wu S-C, *et al.* Comparison of the efficacy of aroma-acupressure and aromatherapy for the treatment of dementia-associated agitation. *BMC Complement Altern Med* 2015;15:93.
- 54 Woods DL, Dimond M. The effect of therapeutic touch on agitated behavior and cortisol in persons with Alzheimer's disease. *Biol Res Nurs* 2002;4:104–14.
- 55 Dowling GA, Graf CL, Hubbard EM, *et al.* Light treatment for neuropsychiatric behaviors in Alzheimer's disease. *West J Nurs Res* 2007;29:961–75.
- 56 Neville C, Henwood T, Beattie E, *et al.* Exploring the effect of aquatic exercise on behaviour and psychological well-being in people with moderate to severe dementia: a pilot study of the Watermemories Swimming Club. *Australas J Ageing* 2014;33:124–7.
- 57 van den Kieboom R, Snaphaan L, Mark R, *et al.* The Trajectory of Caregiver Burden and Risk Factors in Dementia Progression: A Systematic Review. *J Alzheimers Dis* 2020;77:1107–15.
- 58 Rodrigues SL da S, Silva JM da, Oliveira MCC de, *et al.* Physical exercise as a non-pharmacological strategy for reducing behavioral and psychological symptoms in elderly with mild cognitive impairment and dementia: a systematic review of randomized clinical trials. *Arq Neuropsiquiatr* 2021;79:1129–37.
- 59 Ojagbemi A, Owolabi M. Do occupational therapy interventions improve quality of life in persons with dementia? A meta-analysis with implications for future directions. *Psychogeriatrics* 2017;17:133–41.
- 60 Gitlin LN, Liebman J, Winter L. Are environmental interventions effective in the management of Alzheimer's disease and related disorders?: A synthesis of the evidence. *Alzheimer's Care Today* 2003;4:85–107.
- 61 Robinson L, *et al.* A Systematic Literature Review of the Effectiveness of Non-Pharmacological Interventions to Prevent Wandering in Dementia and Evaluation of the Ethical Implications and Acceptability of Their Use. Winchester England: Health Technology Assessment, 2006:10. ix–108.
- 62 van Hoof J, Kort HSM, van Waarde H, *et al.* Environmental interventions and the design of homes for older adults with dementia: an overview. *Am J Alzheimers Dis Other Demen* 2010;25:202–32.
- 63 Cheung G, Appleton K, Boyd M, *et al.* Perspectives of dementia from Asian communities living in New Zealand: A focus group of Asian health care professionals. *Int J Geriatr Psychiatry* 2019;34:1758–64.
- 64 Elizur D, Kantor J, Yaniv E, *et al.* Importance of life domains in different cultural groups. *Am J Psychol* 2008;121:35–46.
- 65 Kramer EJ, Kwong K, Lee E, *et al.* Cultural factors influencing the mental health of Asian Americans. *West J Med* 2002;176:227–31.
- 66 Mazaheri M, Eriksson LE, Heikkilä K, *et al.* Experiences of living with dementia: qualitative content analysis of semi-structured interviews. *J Clin Nurs* 2013;22:3032–41.
- 67 Mazaheri M, Eriksson LE, Nasrabadi AN, *et al.* Experiences of dementia in a foreign country: qualitative content analysis of interviews with people with dementia. *BMC Public Health* 2014;14:794.
- 68 Pinquart M, Sörensen S. Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Ageing Ment Health* 2004;8:438–49.
- 69 Ayalon L, Gum AM, Feliciano L, *et al.* Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. *Arch Intern Med* 2006;166:2182–8.
- 70 Dyer SM, Harrison SL, Laver K, *et al.* An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *Int Psychogeriatr* 2018;30:295–309.
- 71 Wilson M. Some Thoughts on Storytelling, Science, and Dealing with a Post-Truth World. *sss* 2017;13:120–37.
- 72 McCall B, Shallcross L, Wilson M, *et al.* Storytelling as a Research Tool Used to Explore Insights and as an Intervention in Public Health: A Systematic Narrative Review. *Int J Public Health* 2021;66:1604262.