Nursing Care of Family Caregivers: Interventions and Considerations Regarding Current Issues Facing Family Caregivers of Persons with Dementia Relevant to Nursing Practice

Alayna Kent

A Senior Thesis submitted in partial fulfillment of the requirements for graduation in the Honors Program
Liberty University
Spring 2022

#### Abstract

There are an estimated 6.5 million Americans age 65 and older who are currently living with Alzheimer's dementia. A large majority of these individuals receive care from a nonprofessional family caregiver, typically in the home setting. It is well documented that family caregivers of dementia patients experience many unique challenges. These challenges provide valuable opportunities for nurses to provide helpful interventions to aid this vulnerable population. An integrated review of the recent literature was conducted, and articles were chosen by a method modeled after the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowsheet. The research was then analyzed for themes and topics related to the most significant issues family caregivers face and what evidenced-based interventions to address these challenges exist. The identified areas with which caregivers struggle the most include managing the psychological and behavioral symptoms of dementia, dealing with ambiguous and anticipatory grief, feelings of isolation and unpreparedness, and physical health problems. Evidence-based interventions for these major issues include screening caregivers for the effects of caregiver burden and stress, teaching caregivers mindfulness-based interventions, encouraging mutuality between the caregiver and care-recipient, teaching strategies based on cognitivebehavioral therapeutic techniques, and connecting caregivers with resources. However, this review also illustrated the need for further research to be conducted on the effectiveness of nurse-specific interventions on supporting this vulnerable population, especially within acutecare settings.

Nursing Care of Family Caregivers: Interventions and Considerations Regarding Current Issues Facing Family Caregivers of Persons with Dementia Relevant to Nursing Practice

The most recent statistics, as published by the Alzheimer's Association, state that there are currently an estimated 6.5 million Americans ages 65 years and older who are currently living with Alzheimer's dementia (Alzheimer's Association, 2022). This correlates to a ratio of incidence that is about 1 in 9 Americans over the age of 65 with Alzheimer's dementia. By the year 2050, the population of Americans over 65 years of age is expected to increase from 58 million to 88 million, representing the likelihood that the population of Americans living with Alzheimer's dementia or another form of dementia (such as Lewy body or vascular dementia) will increase along with it. A large majority of these individuals living with dementia, (not just in the United States but worldwide) are cared for by unpaid family caregivers, usually family members such as spouses or adult children (Chan et al., 2022). Care is provided to these persons with dementia by unpaid family caregivers due to many factors, including individual preferences, the perceived obligation of the caregiver to the family member with dementia, and associated high costs and limited vacancies of residential care facilities (Chan et al., 2022).

Family caregivers are often responsible for assisting the person with dementia with activities of daily living, providing emotional and practical support, ensuring the safety of the person with dementia, and managing their physical health care (Alzheimer's Association, 2022). Caregivers in the United States are most likely to be women, a spouse or child of the person with dementia, and 50 years of age or older. The vast amount of responsibility and the unique challenges that caregiving for a person with dementia produces tends to cause high levels of emotional stressors, depression, new or worsening physical health issues, and financial burden on the caregiver (Alzheimer's Association, 2022). It is well documented in current literature that

family caregivers of persons with dementia are at an increased risk of developing these issues and experiencing other debilitating challenges (Alzheimer's Association, 2022).

Many caregiver and care recipient dyads do not seek physical or emotional assistance with the challenges of caregiving until the moderate or late stages of dementia (Wawrziczny et al., 2019). By this stage, caregivers tend to be living day-to-day and have already established negative and avoidant habits that increase the likelihood that they experience the negative consequences of caregiving. According to Wawrziczny et al. (2019)., earlier intervention (while the care recipient is in the mild stages of dementia) will allow caregivers to increase their level of preparation for the future, leading to a decreased level of anxiety and a lowered likelihood that negative and at-risk habits will be established. Since nurses are present in long-term, short-term acute care, and community health positions, nurses are in a unique position to assist with this. Nurses have access to these family caregivers when the person with dementia or the caregiver themselves requires a variety of regular or acute health care, even during earlier/milder stages of dementia, before the caregiver seeks help with the challenges of caregiving.

Although there is increasing research that caregiving for a person with dementia has a multitude of negative physical, emotional, and socioeconomic consequences, there is limited research on considerations and interventions nurses must be aware of to assist caregivers in this at-risk population (Alzheimer's Association, 2022). According to Isik et al., (2019), active management of dementia should involve not only caring for the dementia patient, but also identifying and treating of major risk factors for dementia caregiver stress, and the coordination of care to reduce this stress. Nurses are in a unique position to be able to identify risk factors and vulnerable populations, provide interventions, and initiate the process of coordinating care among various healthcare providers and practices to reduce the negative consequences of

caregiving. Therefore, nurses should be aware of recent evidence-based practice and considerations regarding the greatest risk factors for the negative consequences of dementia caregiving and the interventions they can provide to family caregivers of persons with dementia.

This integrative review of the literature will serve to provide modern nurses with the information necessary to best support caregivers of persons with dementia by reviewing recent literature published regarding issues, best practices, and interventions among the population of family caregivers of persons with dementia. The review will seek to identify and explore the greatest current issues that family caregivers of dementia patients face during the daily care of their family members with dementia according to the most recent literature. To accomplish this, current themes and issues present in the literature will be discussed. Then, current interventions and techniques that nurses in routine care settings can employ to best support caregivers of Alzheimer's and dementia patients while caregiving for their family members will be explored.

#### Methods

The literature included in this integrated literature review was identified following a flow-sheet based method included in the PRISMA statement for reporting systematic reviews that evaluate health care interventions as published by the *BMJ* in 2009 (Liberati et al., 2009). Then the articles were placed in a matrix to identify common themes. To begin the search, Boolean-style operators with search terms relevant to the research question were used to identify relevant literature within a large library database of medical and psychological peer-reviewed journals (such as, but not limited to, the *International Journal of Geriatric Psychiatry*, *Aging and Health*, and *Research on Gerontological Nursing*) that is provided and operated by Liberty University. The original search terms were "caregiver", "family," "nurse," "intervention," and

"dementia." This search returned 6,469 results and revealed the need for greater specificity of terms.

The terms and operators "caregiver," "symptoms or challenge" "issue," "family," "child or spouse," "dementia," "nursing and nurse," and "intervention," not "nursing home" were then searched. Then, terms and Boolean operators "child or spouse" and "nurse not nursing home" were removed due to the return of irrelevant and limited articles. The search was then limited to articles published or updated between January 1<sup>st</sup>, 2019, and January 1<sup>st</sup>, 2022 to ensure relevancy. Lastly, they were limited to those published in peer-reviewed scholarly journals with full text available online (for ease of use). This final search returned 1,257 results on the database tool.

From this number, articles were included in the review according to the following criteria. Articles must have evaluated either interventions that were helpful for caregivers of persons with dementia and/or examined a major current issue relevant to caregivers of persons with dementia. They also must have been examining family caregivers of dementia patients (either the spouse or adult child of the adult dementia patient) who are the primary caregivers for their family member with dementia and are caring for the family member primarily at home (i.e. the family member with dementia is not placed in a residential care facility or nursing home). The articles also must have reported on primary research and/or included a scholarly metanalysis on a relevant subject.

The 20 articles that were chosen according to these criteria were placed into a literature matrix for content and thematic analysis. The matrix included a classification of the level of evidence the article represented according to the John's Hopkins Levels of Evidence scale (utilized with permission) published in the fourth edition of *Johns Hopkins evidence-based* 

practice for nurses and healthcare professionals: Model and guidelines (Dang et al., 2022). The articles were then analyzed for themes and subjects relevant to either a major issue that caregivers with dementia patients face or an intervention that nurses should be aware of to assist caregivers of dementia patients as they struggle with those issues.

The studies included in this integrated review use a variety of terminology for the dyad of a family caregiver and the recipient of their care, yet the many terms for this relationship are synonymous. In the interest of clarity, the roles will be identified within this review as follows. The family member with dementia who is receiving primary care (including financial, medical, spiritual, emotional, and physical care) from the family caregiver will be referred to as either the person with dementia (PWD) or the care recipient. The family member (often referred to as an informal caregiver, a family member, a spousal caregiver, or a primary caregiver) who is in the primary position of providing the most direct care to the person with dementia will be referred to as the caregiver.

#### Results

The themes emerging in this literature indicated that there are multiple dimensions to the struggles and issues that caregivers of dementia patients face during their time as caregivers, as well as multiple intervention strategies that nurses can use to combat these challenges. The major issues and challenges include behavioral and psychological symptoms of dementia, which is a direct indication of increased feelings of great personal sacrifice and burden on the caregivers, anticipatory losses and ambiguous grief related to the loss of their loved one as they once were, feelings of isolation or being unprepared in the caregiving experience, and physical health issues. To address these challenges, the literature was also analyzed for themes regarding interventions and strategies that fall within the nursing practice so as to be implemented or utilized by nurses.

Interventions include implementing screening tools, teaching mindfulness-based intervention strategies, coaching and encouraging mutuality, providing cognitive-behavioral therapy or cognitive-behavioral-based interventions, and creating connections with interprofessional interventions and resources.

## **Challenges of Caregiving**

Taking on care for PWD requires an intense amount of responsibility and the need to face challenges regarding the PWD, adapting to a new way of life, and giving up some freedoms (Alzheimer's Association, 2022). These new challenges tend to cause high levels of emotional stressors, depression, new or worsening physical health issues, financial burden in the caregiver, extended family conflicts, and feelings of inadequacy. Although there are many challenges, the most recently published literature identified four themes that caused the greatest amount of hardship during caregiving for a PWD. These challenges are (a) feeling burdened by the care recipient's behavioral and psychological symptoms of dementia, (b) anticipating future losses and dealing with the grief that goes alongside these feelings, (c) feelings of isolation and impreperation, and (d) physical health issues.

# Behavioral and Psychological Symptoms of Dementia

Behavioral and psychological symptoms of dementia are symptoms that occur in many dementia patients. These are new-onset and unrelated to personality, as they are not behaviors or symptoms that the care recipient exhibited before the onset of their dementia (Tampi & Tampi, 2020). Behavioral and psychological symptoms are non-cognitive (meaning they are not related to memory or thought process) and are nearly as common among dementia patients as cognitive symptoms of dementia (Isik et al., 2019). Symptoms might include increased and inconsolable anxiety, depression, agitation, hallucinations, delusions, repetitive speech patterns, apathy, sleep

and appetite disturbance, wandering, aggressive behaviors, and other atypical motor behaviors (Tampi & Tampi, 2020; Lin et al., 2022).

Although aggressive and agitated behaviors are not seen as the "classic" or most common symptoms of dementia, as memory loss is often the only identified symptom of dementia, behavioral symptoms are present in up to 97% of individuals with moderate to late-stage dementia (Isik et al., 2019). Many new caregivers are not aware of the likelihood of these symptoms appearing in their care recipient nor are they able to identify them as part of the disease in the initial stages of caregiving (Isik et al., 2019). Caregivers are therefore at risk for viewing these symptoms as coming from the care recipient out of malice or spite against the caregiver rather than as a symptom. Viewing the symptoms as purposeful has been shown to lead to high levels of anxiety, depression, and burden in the caregiver. Although there are a variety of psychological and physical behaviors that fall into the category of behavioral and psychological symptoms of dementia, not one of the symptoms seems to be more distressing to caregivers than others (Liew at al., 2019; Lin et al., 2022, Isik et al., 2019). Instead, one of the largest predictors for reports of burden and increased stress in caregivers of dementia patients seems to be the presence of any form or combination of behavioral and psychological symptoms of dementia.

When behavioral and psychological symptoms of dementia are present, caregivers report increased distress, decreased personal quality of life, increased depression and grief symptoms, and increased financial burden, all of which are referred to as symptoms of caregiver burden (Tampi & Tampi, 2020; Isik et al., 2019; Rigby et al., 2019). According to Rigby et al. (2019, p. 2), "caregiver burden incorporates the overall experience of dealing with various physical, psychological, emotional, social, and financial stressors." Increased caregiver burden manifests as emotion-oriented rather than problem-focused coping, leading to irritation, anger, and

impatience towards the care recipient when behaviors occur. High negative expressed emotion, in turn, has been shown to increase the incidence of behaviors in the care recipient, which only serve to reinforce emotion-oriented coping in the caregiver. Expressed emotion also increases guilt, shame, regret, and sadness in the caregiver, which can continue to increase negatively expressed emotions (Prunty & Foli, 2019). When negative expressed emotion is high, as occurs when coping is primarily emotion-oriented, caregiver burden and behavioral and psychological symptoms (especially depression and difficulty sleeping) in the care recipient are most likely be severe (Isik et al., 2019; Lin et al., 2022).

The most frequently seen behavioral and psychological symptoms are apathy and indifference to the caregiver, as well as disturbances in sleep and nighttime behaviors/wandering (Lin et al., 2022; Isik et al., 2019). Nearly a third of caregivers reported having difficulty dealing with their care recipient's early morning awakenings, wanderings, and difficulty falling asleep. This leads to a decrease in the caregiver's sleeping hours and stress related to inability to let their guard down; caregivers tend to worry about what might happen if the care recipient was to wander in the nighttime while the caregiver was asleep (Isik et al., 2022). Apathy and indifference in the PWD towards the caregiver can also lead to ambiguous grief as the caregiver grieves the loss of the relationship with their family member as it once was, while simultaneously managing increased burden due to the PWD's declining abilities and need for greater supervision.

When the care recipient exhibits behavioral or psychological symptoms, burden is increased on the family caregivers, leading to decreased overall well-being (Isik et al., 2019). Care recipients exhibiting behavioral and psychological symptoms tend to need supervision for the majority of the day, including during the night, to ensure the safety of the care recipient

(Yquin et al., 2019). Unpredictable symptoms such as wandering lead to a decreased ability of the caregiver to maintain an outside career, hobbies, or relationships outside the home, ultimately resulting in feelings of isolation as well as financial burden on the caregiver (Yquin et al., 2019). The increased commitment required of the caregiver when these symptoms are present lead to increased feelings of personal sacrifice and caregiver reports of being negatively burdened (Chan et al., 2020; Rigby et al., 2019; Lin et al., 2022). In addition, the increased hours of caregiving that are required due to behavioral symptoms tend to lead to the caregiver's decreased ability to engage in productive stress-relieving activities (such as exercise, religious activities, or other productive hobbies) and interests outside the responsibilities of caregiving, leading to further increases in stress.

Behavioral and psychological symptoms of dementia, in addition to causing feelings of increased burden and dissatisfaction in caregiving, are reported by Liew et al. (2019) to be a reminder to the caregiver of their care recipient's progressing disease. The reminder of the progressing disease causes feelings of ambiguous losses, as the caregivers grieve the loss of relationships as they once were in addition to anticipating the future grief that will come with the inevitable death of their loved one. In this way, behavioral symptoms of dementia tend to increase levels of ambiguous and anticipatory grief (Rigby et al., 2019; Liew et al., 2019).

# Ambiguous and Anticipatory Grief

Another major theme in recent literature related to the most common issues facing caregivers is ambiguous and anticipatory grief regarding their family members with dementia (Chan et al., 2020; Liew et al., 2019). Meichsner & Wiltz (2018) define caregiver grief as "the emotional and physical response to the perceived losses of a valued recipient of care," indicating that grief that caregivers experience is atypical and complicated. Caregiver grief is related to a

variety of elements and experiences that caregivers of dementia patients must face during caregiving. Caregivers are slightly more likely to develop disruptive depression and grief symptoms related to caregiver grief when the care recipient has a younger age of onset of dementia than average, when the care recipient is in a later stage of dementia, and when the caregiver has high expressed emotion or other poor coping strategies (Leiw et al., 2019). However, according to Rigby et al., (2019), grief among caregivers is more similar than it is different, regardless of socioeconomic status, age of the caregiver or care recipient, and stage of dementia.

Grief is anticipatory because cognitive and behavioral symptoms of dementia remind the caregiver that dementia as a disease leads inevitably to the death of their loved one (Liew et al., 2019). However, caregiver grief also has elements of ambiguous grief as the caregiver grieves the loss of the relationship they once had with the care recipient. Whether that be a spouse-tospouse or child-to-parent relationship, the relationship they once had has now become a caregiver-to-care recipient relationship (Meichsner & Wilz, 2018). The family member, spouse, or parent is physically present with the caregiver, but they become relationally and psychologically absent. This change in relationships causes grief and frustration. Caregivers are also grieving the loss of their own freedom and the life they knew before becoming a caregiver, as caregiving requires immense personal sacrifice on the part of the caregiver. This form of grief is also chronic, long-lasting, and does not have a readily anticipatable end, as dementia has a long and unpredictable disease trajectory (Meichsner & Wilz, 2018; Liew et al., 2019) All these elements form complicated caregiver grief that causes feelings of intense emotional dysregulation and can lead to depressive symptoms among caregivers when left untreated (Chan et al., 2020; Liew et al., 2019).

Caregiver grief is a psychological and physical syndrome and experience of grief that is not easily definable nor well understood, however, it is a common and expected experience for family caregivers of dementia patients (Chan et al., 2020; Meichsner & Wilz, 2018; Liew et al., 2019). Despite its prevalence, many caregivers are unaware of the effects of caregiver grief and believe their grief symptoms to simply be related to the "stressors" of caregiving, leading to a tendency for caregivers to ignore their grief symptoms or avoid dealing with them (Meichsner & Wilz, 2018). Avoiding grief symptoms has been shown to increase the likelihood of caregivers developing cardiovascular diseases, sleep disturbances, and anxiety disorders, among other chronic diseases (Corey & McCurry, 2018).

Symptoms of caregiver grief, according to Joling et al. (2019), appear similar to symptoms of major depressive disorder in some caregivers, in some cases leading to the presence of suicidal thoughts and ideation. Caregiver grief, due to its complicated and ambiguous nature, has a risk of being improperly managed by both the caregiver and the caregiver's healthcare providers, which in some cases can lead to dangerous, chronic mental health conditions and suicidal ideation. In a recent study, it was found that 76 out of 192 family caregivers of dementia patients experienced some symptoms of major depressive disorder during and after their experience of caregiving, and often times these symptoms persisted even after the caregiving role was passed on or ended (Joling et al., 2019).

If caregivers are predisposed to mental illness or have previous mental health issues from before the caregiving experience began, they have a greater risk for developing suicidal thoughts and ideations alongside caregiver grief (Joling et al., 2019). Individuals that are more likely to experience intense pre-death grief include those caring for a care-recipient with early-onset dementia, those caring for a spouse, and those caring for a care recipient in the later stages of

dementia (Liew et al., 2019). Although depressive symptoms are common among caregivers, intense depressive symptoms and suicidal ideation are not certain to follow caregiver grief (Joling et al., 2019; Meichsner & Wilz, 2018). Poor coping strategies and a lack of mutuality between the caregiver and the care recipient increase the likelihood that caregiver grief can progress into major depression and its related risks and symptoms (Joling et al., 2019). The risk of suicidal ideation serves to emphasize how vulnerable family caregivers of dementia patients are to mental illness due to increased stress, indicating that there is a need for support and intervention to prevent a disastrous outcome.

# Isolation and Unpreparedness

The third major issue facing family caregivers of dementia patients are feelings of isolation within and being unprepared for the caregiving experience. In a study conducted by Corey and McCurry (2018), it was found that nearly every caregiver for dementia patients reported feeling that their role as a caregiver had become the most important issue in their life during caregiving at least one point in their life, taking up a good majority of their time, energy, and focus. Caregiving is a huge commitment, and caregivers tend to self-isolate due to the emotional, physical, and mental strain (Corey & McCurry, 2018). In addition, many caregivers do not have an appropriate social support system that can be used to combat the isolating elements of caregiving (Fauth et al., 2019).

Caregivers are more likely to be isolated without a social support system when they are older, and younger caregivers tend to report dissatisfaction with social support and increased feelings of isolation (Fauth et al., 2019). In the beginning stages of dementia, caregivers may not recognize the need for support, despite evidence that early intervention and support can increase feelings of preparedness and decrease stress (Kabir et al., 2020). The presence and degree of

extended family support and assistance for the caregiver is also a major predictor of felt isolation (Wawrziczny et al., 2019). Caregivers who prioritize maintaining their relationships with other members of their family (not just their relationship with the care recipient) and continue to ask for assistance from the family when it is needed tend to have a better relationship with their care recipient and decreased levels of stress and burden (Wawrziczny et al., 2019). However, family conflict is a major issue for caregivers of dementia patients (Fauth et al., 2019; Wawrziczny et al., 2019). Wawrziczny et al. (2019) continues to propose that conflict arises when extended family members disagree about end-of-life decisions for their family members with dementia, and when the primary caregiver feels as if they are not receiving proper support from their family.

Family conflict is a predictor for caregivers reporting feelings of isolation and being alone in the caregiving experience (Fauth et al., 2019). In addition, many caregivers report feelings of isolation due to both a lack of education and a lack of accessible educational resources about how to provide care to an individual with dementia. In a study conducted by Fauth et al (2019), a majority of the interviewed caregivers reported that they found themselves unprepared and unable to accept the disease, manage behavioral disturbances, take on new caregiving roles such as providing physical care and emotional support, manage daily activities for another person, manage the stress, and even to find joy and pleasure in the entire caregiving experience (Fauth et al., 2019; Alvariza et al., 2020). Unpreparedness is an indication of greater stress and reveals a greater likelihood of developing chronic health conditions as a result of caregiving, and this is a common theme among modern caregivers of PWD.

## Physical Issues

The last major issue present in the literature that caregivers of face are physical health issues and conditions, some of which persist even after the caregiving role has ended (Flanagan et al., 2022; Mohammed et al., 2021). The most distressing and common symptom that caregivers report is insomnia, including difficulty falling asleep and staying asleep, related to anxiety that something may have happened to their care recipient during the night (Corey & McCurry, 2018). Other common symptoms include the development of anxiety-related chronic health disorders such as atrial fibrillation and other cardiovascular conditions. Corey and McCurry (2018) reports that out of the eight caregivers they interviewed via convenience sampling in a local population, six of the caregivers had received chronic health condition diagnoses related to prolonged exposure to unmanaged anxiety and stress.

Heart disease, issues with the immune system, and prolonged and chronic pain syndromes are other reported chronic conditions that are more common among caregivers than in similar populations of non-caregivers (Flanagan et al., 2022; Mohammed et al., 2021).

Mohammed et al. (2021) reports that out of a random sampling of caregivers who have received diagnoses of stress-related chronic illnesses, more than half of them required medication treatment, which serves to add additional financial cost to the caregiver and can increase stress.

Lastly, because providing care to a person with dementia takes precedence over the caregivers own health and well-being, caregivers are less likely to engage in regular physical activity, despite their increased risk of chronic health issues associated with stress (Flanagan et al., 2023). Overall, Flanagan et al. (2023), Mohammed et al. (2021), and Wawrziczny et al. (2019) report that caregivers have an increased risk of chronic health conditions, most likely due to the prolonged stress of the position.

#### **Nursing Interventions**

Recent literature supports that the greatest challenges facing family caregivers of dementia patients are feelings of being burdened by the care recipient's behavioral and psychological symptoms of dementia, caregiver grief related anticipating future losses and loss of relationships, feelings of isolation and impreperation in caregiving, and stress-related physical health issues. All of these challenges that caregivers must face support the idea that family caregivers make up a highly vulnerable population that requires the support of healthcare professionals. However, addressing these challenges is complicated due to the lack of access to regular assistance with caregiving that many family caregivers report (Wawrziczny et al., 2019).

However, nurses have access to caregivers in primary and acute care centers, as well as in community roles, meaning that nurses are in a prime position to provide important interventions and connections to resources to help address these challenges (Yuqin & Chen, 2019; Yuqin et al., 2019; Prunty & Foli, 2019; Mohammed et al., 2021; Flanagan et al., 2022). This review of the recent literature supports the idea that nurse-led interventions are effective in assisting caregivers, and nurses are in an important position to connect caregivers with resources to provide further assistance to them. Because of this, nurses should be aware of interventions including screening caregivers for the effects of caregiver burden and stress, teaching caregivers mindfulness-based interventions, encouraging mutuality between the caregiver and care-recipient, using interventions based on cognitive-behavioral therapy, and connecting caregivers with psychoeducation and other multi-professional resources.

# **Screening Tools**

There are many risks associated with caregiving, as discussed previously. Assessing which caregivers need intervention and assistance with caregiving for a family member should therefore become a regular part of health screenings for caregivers in primary and acute care

settings. Nurses have access to caregivers when they visit care centers for their own preventative care, acute care, or when bringing their care recipients to receive healthcare. Because both current and previous caregivers are at risk of increased chronic health conditions and mental health issues such as extreme anxiety and stress, they should receive regular screening (Corey & McCurry, 2018; Meichsner & Wilz, 2018).

Nurses should be aware of these risks when conversing with these individuals, as grief, burden, anxiety and increased stress as reported by the caregiver are an indication of the need for intervention. In addition, a formalized and evidence-based screening tool such as the Marwit-Meuser Caregiver Grief Inventory (MM-CGI), which is a scale used to assess the experience of family caregivers providing care for individuals with dementia, can be used to assess for increased risk (Chan et al., 2020; Liew et al., 2019; Rigby et al., 2019). Chan et al. (2020) and Rigby et al. (2019) have shown that higher scores on the MM-CGI indicate more intense feelings of caregiver grief and therefore also indicates a need for assistance and intervention. Because of the high risk, nurses should be aware of screening tools like the MM-CGI and incorporate them into practice to assess caregiver grief.

#### Mindfulness-based Interventions

Once Mindfulness teaching is an evidenced-based practice shown to decrease depressive symptoms, anxiety, and stress, as well as increase the quality of life (Han, 2021). The practice of mindfulness, which is defined by Han (2021, p. 494) as the "moment-to-moment awareness of one's personal experience in a non-judgmental and accepting way" is a practice of being aware of one's thoughts, then practicing the act of recognizing and releasing of unhelpful thoughts to reduce stress and anxiety. Regularly practicing mindfulness and disengaging from automatic dysfunctional thoughts has been shown to have moderate to significant effects on reducing

depressive symptoms as well as anxiety (Lee et al., 2019; Han, 2021). Specifically for caregivers, mindfulness looks like "acknowledging and accepting unwanted thoughts and emotions that arise in caregiving situations as they are," and this practice has been shown to help family caregivers of persons with dementia to manage their difficult emotions and improve their day-to-day quality of life (Han, 2021).

Nurses can teach the importance of being aware of and recognizing unhelpful automatic thoughts to caregivers (Han, 2021). Even in the short amount of time a nurse may have with caregivers on a daily basis, conversation can be had in which the nurse can encourage the caregiver to be honest and mindful of their internal thoughts and struggles. Han (2021) proposes that mindfulness can be encouraged in caregivers by maintaining an open, honest and direct manner. Enouraging mindfulnesss in this way can allow the caregiver to challenge their own maladaptive thoughts and behaviors. Providing emotional support to caregivers by having open conversations, facilitating sharing of honest challenges and thoughts, and encouraging mindfulness during patient contact will also allow the caregiver to express their personal feelings, decreasing feelings of social isolation and being alone in the caregiving experience (Lee et al., 2019).

Another method to connect with caregivers and assess them for risk factors associated with caregiving is a practice called "psychological first aid" which nurses can implement in their care of caregivers (Mohammed et al., 2021). Psychological first aid is a method for assessing caregivers for worries and difficulty meeting their personal basic needs (rest, sleep, exercise, and healthy diet), as well as listening without pressure, connecting them to helpful resources and services, encouraging positive distractions as needed, and helping to maintain a normal schedule. Because nurses often represent the first line of connection with caregivers, nurses must recognize

the importance of providing psychological assistance to them as well as physical assistance. This involves encouraging conversation and being "active listeners to the caregivers, carefully [assessing] their needs and concerns, and then [tailoring] the nursing interventions... according to those needs" (Mohammed et al., 2021, p. 12). The practice of active listening to caregivers to increase their mindfulness has been shown to establish feelings of security, self-efficacy, belongingness, hope, and comfort in caregivers, decrease stress and anxiety, and promote long-term well-being.

# Mutuality

Another support that nurses can provide to caregivers as identified in the literature is encouraging mutuality between the caregiver and their care recipient (Yuqin et al., 2019). Caregivers who have a positive relationship with their care-recipient and view that relationship as one that requires effort and maintenance, despite the many challenges of dementia, are associated with having less caregiver burden, less reports of disruptive depressive symptoms, and better overall well-being. Mutuality, which is a positive quality within any kind of relationship, involves mutual affection, reciprocity of communication, sharing of activities that are mutually enjoyed, and sharing of values with the other individual, all of which are important to a successful relationship.

Mutuality allows caregivers to focus on the aspects of caregiving that they enjoy, such as being able to spend significant amounts of time with their loved ones. Mutuality can lower the stress and burden associated with the strain of caregiving. Nurses can encourage caregivers to focus on mutuality with their care recipient by purposely engaging in activities that they both enjoy, sharing memories, and showing genuine affection to their care recipient (Yuqin et al., 2019). Another strategy that the nurse can encourage to increase mutuality is for the caregiver to

allow the care recipient to do as much self-care as they possibly can, as this is shown to improve the relationship quality between the dyad, especially between spouses (Wawrzicny et al., 2019). Nurses should also encourage mutual communication between the dyad, especially regarding early conversations about what the care recipient desires to happen when death is nearing or occurring, as this has been shown to decrease anxiety and stress about the future and increase feelings of preparedness in the caregiver.

# Cognitive-behavioral Interventions

As with mindfulness, cognitive-behavioral interventions can be taught to caregivers, in small scale, by the nurse at the bedside or in a care setting when trained psychologist interventionists are not available or not easily accessible (Yuqin et al., 2019). Many times, caregivers interact with nurses more than any other healthcare professional. Yuqin et al. (2019) found that nurse-led cognitive behavioral interventions can be effective in supporting caregivers of dementia patients in the absence of trained professional therapy, so nurses should be aware of cognitive-behavioral techniques and strategies that can be provided to caregivers. Although cognitive-behavioral intervention is not typically thought of as falling within the traditional role of a bedside nurse, mental health nursing services such as cognitive-behavioral intervention training are an "important source of support for family caregivers of persons with dementia" (Yuqin & Chen, 2019, p.7).

Cognitive-behavioral interventions for caregivers involve assisting the caregiver to assess their own thoughts and behaviors for maladaptive patterns and coping strategies, and assisting them to change those patterns and strategies into helpful ones (Meichsner & Wilz, 2018; Yuqin et al., 2019; Yuqin & Chen, 2019). These interventions aim to assist caregivers to verbalize and understand the changes in their life that come with caregiving, then verbalizing and accepting the

emotions that come along with those changes (Meichsner & Wilz, 2018). Some of the changes that caregivers struggle to accept, as discussed above, are the changes in the personality and behavior of their care recipient, as well as the shift in their relationship from what it was before the disease to what it has become after the disease. Caregivers also tend to feel unprepared for caregiving and experience anxiety regarding the future. Cognitive behavioral interventions help the caregiver to identify stressors, resources, and coping strategies to increase their understanding of themselves and decrease stress, anxiety, and depression (Yuqin et al., 2019).

Stressors, as identified by the cognitive-behavioral method, arise when the caregiver perceives that the demands on them do not meet their available physical, cognitive, financial, and emotional resources (Yuqin et al., 2019; Meichsner & Wilz, 2018). Coping (or coping strategies) refer to the cognitive strategies (the way a caregiver thinks) and behaviors that work to meet those demands and manage the demands when they tax or exceed the caregiver's available resources. Research supports that caregivers can be taught strategies by a nurse that can help them to cope with the painful emotions of caregiving (Yuqin & Chen, 2019). One strategy is to encourage caregivers to identify and verbalize the positive aspects/rewards of caregiving, such as the chance to have a close relationship with the care recipient and the "nobility" of the role (Yuqin & Chen, 2019). This can increase positive emotions and decrease depressive symptoms.

Other strategies can be taught to assist caregivers through coping, such as "adaptive coping strategies" (Yuqin & Chen, 2019; Liew et al., 2019). These strategies, which include exploring new ways to maintain a positive relationship with the care recipient and involving other family members in the complicated grieving process by positively sharing emotions, are focused on teaching the caregiver to face and deal with complicated emotions rather than seeking to escape from them. The literature emphasizes the importance of teaching the caregiver to

maintain a positive outlook on the future, employ problem-solving strategies (which involve defining the problem immediately, then exploring, proposing, and implementing solutions in the moment), and to seek help from appropriate sources often (Yquin et al., 2019; Yquin & Chen, 2019). It was also found that discouraging passive coping, which involves denial and avoidance strategies, can be as effective as teaching active coping. Yquin and Chen (2019) found that passive coping such as denial was reduced when caregivers were able to verbalize acceptance that dementia is not curable and will likely involve disease progression. Passive coping was also found in caregivers with higher scores of depression and burden, and increasing active coping skills strongly predicted a decline in depressive symptoms.

Cognitive reframing with involved physical activity is another cognitive-behavioral based intervention strategy mentioned by Flanagan et al. (2022). They emphasize the importance of daily physical activity, as well as regular contact with individuals such as health education nurses that can help caregivers to refocus and reframe frustrating situations related to caregiving as helpful and good (even if the situation did not resolve as they had intended). According to Flanagan et al. (2022, p. 474), "[contact with professional nurses] can address some [major caregiving] issues through cognitive reframing and motivational interviewing." Caregivers in this study found that real-time tips and being able to reflect on daily frustrating situations with the help of a nurse helped to manage the issues of caregiving.

Finally, behavioral activation is a cognitive behavioral intervention strategy that can be taught to caregivers by nurses (Lee et al., 2019). This strategy involves "identifying and modifying maladaptive thoughts, developing a new behavioral pattern, and increasing pleasant leisure activities" (Lee et al., 2019, p. 2371). Nurses can teach caregivers to identify leisure activities that they enjoy apart from the experience of caregiving, schedule them regularly, and

then identify and decrease avoidance behaviors and unhelpful activities. All of this has been shown to reduce depressive symptoms, and the process requires minimal time and effort for the nurse to convey to the caregiver. Overall, cognitive behavioral interventions largely result in a positive change in caregiver behavior, a verbalization of greater acceptance of the care recipient's dementia, and a reduction in symptoms of caregiver grief (Lee et al., 2019; Meichsner & Wilz, 2018; Flanagan et al., 2022; Yuqin & Chen, 2019).

# Multi-Professional Interventions and Resources

In addition to performing and facilitating interventions to support caregivers, the role of the nurse may involve connecting caregivers with appropriate outside resources such as respite centers, professional counseling services, and psychoeducation (Rigby et al., 2019; Chan et al., 2020, Isik et al., 2019). Family counseling can be very useful to caregivers to reduce stress and increase mutuality between members of the caregiving family. According to Fauth et al. (2019) and the New York University Caregiver Intervention program, as few as four professional family counseling sessions conducted with caregivers and their immediate families resulted in decreased family conflict and burden and increased quality of life. Counseling also assisted the caregiver to incorporate their family as a support network.

Psychoeducation was found by Isik et al. (2019) and Rigby et al. (2019) to reduce caregiver distress and decrease the incidence of neuropsychiatric and behavioral symptoms of dementia. Psychoeducation for caregivers of dementia patients prioritizes health literacy, symptoms and typical progression of dementia, preparing for and accepting the inevitability of the death of their care recipient, and awareness of available resources for caregivers (Kabir et al., 2020; Rigby et al., 2019; Cheng et al., 2020). This can even be implemented digitally for ease of use (Kabir et al., 2020). By helping the caregiver to understand dementia as a disease and what to

expect as it progresses, focusing on increasing their preparedness and knowledge about the disease, caregiver feelings of unpreparedness and fear of the future have been shown to decrease (Cheng et al., 2020; Lee et al., 2019). Having a plan for the future also decreases anxiety and allows the caregiver to plan how to manage the responsibilities of caregiving before unhelpful habits arise in the high-stress environment of caregiving (Alvariza et al., 2020; Cheng et al., 2020).

#### **Discussion**

In conclusion, an integrated review of the most recent literature on interventions to support caregivers of dementia patients reflects a number of key ideas and interventions that can be incorporated into nursing practice. Although this review was limited to twenty of the most recently published articles, the included literature supports that caregivers struggle the most with managing the burden and responsibilities of caregiving, especially when the care recipient experiences the behavioral and psychological symptoms of dementia. They also tend to struggle with ambiguous and anticipatory grief, isolation and unpreparedness, and physical health problems. Nurses should be aware of evidence-based interventions for these major issues, including screening caregivers for the effects of caregiver burden and stress, teaching caregivers mindfulness-based interventions, encouraging mutuality between the caregiver and care-recipient, using and teaching interventions based on cognitive-behavioral techniques, and connecting caregivers with psychoeducation and other multi-professional resources.

# Implications for Future Research

Although there were a number of interventions mentioned in the literature that could be incorporated into nursing practice, this literature review revealed a significant gap in the literature. There is little evidence in recent literature of the impact or significance of

interventions that can be provided by nurses in the inpatient or long-term care setting aimed at directly supporting caregivers of dementia patients. This review, which outlined the potential significance of interventions that could be provided by nurses to the high-risk population of family caregivers in typical, frequented care settings, illustrated the need for nurses to be aware of the need for routine family caregiver assistance. However, there is little evidence of nurses providing these interventions in these settings or the impact this would have. In addition, there is little evidence of the impact of inpatient and acute care nurses implementing interventions to support caregivers of dementia patients when care recipients or caregivers are admitted to acute care centers.

To address these gaps in the literature, research could be conducted on acute care inpatient units within hospitals. The patient, not the caregiver, is the immediate focus of nurses caring for patients with dementia on inpatient medical units in hospital care settings. However, as caregivers tend to accompany PWD to hospital inpatient stays, research could be conducted utilizing admission questionarres that include screening questions for the primary caregives of PWD. The questions could refer to the major risk factors identified in the literature, as discussed above, and allow caregivers to speak to what they struggle with in the caregiving experience. The answers to these questionarres could assist nurses in identifying vulnerable careigvers of PWD.

As discussed above, much of the current evidence supports that nurses can significantly assist caregivers of dementia patients in outpatient or professional/organized therapeutic settings. However, many caregivers do not have access to professional counseling or do not know how to find the necessary assistance. Acute care nurses would have significant access to caregivers of dementia patients for the purpose of screening and assisting with the significant issues of

caregiving. Overall, this review illustrated that while many helpful interventions for family caregivers exist, there is limited research on how nurses in most settings can support this population, despite the population's high risk of physical, emotional, and spiritual illness. Further research, therefore, would be useful in this area.

#### References

- Alvariza, A., Hager-Tibell, L., Holm, M., Steineck, G., & Kreicbergs, U. (2020). Increasing preparedness for caregiving and death in family caregivers of patients with severe illness who are cared for at home- study protocol for a web-based intervention. *BMC Palliative Care*, 19(1), 1-8. <a href="https://doi.org/10.1186/s12904-020-0530-6">https://doi.org/10.1186/s12904-020-0530-6</a>
- Alzheimer's Association. (2022). 2022 Alzheimer's Disease Facts and Figures. https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf
- Chan, I., Yap, P., Liang-Wee, S., & Liew, T. M. (2020). The three dimensions of caregiver grief in dementia caregiving: Validity and utility of the subscales of the Marwit-Meuser Caregiver Grief Inventory. *Geriatric Psychiatry*, 35(2), 213-222. <a href="https://doiorg.ezproxy.liberty.edu/10.1002/gps.5238">https://doiorg.ezproxy.liberty.edu/10.1002/gps.5238</a>
- Cheng S. T., Li K. K., Losada A., Zhang F., Au A., Thompson L. W., Gallagher-Thompson D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis. *Psychology and Aging*, 35(1), 55-77. https://doi.org/10.1037/pag0000401
- Corey, K. L. & McCurry, M. K. (2018). When caregiving ends: The experiences of former family caregivers of people with dementia. *The Gerontologist*, 58(2), e87-96. https://doi.org/10.1093/geront/gnw205
- Dang, D., Dearholt, S., Bissett, K., Ascenzi, J., & Whalen, M. (2022). *Johns Hopkins evidence-based practice for nurses and healthcare professionals: Model and guidelines* (4th ed). Sigma Theta Tau International.
- Fauth, E. B., Jackson M. A., Walberg, D. K., Lee, N. E., Easom, L. R., Alston, G., Ramos, A., Felten, K., LaRue, A., & Mittelman, M. (2019). External validity of the New York

- University Caregiver Intervention: Key caregiver outcomes across multiple demonstration projects. *Journal of Applied Gerontology*, *38*(9), 1254-1281. https://doi.org/10.1177/0733464817714564
- Flanagan, J., Post, K., Hill, R., & DiPalazzo, J. (2022). Feasibility of a nurse coached walking intervention for informal dementia caregivers. *Western Journal of Nursing Research*, 44(5), 466-476. doi:10.1177/01939459211001395
- Han, A. (2021). Effects of mindfulness-based interventions on depressive symptoms, anxiety, stress, and quality of life in family caregivers of persons living with dementia: A systematic review and meta-analysis. *Research on Aging*, 44 (7), 494-509. https://doi.org/10.1177/01640275211043486
- Isik, A. T., Soysal, P., Solmi, M, & Veronese, N. (2019). Bidirectional relationship between caregiver burden and neuropsychiatric symptoms in patients with Alzheimer's disease: A narrative review. *International Journal of Geriatric Psychiatry*, *34*(9), 1326-1334. https://doi.org/10.1002/gps.4965
- Joling, K. J., O'Dwyer, S. Hertogh, C. M., & van Hout, H. P. J. (2017). The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. *International Journal of Geriatric Psychiatry*, 33(2), 263-270. https://doi.org/10.1002/gps.4708
- Kabir, Z. N., Leung, A. Y. M., Grundberg, A., Bostrom, A., Lamas, K., Kallstrom, A. P., Moberg, C., Cronfalk, B. S., Meijer, S., & Konradsen, H. (2020). Care of family caregivers of persons with dementia (CaFCa) through a tailor-made mobile app: Study protocol of a complex intervention study. *BMC Geriatrics*, 20, 305.
  https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01712-7

- Lee, M., Ryoo, J. H., Chung, M., Anderson, J. G., Rose, K., & Williams, I. C. (2019). Effective interventions for depressive symptoms among caregivers of people with dementia: A systematic review and meta-analysis. *Dementia*, 19(7), 2368-2398.

  https://doi.org/10.1177/1471301218822640
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gotzsche, P. C., Loannidis, P. A., Clarke, M., Devereaux, P. J., Kleiknen, J., & Moher, D. (2009). The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. *BMJ*, b2700, 339.
  <a href="https://doi.org/10.1136/bmj.b2700">https://doi.org/10.1136/bmj.b2700</a>
- Liew, T.M., Tai, B. C., Yap, P., & Koh, G. C. (2019). Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis. *International Journal of Geriatric Psychiatry*, *34*(2), 258–264. <a href="https://doiorg.ezproxy.liberty.edu/10.1002/gps.5014">https://doiorg.ezproxy.liberty.edu/10.1002/gps.5014</a>
- Lin, P., Lin, H., Yang, Y. H., & Yang, Y. (2022). The effects of caregiver characteristics on behavioral and psychological symptoms of dementia of patients with dementia. *Aging and Mental Health*, 26(2), 263-269. <a href="https://doi.org/10.1080/13607863.2020.1857693">https://doi.org/10.1080/13607863.2020.1857693</a>
- Meichsner F. & Wilz G. (2018). Dementia caregivers' coping with pre-death grief: effects of a CBT-based intervention. *Aging and Mental Health*, 22(2), 218-225. http://dx.doi.org/10.1080/13607863.2016.1247428
- Mohammed Shoukr, E. M., El-Rahman Mohamed, A. A., El-Ashry, A. M., & Mohsen, H.

  A. (2021). Effect of psychological first aid program on stress level and psychological

- well-being among caregivers of older adults with Alzheimer's disease. *BMC Nursing*, 21. https://doi.org/10.1186/s12912-022-01049-z
- Prunty, M. M. & Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A concept analysis. *International Journal of Older People Nursing*, *14*(2), e12227. https://doi.org/10.1111/opn.12227
- Rigby, T., Ashwill, R.T., Johnson, D. K., & Galvin, J. E. (2019). Differences in the experience of caregiving between spouse and adult child caregivers in Dementia with Lewy Bodies.

  \*Innovation in Aging, 3(3). https://doi.org/10.1093/geroni/igz027
- Tampi, R. R., & Tampi, D. J. (2020). Managing behavioral and psychological symptoms of dementia. *Psychiatric Times*, *37*(3). <a href="https://www.psychiatrictimes.com/view/managing-behavioral-and-psychological-symptoms-dementia?utm\_source=sfmc&utm\_medium=email&utm\_campaign=12082022\_PT\_KAI-22-PSD0438\_Pemanente\_eNL&eKey=dHJhc2JlcnJ5QGxpYmVydHkuZWR1">https://www.psychiatrictimes.com/view/managing-behavioral-and-psychological-symptoms-dementia?utm\_source=sfmc&utm\_medium=email&utm\_campaign=12082022\_PT\_KAI-22-PSD0438\_Pemanente\_eNL&eKey=dHJhc2JlcnJ5QGxpYmVydHkuZWR1</a>
- Wawrziczny, E., Larochette, C., Papo, D., Constant, E., Ducharme, F., Kergoat, M., Pasquier, F., & Antoine, P. (2019). A customized intervention for dementia caregivers: A quasi-experimental design. *Journal of Aging and Health*, 31(7), 1172-1195.
  https://doi.org/10.1177/0898264318770056
- Yuqin, P. & Chen, R. (2019). The effect of a nurse-led cognitive behavioral protocol on depressive symptoms and coping strategies of dementia caregivers. *Journal of Nursing Research*, 27(6), e55. doi: 10.1097/jnr.0000000000000327
- Yuqin, P., Chen, R., & Yang, D. (2019). The role of mutuality and coping in a nurse-led cognitive behavioral intervention on depressive symptoms among dementia caregivers.

Research in Gerontological Nursing, 12(1), 44-55. <a href="https://doi.org/10.3928/19404921-20181212-01">https://doi.org/10.3928/19404921-20181212-01</a>

# Appendix I

36/23, 1:41 PM

Johns Hopkins EEP Model and Tools- Permission | LIHN Learning System

# JOHNS HOPKINS EBP MODEL AND TOOLS-PERMISSION





Thank you for your submission.

We are happy to give you permission to use the Johns Hopkins Evidence-Based Practice model and tools to adhere to our legal terms noted below.

No further permission for use is necessary.

You may not modify the model or the tools without written approval from Johns Hopkins.

All references to source forms should include "© 2022 Johns Hopkins Health System/Johns Hopkins School of Nursing." The tools may not be used for commercial purposes without special permission.

If interested in commercial use or discussing changes to the tool, please email ijhn@jhmi.edu.

Downloads:

2022 JHEBP Tools- Printable Version

2022 JHEBP Tools- Electronic Version

# Appendix II

**Table 1**Comparative Matrix of Reviewed Literature

Author/	Topic/focus and	Theoretical	Level of	Setting		Identified	Identified Nursing
Year	Question	Model with Design	Eviden ce	Sample	Findings	Caregiver Challenge	Intervention
Tampi, R. R., Tampi, D. J. (2020)	Managing Behavioral/Psychi atric Symptoms of Dementia	Clinical guideline based on a meta- analysis	4	Opinion of experts based on a scientific meta-analysis	Behavior and psychological symptoms of dementia (BSPD) are a distressing and non-cognitive symptoms, and are best treated with a combination of caregiver training, pharmacologic, and non-pharmacological interventions	Behavior and psychological symptoms of dementia (psychosis, hallucinations, delirium, anxiety, depression, agitation, etc.)	Careful assessment for BSPD involving interviewing caregiver Training caregivers for how to manage BSPD
Chan, I.,	Evaluate the	Quantitative	1	Multiethnic	The	Personal	Recommend day
Yap, P.,	Marwit-Meuser	Cronbach α;		Asian	characteristics of	Sacrifice/feeli	care centers,
Liang-	Caregiver Grief	test-retest		population	the following	ng of loss of	caregiver training
Wee, S.,	Inventory (MM-	reliability using		of	have internal	individual	programs, and
& Liew,	CGI) validity of	intraclass			consistency	freedom	helper training

T. M. (2020)	four different dimensions/ variables/ challenges of caregiver loss	correlation coefficient		caregivers (n= 394)	among a population of caregivers Personal sacrifice and burden Heartfelt sadness, longing, and worry Felt isolation In Mild dementia- Felt isolation is most common Moderate- Personal sacrifice was greatest Severe- HSLW was greatest (especially in spouse caregivers)	Heartfelt sadness, longing, and worry Felt Isolation/lack of outside assistance/feel ing of being alone	programs for personal sacrifice/burden Professional grief counseling for sadness, longing and worry Caregiver support groups for felt isolation
Meichsner F. & Wilz G. (2018).	Determine if a cognitive-behavioral intervention (therapy) could increase caregiver's ability	Qualitative Latent change models	2	IN-HOME caregivers of dementia patients (n= 273)	The intervention received 12 50-minute therapy sessions with clinical psychologists trained in CBT	Pre-death grief, which can appear to be stress but is a syndrome with physical and	Recommend to the caregiver CBT-grief symptoms have improved with cognitive-behavioral therapeutic

	to cope with pre- death grief				From the baseline to the 6 mo follow-up period after the study was done, grief scores according to the <i>Caregiver grief scale</i> were lower CBT helps caregivers to cope with the grief of caregiving Change of situation	psychological effects	intervention with trained professional
Liew, T.M., Tai, B. C., Yap, P., & Koh, G. C. (2019).	Compilation of the differences of risk factors for the identified challenges of caregiving in dementia patients: pre-death grief and caregiver burden	Multivariate linear regression (to identify factors and relationships)	3	Spouse or child caregivers of dementia patients who are patients at one of two tertiary hospitals in Singapore (n=394)	decreased coping ability Pre-death grief symptoms were associated with (age of PWD- younger=more grief, educational attainment (secondary of lower had higher association) and relationship with PWD). Both were associated	Pre-death (anticipatory) grief Caregiver Burden	Identifying caregiver burden as a risk factor for predeath grief Recommend interventions based on if caregiver burden is primary of if grief is primary

					with (advanced	
					stage of	
					dementia,	
					presence of	
					behavioral	
					problems in	
					PWD, and the	
					status as a	
					primary	
					caregiver) and	
					primary	
					caregiver status	
					had the highest	
					association with	
					caregiver	
					burden.	
Corey, K.	What are the	Qualitative	3	Convenien	Three themes	Sleep
L. &	experiences of	interview-		ce	emerged	disturbance
McCurry,	caregivers after	driven		sampling of	regarding the	during and
M. K.	their loved one	descriptive		8 former	experience	after
(2018).	passes away?	design with		family	Sleep	caregiving
,	How is their	qualitative		caregivers	disturbances	Depressive
	physical health?	content		(n=8) in	Sleep quality	symptoms
	1 7	analysis		Massachus	was poor during	while
		J		etts	caregiving, and	caregiving
					some did not	related to
					return up to 10	high, constant
					years after	stress and
					Health status	isolation
					Ongoing	Cardiovascula
					depressive	r issues and
					symptoms that	anxiety

					began while caregiving Leading to cardiac issues and other chronic conditions Other Lack of desire to do "normal activities" — depression? Helped when caregiving desires were focused on another- children, grandchildren, other individuals	present during and after caregiving related to prolonged stress	
Joling, K. J., O'Dwyer, S. Hertogh, C. M., & van Hout, H. P. J. (2017)	Explore the occurrence and persistence of suicidal thoughts among caregivers of dementia patients	Statistical analysis of the incidence of occurrence using Fisher's exact test then Bonferroni post-hoc analysis	3	Primary family caregivers of a relative with a clinical dementia diagnosis in	76 of 192 caregivers (39.6% reported symptoms of major depression 9/192, or 4.7% of total sample, reported potential major depression.	Major depression and caregiver grief appear to have similar symptoms, and this includes a risk of suicidal ideation	Nurses need to be aware of the risk of suicidal ideation that may be present alongside caregiver grief

Amsterdam	Most cases
(n=192)	occurred in the
-mostly	second follow-
female	up year
-mostly	4/9 eventually
spouses	admitted their
-	family member
	to a long-term
	care facility,
	although the
	study began
	when they were
	cared for at
	home
	Suicidal
	thoughts
	persisted for 3 of
	them, one
	developed them
	after admitting
	them to long-
	term care
	1 in 8 reported
	any kind of
	suicidal thoughts
	over 2 years,
	and 1/3 of that
	population
	experienced
	them multiple times over the
	course of 2 years

Rigby, T., Ashwill, R.T., Johnson, D. K., & Galvin, J. E. (2019	What are the differences in the experience of dementia caregivers who are spousal or children? What are their experiences?	Cross-sectional analytic study	3	Children n=160  Spouses n=255 Primary caregivers caring at home	Children more likely to care for mothers than fathers Children tend to spend less time with care recipient, but have greater social support Spouses have greater grief with advanced disease	Grief, burden, and decreased well being are all associated with caregiving for dementia More advanced age led to increased quality of life Neuropsychia tric symptoms led to a higher incidence of grief and burden, but this was the same for spouses and children, called "most distressing symptom"	Screening caregivers for burden, grief, and depression is suggested to identify those that may benefit the most from psychoeducation Psychoeducation Providing resources for social support for spouses Providing interventions aimed at improving quality of life and managing burden is important
Lin, P., Lin, H., Yang, Y. H., &	Is there an association between the characteristics of the caregiver and	Cross-sectional analytic study about the relationship	2	190 dyads of dementia patients and their	Delusions were more likely to occur with spousal caregivers, as is	Behavioral and psychological symptoms of dementia are	Because caregiver role may have an impact on symptoms, nurses should be aware

Yang, Y. (2022)	the presence of behavioral and psychological symptoms of dementia?	between two variables	informal caregivers	increased anxiety and eating difficulties Children caregivers were related to increased disinhibition but decreased anxiety. Caregiver education was positively correlated to severity of hallucinations, agitation/aggress ion, and apathy/indiffere nce, and distress of agitation/aggress ion. Child primary caregiver was positively related to severity and distress of	extremely distressing-specifically  Delusions, agitation, repetitive speech, anxiety, disturbances in sleep and appetite are symptoms of behavioral and psychological symptoms of dementia (BPSD)	that different groups have different risk factors
				•		

					related to severity of anxiety. Spouse primary caregiver was positively related to severity and distress of anxiety and appetite/eating, and distress of nighttime behaviors		
Kabir, Z. N., Leung, A. Y. M., Grundberg , A., Bostrom, A., Lamas, K., Kallstrom, A. P., Moberg, C., Cronfalk, B. S., Meijer, S.,	How effective is telehealth technology through a custommade mobile phone app at providing social and health support to caregivers of dementia patients?	Pragmatic intervention design, using pre- post-interviews to assess effectiveness of intervention	3	78 family caregivers connecting with 5 health care professionals in Sweden		Isolation in the beginning stages of dementia is primary concern and reason for intervention	Telehealth and mobile apps can be used to increase social support for caregivers, and provide information, brainstorm interventions, and allow for connection with a specialized health care professional at least weekly

, H. (2020)							
Fauth, E. B., Jackson M. A., Walberg, D. K., Lee, N. E., Easom, L. R., Alston, G., Ramos, A., Felten, K., LaRue, A., & Mittelman , M. (2019).	How effective is the counseling/suppor t intervention put forth by the New York University?	External validity testing using baseline and follow-up visit interviews	3	294 caregivers' information collected by interviews: baseline and follow- up visits at 4,8,12 mo	Caregiver burden Family conflict Depressive symptoms	Family conflict/isolati on Burden	Family counseling by a trained counselor/interventi onist to assist with family communication and building a family support network
Isik, A. T., Soysal, P., Solmi, M, & Veronese, N. (2019)	How do neuropsychiatric symptoms of dementia affect caregiver stress, and how does caregiver stress affect the symptoms?	Literature Review	5	Articles published on PubMed and Google scholar about caregiver stress and symptoms of dementia	Neuropsychiatri c symptoms and high expressed emotion/burden of the caregiver do have a bidirectional relationship that should be considered in care	Burden/Stress Neuropsychia tric symptoms of dementia	Reducing neuropsychiatric symptoms both pharmacologically and nonpharmacological ly Reducing caregivers stress with education and mindfulness

Han, A. (2021)	How do mindfulness- based interventions affect anxiety, stress, and quality of life?	Literature Review/System atic Analysis	5	Recent articles published regarding mindfulnes s-based interventio ns	Small to large effects of mindfulness- based interventions were present	Depression, Anxiety, Stress, Low/decrease d quality of life for the caregiver	Mindfulness-based techniques- should nurses be able to recommend these or assist with them in the hospital setting?
Yuqin, P. Chen, R., & Yang, D. (2019)	How does cognitive-behavioral therapy led by nurses impact caregiver depressive symptoms and burden?	Randomized- controlled trial of qualitative variables	2	n=98 primary caregivers providing care to a dementia patient and had baseline depressive symptoms	Cognitive behavioral therapy as led by nurses was effective in reducing depressive symptoms over time Active coping was a strong predictor of depressive symptoms Mutuality was a weaker predictor of mutuality	Depressive symptoms Lack of mutuality Passive coping	Cognitive behavioral techniques as led by nurses
Wawrzicz ny, E., Larochette , C., Papo, D., Constant, E.,	How does a customized intervention of distress affect their levels of distress?	Quazi- experimental design	3	Nn=51 spouse caregivers in control group, 51 in	The analyses indicated a stabilizing effect of the intervention on caregivers' perceptions of		Encourage daily routine and seeking of personal values Encourage spouses to be aware of their family member's abilities

Ducharme, F., Kergoat, M., Pasquier, F., & Antoine, P. (2019).				experiment al group	PWD's daily functioning, self-esteem related to caregiving, quality of family support, and feeling of distress.		Be aware of community resources at their disposal
Alvariza, A., Hager- Tibell, L., Holm, M., Steineck, G., & Kreicberg s, U. (2020).	How does a web- based intervention increase caregiver preparedness for caregiving?	Quazi- experimental design	3	n= 200 caregiver/c are recipient dyads	Web-based interventions most likely "increase preparedness for caregiving and death in family caregivers of patients affected by severe illness and to decrease the risks of negative health consequences"	Feeling unprepared	Increasing preparedness via online resources
Lee, M., Ryoo, J. H., Chung, M., Anderson, J. G., Rose, K.,	What interventions are effective treatments for caregiver depressive symptoms?	Systematic analysis of qualitative and quantitative control trials	1	n=31 randomized controlled trials	Cognitive- behavioral therapy showed moderate significant effects, and psychoeducation showed small effects		Cognitive behavioral therapy interventions are most effective Small effects on psychoeducation

Williams, I. C. (2019).							
Yuqin, P. & Chen, R. (2019).	How effective are nurse-led mental health programs for family caregivers of persons with dementia?	Randomized controlled trial study	1	n= 82 caregiver participants , 47 in interventio n and 35 in control	Nurse-led cognitive behavioral interventions are effective in decreasing depressive symptoms and improving active coping skills		Nurse-led cognitive behavioral therapy is effective in reducing depressive symptoms
Prunty, M. M. & Foli, K. J. (2019).	How do caregivers of dementia patients experience guilt related to caregiving? What are the dimensions of this grief?	Literature review of qualitative articles related to caregiver grief	5	n= 26 articles used to define caregiver guilt	The expectation of a moral responsibility to care for the individual with dementia; (b) a negative, subjective appraisal of one's own caregiving performance, including neglecting other roles and responsibilities and self-neglect; and (c) a sense of transgression	Caregiver guilt is a significant issue for caregivers	

Flanagan, J., Post, K., Hill,	How effective is a nurse-coached walking	Randomized controlled trial study using	2	n= 32 family caregivers	or violation of a moral standard as a caregiver to the individual with dementia  There was a moderate improvement on	Stress, emotional distress, and	Walking/regular daily exercise Nurse-coaching
DiPalazzo, J. (2022).	reducing family caregiver stress and chronic illness?	sampling			group when compared to the control group on well-being increase and a large effect on stress reduction Having a nurse- coach allowed the caregivers to refocus and reframe their activity as helpful and good, even when it did not go as planned	personal health Chronic health conditions such as immune issues and chronic pain	
					It also allowed real-time tips to manage frustrating dementia		
					behaviors.		

				100	Caregivers reported that it was helpful to undergo intervention in a group setting if they were with other people caregiving for dementia patients, but not those who "did not understand"		
Mohamme d Shoukr, E. M., El- Rahman Mohamed, A. A., El- Ashry, A. M., & Mohsen, H. A. (2021).	How effective is the concept of "psychological first aid" on caregiver stress, burden and self- esteem?	Pre-test/post-test design following a single group of caregivers	3	n= 100 family primary caregivers	indings support the study hypotheses, as the caregivers of older adults with AD experienced a decrement in stress levels and an improvement in their knowledge and psychological well-being after the application of the PFA program. This can be explained by the fact that	Burden Stress Time- commitment Self-esteem	"Psychological first aid"- as completed by a nurse who has contact with the caregiver during times of increased stress

the researchers acted as active listeners to the caregivers, carefully assessed their needs and concerns, and then tailored the nursing interventions and sessions according to those needs. PFA aided in establishing feelings of security, comfort, selfsocial efficacy, belongingness, and hopefulness"