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Occupational Therapy’s Ability to Address Perceived Stress Levels in Caregivers of Individuals with Dementia

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Kjerstin Drugan, Molly Van Drehle, & Jadalyn Wagner, 2022

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Focused Question

How does addressing the perceived levels of emotional and mental stress experienced by formal and informal caregivers caring for individuals with dementia improve the caregivers' ability to provide care and participate in their own personal occupations?

Case Scenario

Importance of Caregiving

The occupation of caregiving can occur in formal or informal positions. Caregiving is increasing in importance as the U.S. population ages (Sheehan et al., 2021). Most individuals with dementia require assistance from either formal or informal caregivers. Through the experience of providing care to individuals with dementia, both formal and informal caregivers reported higher levels of mental or emotional strain (Sheehan et al., 2021). Informal caregivers are more likely to describe the occurrence of occupational imbalance and deprivation due to the demands of caring for an individual with dementia (Yong et al., 2020). Occupational imbalance occurs when individuals have a misalignment between occupation and their values (Yong et al., 2020). In contrast, occupational deprivation results from an inability to participate in meaningful occupations due to outside factors outside of their control (Yong et al., 2020). Caregiver burden, which is stress experienced by caregivers caused by caring for another person, occurs in high amounts and continues to rise in formal and informal caregivers (Connors et al., 2020).

Paid formal caregivers can experience increased emotional stress due to varying complex dynamics within families and perceived differences in the worker's role (Franzosa et al., 2019; Hale et al., 2021). Other challenges formal caregivers face are an inability to build a connection with their clients and a lack of respect received by superiors (Franzosa et al., 2019; Hale et al., 2021). These conditions can lead to high burnout and turnover rates within this professional field. Providing support for formal and informal caregivers and addressing their needs can improve caregivers' overall well-being (Raj et al., 2020; Yong, 2020). The U.S. Bureau of Labor Statistics (2021) projected the growth of formal caregivers at 33%, indicating this field will grow much faster than average from 2020 to 2030. Caring for individuals with dementia is a specific occupation that impacts the lives of those engaging in it. It presents unique challenges and has been recognized as overwhelming for caregivers due to the lack of understanding, stigma, and barriers to diagnosis and care (World Health Organization, 2018).

Defining the Population

The U.S. Department of Health And Human Services (2016) defined informal caregivers as "unpaid individuals (spouses, partners, family members, friends, or neighbors) involved in assisting others with activities of daily living or medical tasks" (para. 1). Informal caregivers were commonly spouses or family members of individuals with dementia (Armstrong et al., 2019; Dalgarno et al., 2021; Lloyd et al., 2019; Osborne & Juengst, 2021; Yong et al., 2020). Most studies included participants who predominantly identified as white females so, generalizing to male caregivers should be done with caution (Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Sterling et al., 2021). Formal positions refer to individuals paid as home health care workers or home health aides providing medical, personal, and emotional support that is similar to informal caregivers, but these individuals have received training to provide care for older adults with conditions and disabilities (Sterling et al., 2021; U.S. Department of Health and Human Services, 2016). Formal caregivers were primarily women older than 30 years old and nonwhite individuals identifying as African American, Chinese, Hispanic, or Pacific Islander (Franzosa et al., 2019; Gleason & Miller, 2021; Sterling et al., 2021).



Caring for individuals with dementia is a specific occupation that impacts the lives of those engaging in it. Caregiving presents unique challenges and has been recognized as overwhelming for caregivers due to the lack of understanding, stigma, and barriers to diagnosis and care (World Health Organization, 2018). The literature identified included populations from Australia (Connors et al., 2020), Belgium (Raj et al., 2020), Canada (Raj et al., 2021), France (Raj et al., 2020), New Zealand (Hale et al., 2021), United Kingdom (Burgess et al., 2021; Cooper et al., 2010; Dalgarno et al., 2021; Raj et al., 2021), and the United States (Armstrong et al., 2019; Franzosa et al., 2019; Gleason & Miller, 2021; Lloyd et al., 2019; Osborne & Juengst, 2021; Raj et al., 2021; Roth et al., 2015; Sterling et al., 2021); provided a distribution of source data of different cultural backgrounds considered in the synthesis of data. Some authors evaluated caregivers in exclusively urban settings (Franzosa et al., 2019; Roth et al., 2015). Populations spanning urban, suburban, and rural areas were also identified (Burgess et al., 2021; Cooper et al., 2010; Gleason & Miller, 2021; Hale et al., 2021; Sterling et al., 2021) though where the caregiver provided care was not identified in most of the articles (Armstrong et al., 2019; Connors et al., 2020; Dalgarno et al., 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Raj et al., 2020; Raj et al., 2021; Sheehan et al., 2021; Yong et al., 2020).

Theoretical Lens

The Person-Environment-Occupation Model (PEO) was used when building the focus question. For this critically appraised topic, the transaction between the person, environment, and occupation within the PEO model was considered (Baptiste, 2017). PEO can help determine the interactions between domains to select the right environment for a person to perform an occupation, known as the goodness of fit (Baptiste, 2017). Upon researching the person (caregiver), the environment (at home or in a facility), and the occupation (caring for someone with dementia), Dooley and Hinojosa (2004) stated that "individualized occupational therapy intervention based on the person-environment fit model appears effective for both caregivers and client" (p. 561). Due to the high level of psychosocial stress that caregivers experience, occupational therapy interventions like education and environmental adaptation help decrease caregiver burden and increase individuals with dementias' well-being (Dooley & Hinojosa, 2004). The PEO model can help determine a good fit for caregivers' quality of life by assessing the environment's impact on the person completing their occupation (Dooley & Hinojosa, 2004). A good fit occurs when a person engages or participates in an occupation within an environment that enhances occupational performance (Baptiste, 2017).

Purpose Statement

Caregivers of individuals with dementia face unique challenges that affect their ability to participate in their occupations and maintain low-stress levels (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Sterling et al., 2021; Yong et al., 2020). Evidence has supported the benefits of occupational therapy intervention for caregiver well-being (Burgess et al., 2021; Lloyd et al., 2019; Raj et al., 2021; Sztramko et al., 2021; Yong et al., 2020). In this critically appraised paper, we examined the effects of occupational therapy interventions that focus on caregiver participation in personal occupations and stress levels among formal and informal caregivers to determine the implications of various occupational therapy interventions. These findings can guide occupational therapists while developing intervention plans for caregivers to lower stress levels and improve participation in the caregiver's meaningful occupations.

Methodology

An initial literature search was conducted from March 1, 2022 to March 9, 2022. Searches occurred on occupational therapy, education, and multidisciplinary databases, including the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, and the American Journal of Occupational Therapy (AJOT). When searching for sources, articles were excluded that were published prior to 2016. The following terms were used to search the databases: "occupational therapy," "caregiver," "dementia," "caregiver burden," and "environment." Terms "AND" or "OR" were added between keywords and phrases to increase the specificity of the search. Seven of the articles that were added were published before 2016. The studies were included because the evidence was relevant to the topic and provided additional information not found in the original search articles.

Types of Articles Reviewed

A total of 37 articles were reviewed, and 26 were selected for further review. Of the 26 articles reviewed in-depth, five were level I studies (Chiao et al., 2015; Medruga et al., 2020; Piersol et al., 2017; Raj et al., 2021; Sztramko et al., 2021), one was a level II study (Connors et al., 2020), three were level III studies (Dooley & Hinojosa, 2004; Osborne & Juengst, 2021; Sheehan et al., 2021), eight were level IV studies (Armstrong et al., 2019; Cooper et al., 2010; Gleason & Miller, 2021; Lloyd et al., 2019; Raj et al., 2020; Ranucci & Berry, 2021; Roth et al., 2015; Sterling et al., 2021), and five were level N.A. studies (Burgess et al., 2021; Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Yong et al., 2020). Other resources reviewed included two government sites (U.S. Department of Health and Human Services, 2016; U.S. Bureau of Labor Statistics, 2021; World Health Organization, 2018). A chapter in an occupational therapy textbook was also used (Baptiste, 2017).

Synthesis

Theoretical Base

The PEO model was used to guide the synthesis of findings relating to the unique challenges of formal and informal caregivers with dementia. Informal and formal caregivers' challenges were addressed in separate sections to prevent generalization between populations not based on the literature. The following sections contain the evidence about the caregivers of individuals with dementia, the environments related to the occupation of caregiving for people with dementia, and the occupational demands and effects of caregiving. Each section also contains suggestions for intervention strategies based on the research found.

Person

Informal Caregivers

Caregivers have reported positivity when caring for an individual with dementia (Roth et al., 2015). Evidence has shown that caregiving can also cause decreased well-being and increased feelings of stress, anxiety, and depression (Armstrong et al., 2019; Lloyd et al., 2019; Piersol et al., 2017). In a cross-sectional survey, Lloyd et al. (2019) found that decreased well-being can be associated with caregivers managing the loss of a relationship with someone who now requires their care. An integrative data analysis was conducted by Armstrong et al. (2019), which supported the findings of Lloyd et al. (2019), and indicated that caring for individuals with dementia who require a higher level of dependency on activities of daily living increase the feelings of caregiver burden and depressive symptoms in caregivers. Informal caregivers face increased stress levels as the individual they care for cognitively declines and becomes more reliant on their support. A systematic review (Chiao et al., 2015) and a survey (Cooper et al., 2010) expounded that an informal caregiver may experience physical, psychological, social, and

financial stress due to physical or psychological abuse by an individual with dementia. Of 220 referred caregivers in the U.K., "over a third of family carers reported significant abuse from the people they cared for" (Cooper et al., 2010, p. 592). Throughout these studies, increased demands of caring for an individual with dementia were associated with increased stress and caregiver burden (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Lloyd et al., 2019; Piersol et al., 2017).

Formal Caregivers

When addressing the overall well-being of formal caregivers, the quality of relationships indicated levels of perceived stress (Dalgarno et al., 2021; Franzosa et al., 2019). In a mixed-methods sequential design of qualitative focus groups and survey, Dalgarno et al. (2021) collected family members' perspectives on the care provided by formal caregivers related the quality of care provided by formal caregivers with the level of the burden felt by the family, as well as the experiences and well-being of the individual with dementia. Formal caregivers also reflected these beliefs who participated in a phenomenological study done by Franzosa et al. (2018). In a survey study by Sterling et al. (2021) on demographic information of Massachusetts based formal caregivers, the researchers identified home health aides as having higher rates of poor mental health, such as depression, and poor physical health, such as diabetes or hypertension, compared to health care aides in institutional settings.

Interventions for the Caregiver

Various interventions for caregivers' mental and physical aspects were analyzed in the previously described articles (Franzosa et al., 2019; Lloyd et al., 2019; Piersol et al., 2017; Sterling et al., 2021; Yong et al., 2020). Formal and informal caregiving presented varying challenges, but both types of caregivers often experienced physical and mental strains relating to their occupations (Franzosa et al., 2019; Lloyd et al., 2019; Piersol et al., 2017; Yong et al., 2020). Mental health interventions for caregivers were more frequently addressed in the articles reviewed (Franzosa et al., 2019; Lloyd et al., 2019; Piersol et al., 2017; Yong et al., 2020). The findings of Lloyd et al. (2019), Piersol et al. (2017), and Yong et al. (2020) all specifically addressed the informal caregiver for individuals with dementia. The use of emotion-focused strategies was shown to lower the perceived levels of the burden felt by caregivers (Lloyd et al., 2019). Coping strategies can also mediate the impact of caregiving-related stress and manage new occupational roles and activities (Lloyd et al., 2019; Yong et al., 2020). These coping strategies relied on mindfulness techniques and showed that with increased self-compassion, there are decreased feelings of burden (Lloyd et al., 2019). Coping strategies can also incorporate technology or new occupational routines to improve feelings of occupational balance (Yong et al., 2020). Similar to coping strategies, cognitive-behavioral interventions can also be used. In a systematic review, Piersol et al. (2017) defined cognitive-behavioral interventions as cognitive reframing, mindfulness techniques, and stress reduction strategies showed strong evidence to improve a caregiver's depression, burden, and stress. Piersol et al. (2017) also described the benefits of professionally-led in-person caregiver support groups to improve caregiver well-being.

Limited research was identified for interventions to support formal caregivers' mental and physical health. Franzosa et al. (2018) found that formal caregivers noted that positive feedback from the family of the individual with dementia "gave them a sense of accomplishment; appreciation and respect mediated the strain of working and built confidence" (p. 1058). This finding supports positive reinforcement as an intervention technique for formal caregivers

(Franzosa et al., 2019). Further research could be done to test the reliability of these findings for formal caregivers of individuals with dementia.

Environment

Informal Caregiving

There is limited published research about informal caregivers and their environment. In a longitudinal single-group study, Sheehan et al. (2021) identified an environment of caregiving within the home of an individual with dementia who receives care from informal caregivers. The components of the environment, such as the physical, social, cultural, and institutional, impact the individual with dementia, caregivers, and society (Sheehan et al., 2021). In a phenomenological study, Yong et al. (2020) described informal caregivers' attempts to provide for an individual with dementia, either within their own home or within the community, to control their environment, but failed to do so. The lack of control affects the caregiver's perceived capacity and ability to participate in desired occupations, thus impacting the caregiver's mental and emotional well-being (Yong et al., 2020).

Formal Caregiving

The literature lacked information outside of Sterling et al.'s 2021 research addressing the physical environment for formal caregivers. Sterling et al. (2021) compared multiple physical, mental, and overall health criteria between home health workers, health care aides not in the home, and health care support workers in which only physical settings separated them in a standardized health survey. The environment of caregiving in the home was identified as a factor in the health status of formal caregivers. Sterling et al. (2021) found "one in five participants reported poor mental health and one in seven reported physical health, significantly higher than those of formal caregivers not in the home" (pp. 2243-2244).

For the institutional component of the environment, Dalgarno et al. (2021) found time provided by companies for the formal caregiver to complete tasks was inefficient in fostering the ability to form high-quality relationships with the individual with dementia they served. Multiple studies addressed a lack of support and appreciation from the company they worked for (Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021). In a phenomenological study completed by Hale et al. (2019), participants identified a lack of say in rule development, difficulties communicating with senior staff, and lack of understanding of the workload experienced by formal caregivers as negative aspects of policies practiced by the companies they worked for. In a retrospective survey, Gleason and Miller (2021) found that support from the company increased job satisfaction, highlighting a need to identify ways in which their agencies can support the occupational performance of formal caregivers. Dalgarno et al. (2021) also signified the value of family members recognizing the importance of formal caregivers.

Interventions for the Caregiving

Interventions for the home environment of informal caregiving for individuals with dementia were readily accessible during database searches (Madruga et al., 2020; Raj et al., 2020). In a randomized control trial, Madruga et al. (2020) found home-based interventions to be more successful due to convenience for the population of at-home caregivers, required less time, and had less financial resources compared to conventional community-based programs. Implementing a physical activity intervention in the home for the caregiver provides structure and aims to improve the physical, health-related quality of life, mental health, and lower psychological stress experienced by caregivers (Madruga et al., 2020). In a survey study, Raj et al. (2020) also reported a moderate strength of evidence for home-based occupational therapy to promote ADL performance of the individual with dementia and reduce caregiver burden.

Common themes of interventions included addressing physical activity, environmental modifications or adaptations to the home routines, and joint caregiver and individual with dementia interventions (Madruga et al., 2020; Raj et al., 2020). Their findings supported incorporating a home-based physical activity regime for those caring for individuals with dementia (Madruga et al., 2020; Raj et al., 2020).

Interventions addressing the ability of caregivers and individuals with dementia to participate in their occupations within the home were addressed by Yong et al. (2020) and Burgess et al. (2021). According to Yong et al. (2020), caregivers often attempt to maintain control of their roles and routines by managing their environment by supporting the individual with dementia's abilities and encouraging them to do as much as possible. This process could be accomplished through an occupational therapist's emphasis on continued and adapted engagement in occupations as well as adaptations to the environment to encourage prolonged independence in occupations and a sense of competence in the individual with dementia, therefore allowing less dependence on the caregiver (Yong et al., 2020). These practices were evaluated in a phenomenological study on occupational therapists using this approach by Burgess et al. (2021) through the use of "Community Occupational Therapy in Dementia (COTiD-UK)." COTiD-UK consisted of an individual with dementia and their caregiver, each identifying their meaningful occupations and then selecting individual and joint activities to participate in with the assistance of an occupational therapist (Burgess et al., 2021). Implementation of COTiD-UK was found to be of value for its opportunity to set meaningful and realistic goals, provide resources, and increase confidence to engage in their chosen activities (Burgess et al., 2021).

Regarding interventions addressing the environment of formal caregiving, a retrospective longitudinal study conducted by Ranucci and Berry (2021) addressed institutional changes in the rights and benefits of workers should be necessary due to the quality of performance reflected in the organization. Focus group interviews conducted by Hale et al. (2019) addressed areas of changes that could occur with employers facilitating support workers' (caregiver) self-worth through allowing the freedom of choice at work, looking from a caregivers perspective, encouraging initiative, and being responsive to caregivers feelings, questions, and ideas. Implementing these interventions can increase meaningful communication between employers and caregivers, improving caregivers' self-worth and the organization's quality of work (Hale et al., 2021).

Occupation

Informal Caregiving

Yong et al. (2020) conducted an interview reviewing the experiences of United Kingdom caregivers of an individual with dementia. Caregivers often lose occupational roles and activities, often social and leisure-based, due to caring for an individual with dementia (Yong et al., 2020). The lack of participation in personal occupations can cause a burden to the caregiver, which may impact the quality of care that they are providing to the individual with dementia (Madruga et al., 2020; Yong et al., 2020). Madruga et al. (2020) hypothesized that informal caregivers spend their time and resources caring for the individual with dementia, and Yong et al. (2020) stated that caregivers might have "difficulties in perceived or actual time constraints for their occupational pursuits" (p. 600).

Formal Caregiving

Quality caregiving was identified as an ability to provide personalized and compassionate care to individuals with dementia (Dalgarno et al., 2021; Franzosa et al., 2019). Dalgarno et al.

(2021) found that families of individuals with dementia viewed it as vital for formal caregivers to address the client's emotional, social, and cultural needs. Rapport was established between formal caregivers, the individual with dementia, and their support system when the formal caregiver could incorporate skills and qualities such as warmth and kindness into their interactions (Dalgarno et al., 2021). These positive relationships between all parties were viewed as helpful in limiting increased stress levels experienced by the formal caregiver (Franzosa et al., 2019).

The success of caregiving by formal caregivers was often measured by their ability to form connections with clients but was often also impacted by the high demands of the job and lack of resources (Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021). In a survey study, Gleason and Miller (2021) reported that the quality of caregiving is negatively impacted by "high turnover related to the demands and challenges of the job: inconsistent schedules, low pay, limited benefits, physical and emotional demands in tasks performed" (p. 517). Dalgarno et al. (2021) and Franzosa et al. (2018) reported similar findings of poor relations between the caregiver and individual with dementia due to the factors reported by Gleason and Miller (2021). Support systems of the individual with dementia found connections could not be established when frequent changes in carer occurred, and they often noticed caregivers experienced high levels of stress, impacting their ability to give compassionate care (Dalgarno et al., 2021). Formal caregivers also reported high levels of stress when difficulties with rapport building were occurring (Franzosa et al., 2019). Overall, the occupation of caregiving was impacted when workers could not establish a routine with the individual with dementia and did not receive the support they felt necessary to provide quality care (Dalgarno et al., 2021).

Interventions for the Occupation of Caregiving

Interventions for caregiving were found to be most beneficial when offered as soon after diagnosis as possible (Burgess et al., 2021; Yong et al., 2020). Caregivers reported that the most beneficial time for intervention is early on after diagnosis due to the ability to then "plan and adapt to changes in the future and still focus on engaging in their valued activities" (Burgess et al., 2021, p. 2070). Incorporating intervention early on was also supported by Yong et al. (2020), who described caregivers as then feeling "actively involved and empowered" in the individual with dementia (p. 601). Burgess et al. (2021) discussed the unique focus occupational therapy could have on viewing caregiving as an occupation one engages in versus the aspect of caregiving as solely a role one fulfills. This viewpoint supports the idea that caregivers of individuals with dementia face unique challenges and require interventions targeted to their occupations and own needs (Burgess et al., 2021). Published evidence identified the incorporation of technology, caregiver education, and collaboration with all stakeholders as common interventions for caregiving (Burgess et al., 2021; Dalgarno et al., 2021, Raj et al., 2021; Sztramko et al., 2021; Yong et al., 2020).

Incorporating technology into caregiving can further social connections, increase feelings of support, and maintain personal occupations. Yong et al. (2020) described using technology and digital applications by caregivers to maintain occupational engagements outside of caregiving. The use of technology was identified as electronic devices that digital applications could be used on (Yong et al., 2020). The use of digital applications consists of social media, emails, and audiovisual applications that allow connections to others (Yong et al., 2020). Using these applications allows caregivers to maintain connections with others outside of the caregiving occupation regardless of their location. The applications can also allow caregivers to form social connections with others facing stress due to caregiving (Yong et al., 2020). Similar to

using technology in caregiving, Sztramko et al. (2021) supported online educational tools for caregiver self-efficacy, increased quality of life, and decreased perceived burden, depression, and anxiety. Online educational tools can consist of live forums, caregiver educational modules, and individual sessions (Sztramko et al., 2021). These online tools were most beneficial when tailored to the individuals' needs and can be archived for later viewing (Sztramko et al., 2021).

Caregiver education was commonly addressed as an intervention for the occupation of caregiving (Dalgarno et al., 2021; Raj et al., 2021; Sztramko et al., 2021). Dalgarno et al. (2021) found that caregivers often lacked dementia-specific training and education, therefore, undervalued their work. Additionally, Raj et al. (2021) found that when studies focused on addressing caregiver burden, they often used education as the intervention strategy. The educational interventions addressed "compensatory strategies for adults with dementia, promotion of caregiving skills, and access to community support service" (Raj et al., 2021, p. 2) and education on home environmental safety and equipment use. Using caregiver education as an intervention can increase caregivers' felt competence, value, and level of care provided, which was shown to then decrease negative feelings about caregiving and the level of burden perceived (Dalgarno et al., 2021).

Compensatory and collaborative strategies between the caregiver, individual with dementia, and occupational therapist were beneficial interventions (Burgess et al., 2021; Dalgarno et al., 2021; Yong et al., 2020). This collaboration can be done through occupational therapists working with caregivers to "examine life roles, emphasize continued and adaptive engagement in personally meaningful occupations, provide assistance with time management, support caregivers and organizations to adapt their environment, or help caregivers to work through barriers and see possibilities" (Yong et al., 2020). These interventions can be implemented as individual sessions between caregiver and occupational therapist to allow the caregiver to speak freely, feel valued, and explore coping strategies for the unique difficulties being faced (Burgess et al., 2021). In addition to interventions based on the caregiver and occupational therapist collaboration, increasing collaboration between formal caregivers, support systems, individuals with dementia, and occupational therapists can promote a shared vision for developing and maintaining care plans (Dalgarno et al., 2021). Including all stakeholders in the care plan can benefit the users, caregivers, and family (Dalgarno et al., 2021).

Summary

Overall, 36 articles were reviewed, and 26 were chosen for further review. The articles included definitions of the population, addressed concerns regarding each component of the PEO model, and identified areas of possible occupational therapy interventions. The main points were as followed:

- Caregivers can be informal such as family, friends, and neighbors, or formal caregivers, such as home health workers (Osborn & Juegst, 2021; Sterling et al., 2021; U.S. Department of Health and Human Services, 2016; World Health Organization, 2018).
- Those providing care for individuals with dementia can experience stress affecting their physical and mental health, in addition to financial difficulties (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Dalgarno et al., 2021; Franzosa et al., 2019; Lloyd et al., 2019; Piersol et al., 2017; Sterling et al., 2021).
- The physical, social, cultural, and institutional components of the environment are associated with increases in stress experienced by caregivers of individuals with dementia (Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Sheehan et al., 2021; Sterling et al., 2021; Yong et al., 2020).

- The occupation of caregiving is associated with occupational loss or deprivation for the individuals providing care (Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Madruga et al., 2020; Yong et al., 2020).
- Interventions evaluated addressed the mental and physical health of caregivers, utilization of different aspects of the environment to support the occupational performance of caregivers, and improving the task demands within the occupation of caregiving (Burgess et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Raj et al., 2020; Ranucci & Berry, 2021; Sterling et al., 2021; Sztramko et al., 2021; Yong et al., 2020).

The purpose of researching these topics was to examine potential interventions to decrease caregiver stress and increase participation in meaningful occupations. A review of the articles selected indicated enough evidence to determine whether or not occupational therapy interventions can decrease caregiver stress and increase caregiver occupational participation.

Clinical Bottom Line

How does addressing the perceived levels of emotional and mental stress experienced by caregivers caring for individuals with dementia improve the caregivers' ability to provide care and participate in their own personal occupations?

The literature evaluated included multiple areas for interventions to address the stress experienced by caregivers (Burgess et al., 2021; Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Raj et al., 2020; Ranucci & Berry., 2021; Sterling et al., 2021; Sztramko et al., 2021; Yong et al., 2020) The majority of findings applied to either informal caregivers (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Dalgarno et al., 2021; Lloyd et al., 2019; Madruga et al., 2020; Osborne & Juengst, 2021; Piersol et al., 2017; Roth et al., 2015; Sheehan et al., 2021; Sterling et al., 2021; Yong et al., 2020) or formal caregivers (Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Lloyd et al., 2019; Gleason & Miller, 2021; Piersol et al., 2017; Sterling et al., 2021; U.S. Department of Health and Human Services, 2016; Yong et al., 2020) instead of all caregivers Study designs varied based on evidence, with higher-level studies having larger populations (Armstrong et al., 2019; Chiao et al., 2015; Connors et al., 2020; Cooper et al., 2010; Dooley & Hinojosa, 2004; Gleason & Miller, 2021; Lloyd et al., 2019; Madruga et al., 2020; Osborne & Juengst, 2021; Piersol et al., 2017; Ranucci & Berry, 2021; Raj et al., 2020; Raj et al., 2021; Roth et al., 2015; Sheehan et al., 2021; Sterling et al., 2021; Sztramko et al., 2021) while the level NA studies (Burgess et al., 2021; Dalgarno et al., 2021; Franzosa et al., 2019; Hale et al., 2021; Yong et al., 2020) frequently address small groups, thus limiting the generalizability and transferability of research findings. The PEO model guided the synthesis of evidence as we evaluated the transactions between person, environment, and occupation during the review (Baptiste, 2017). Informal and formal caregivers experience stress related to caregiving for individuals with dementia, which can negatively impact their mental and physical health, as well as cause occupational loss or deprivation (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Sterling et al., 2021; Yong et al., 2020). Interventions identified for caregivers provided opportunities to develop strategies addressing mental health and identify opportunities for caregivers to participate in meaningful occupations in hopes of reducing stress and improving well-being (Burgess et al., 2021; Dalgarno et al., 2021; Hale et al., 2021; Lloyd et al., 2019; Piersol et al., 2017; Sztramko et al., 2021; Yong et al., 2020).



After analyzing the selected articles, we discovered that there is a large amount of information available regarding the stress and decline in personal occupation experienced by caregivers. Caregiver stress was consistently found to be negatively correlated with mental health, physical health, and ability to provide quality care (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Sterling et al., 2021; Yong et al., 2020). Additionally, satisfaction in occupational performance was found to frequently correlate with communication between caregivers, support systems, organizations, and the individual with dementia (Dalgarno et al., 2021; Hale et al., 2021; Madruga et al., 2020; Raj et al., 2020; Ranucci & Berry, 2021; Yong et al., 2020). In the articles in which researchers examined interventions to support formal and informal caregiving, a majority of interventions specifically addressed either informal (Armstrong et al., 2019; Chiao et al., 2015; Cooper et al., 2010; Lloyd et al., 2019; Madruga et al., 2020; Piersol et al., 2017; Yong et al., 2020) or formal (Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Sterling et al., 2021) caregiving but not both. The lack of research regarding the applicability of informal caregiver interventions to apply to formal caregiver interventions, and vice versa, indicated an area of potential future research. Synthesis of authors' research considered demographics of caregivers of individuals with dementia from multiple countries, in settings of urban, suburban, rural, and some unspecified, with a majority of the population being women, and high presence of minority ethnicities in formal caregiving positions (Armstrong et al., 2019; Burgess et al., 2021; Connors et al., 2020; Cooper et al., 2010; Dalgarno et al., 2021; Franzosa et al., 2019; Gleason & Miller, 2021; Hale et al., 2021; Lloyd et al., 2019; Madruga et al., 2020; Osborne & Juengst, 2021; Piersol et al., 2017; Raj et al., 2020; Raj et al., 2021; Roth et al., 2015; Sheehan et al., 2021; Sterling et al., 2021; World Health Organization, 2018; Yong et al., 2020).

Implications for Practice

The literature analyzed can help guide occupational therapy practice in the home and mental health settings. Beneficial occupational therapy interventions concerning caregiver stress and personal occupational engagement include the following:

- Occupational therapy intervention occurring within the home
 - Occupational therapy interventions occurring within the caregiver's home are effective due to the lack of necessary travel time, decreased costs associated with travel, and equal availability of resources regardless of geographical location (Madruga et al., 2020).
- Modifications and adaptations to the home and routine
 - Allowing the individual with dementia to carry out their activities as long as possible and maintain shared activities with the caregiver removes the burden from the caregiver (Yong et al., 2020)
- Physical activity-based intervention
 - Success was shown in improving well-being and lowering perceived psychological stress by caregivers with twice-weekly one-hour-long physical activity sessions led by physical trainers with a sports science degree (Madruga et al., 2020). Sessions consisted of aerobic exercises of moderate-intensity and varying heart rate intensities and once monthly health-counseling sessions to discuss topics including rest, proper body mechanics, and incorporation of personal social activities (Madruga et al., 2020).
- Mindfulness techniques



- Mindfulness techniques such as cognitive reframing and stress reduction can assist caregivers who exhibit anxiety, stress, and depression symptoms (Piersol., 2017)
- Emotion-focused coping strategies
 - Building solid relationships with individuals with dementia and receiving positive feedback from loved ones of those with dementia were reported to reduce the emotional demand for formal caregiving (Franzosa et al., 2019; Hale et al., 2021; Sterling et al., 2021).
 - Self-reliance, faith, prayer, social support, and education were identified as primary coping strategies in caregivers with dementia. (Franzosa et al., 2019).
 - Acceptance, positive restructuring, and humor are strategies used to reduce emotional distress associated with caregiving and lower levels of depression and anxiety in caregivers (Lloyd et al., 2019).
- Caregiver-centered education
 - These interventions should be carried out once the actuality of the dementia diagnosis has set in (Burgess et al., 2021). Early-on and hands-on information provided to the caregiver regarding dementia, behavior management, communication skills, environmental modifications, coping skills, respite options, and use of assistive devices can lessen stress and improve self-efficacy, knowledge, and quality of life experienced by caregivers (Piersol., 2017; Sztramko et al., 2021).

Addressing the occupational concerns of caregivers for individuals with dementia can improve their quality of life by reducing perceived stress levels experienced and engagement in meaningful occupations.

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