Chapter 10
Depressive Disorders Among Family Caregivers of People Living with Dementia

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10.1 Dementia

The global number of older people (aged ≥60 years) is expected to more than double by 2050 and more than triple by 2100, increasing from 962 million in 2017 to 2.1 billion in 2050, and 3.1 billion in 2100 (United Nations, 2020). Although dementia does not affect only older people, it is one of the leading causes of care dependency and disability among older people, being one of the top ten causes of years of healthy life lost due to disability (YLDs) (World Health Organization, 2021). The WHO estimates that 55.2 million people are living with dementia worldwide, and this number is forecasted to rise to 78 million by 2030 and 139 million by 2050 (World Health Organization, 2021). In 2019, the estimated global cost of dementia was US$1.3 trillion and is projected to increase to US$1.7 trillion by

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2030. However, if projections are corrected for increases in care costs, global dementia costs can reach US$2.8 trillion by 2030 (World Health Organization, 2021).

Dementia is a neuropsychiatric syndrome characterized by progressive and chronic cognitive impairment, behavioral and psychological symptoms, and decreased functional capacity. It is a multifaceted condition caused by a myriad of brain disorders, such as Alzheimer's disease, vascular diseases in the brain, and Lewy body dementia, among others. Approximately 40% of all cases of dementia are thought to be caused by modifiable risk factors, such as diabetes, obesity, hypertension, tobacco smoking, alcohol abuse, brain injury, hearing impairment, and excessive exposure to air pollution (Livingston et al., 2020b). Known non-modifiable causes of dementia include advanced age, female sex, and genetic causes. The number of people with dementia is significantly higher in lower-income countries, with nearly 70% living in such settings, and dementia is twice as likely to affect women (World Health Organization, 2021). In the United Kingdom, for example, 61% of all people living with dementia are women, and dementia is the leading cause of death in all women (Alzheimer's UK, 2018).

The symptoms and other disease manifestations affecting each person living with dementia will vary and depend on, for example, the type of the disease affecting the brain, the parts of the brain affected by the disease, and the point of the disease trajectory at which the person is. Some pharmacological and non-pharmacological interventions can help control the neuropsychiatric manifestations that affect the quality of life of both the person living with dementia and their family caregivers (Watt et al., 2019). However, dementia has no cure and no treatment can effectively modify the disease progression.

10.2 Care and Support for People Living with Dementia

Throughout the years, dementia progressively leads to a deterioration in the person's ability to independently perform activities of daily living, which leads to an increase in the need for care and support from others. In more advanced stages of dementia, the person will need care and support to perform basic activities, such as cooking and feeding, as well as personal hygiene.

Most people living with dementia live at home, particularly in low- and middle-income countries (96%) (World Health Organization, 2021), and receive the care and support they need from family members and friends. Family caregivers (often also called "care partners," "informal caregivers," or "unpaid caregivers") perform this role without receiving any payment and with little support and training from services and governments. Globally, 70–80% of all family caregivers are women (World Health Organization, 2021), who bear not only the physical and mental health impact of care provision but also most of the care-related costs (Wimo et al., 2018).

The majority of the family caregivers of people living with dementia are spouses or adult and middle-aged daughters. Spouses are often older people themselves and have their own health needs, whereas adult and middle-aged daughters are likely to have to compete for other caring needs (i.e., childcare), household chores, and work responsibilities (Conde-Sala et al., 2010; Greenwood & Smith, 2016; Oliveira et al., 2019; Rigby et al., 2019). Several studies show that providing unpaid care can impact the mental and physical health of caregivers differently depending on their age, gender, and relationship to the person cared for, suggesting that interventions might need to be tailored to each group to have optimal effects (Walter & Pinquart, 2020).

10.3 Depression in Family Caregivers of People Living with Dementia

It is widely known that family caregivers of people living with dementia experience a negative impact on their physical and emotional health. Possible explanations for this effect have been formulated around two main perspectives. The first relates to stress. It has been reported that the experience of stress in caregivers can lead to high risks of illness (Haley et al., 2010; Martire & Schulz, 2012) and death (Perkins et al., 2013). The second explanatory perspective considers emotional, economic, and family-related costs that dementia caregivers have to face, which have been linked to mental health problems such as burden, anxiety, and depression (Cheng, 2017; De Fazio et al., 2015; Madaleno et al., 2019; Pinquart & Sörensen, 2003). According to a recent review, the latter is one of the most studied issues in dementia caregivers (Queluz et al., 2020).

Depression differs according to symptomatology and timing. The World Health Organization’s diagnostic manual, ICD-11, classifies different types of depressive disorders as single episode depressive disorder, recurrent depressive disorder, dysthymic disorder, mixed depressive and anxiety disorder, going from single episodes to chronic disorders (World Health Organization, 2018). Depending on the methodology and instrument used to measure depression, there is a 30–60% prevalence in dementia caregivers (Madaleno et al., 2019; Sallim et al., 2015; Tzuang & Gallagher-Thompson, 2015). Furthermore, there have been reports indicating that there is a higher prevalence of depression and/or depressive symptomatology in caregivers of people living with dementia compared to individuals caring for people with chronic or psychiatric disorders (D’Aoust et al., 2015; Schoenmakers et al., 2010) and anxiety (Cooper et al., 2007; Joling et al., 2010).

Characteristics of caregivers themselves, which have been related to depressive symptoms, are being younger (O’Rourke et al., 2010), having a close relationship with the person with dementia (Fauth et al., 2012; Ornstein et al., 2014), high levels of burden (Epstein-Lubow et al., 2008), low levels of self-efficacy, few leisure activities (Romero-Moreno et al., 2012), low levels of mastery in dealing with caregiving (Mausbach et al., 2007), poor perception of caregiving as a challenge and lack of control over the situation (O’Rourke et al., 2010), perception of poor physical health, and previous presence of depressive symptoms (Joling et al., 2015).

In addition, more dysfunctional, disengaging, or less emotional coping is more robustly associated with depressive and anxious symptoms (García-Alberca et al., 2012; Li et al., 2014). A review by Watson et al. (2019) identified a set of factors that are consistently associated with the presence of depressive symptoms in dementia caregivers, namely, being a female and adult-child caregiver, coping strategies employed, activity restrictions, the severity of problematic behaviors associated with dementia, as well as the nature and quality of relationships that caregivers establish with care recipients (Watson et al., 2019).

Contextual factors that have been related to higher depressive symptomatology in family caregivers include low socioeconomic status, lower satisfaction with social support received (Clay et al., 2008), higher educational level (O'Rourke et al., 2010), and unemployment (Ornstein et al., 2014).

Evidence also suggests that family caregivers of people living with dementia are a high-risk group for suicide. In this regard, O'Dwyer et al. (2016), in a cross-sectional study of over 500 caregivers, found that 16% of caregivers had contemplated suicide more than once in the previous year. In addition, low satisfaction with social support received and the use of dysfunctional coping strategies had an indirect effect on suicidal ideation through depression. Meanwhile, Joling et al. (2018) assessed 192 family caregivers who did not have a clinical diagnosis of depression or anxiety at baseline for 2 years. Thirty-nine percent of them presented depressive symptomatology, and of the latter, 11.8% (4.7% of the total sample) reported suicidal thoughts at different times in the caregiving trajectory. This last group, compared to the rest of the sample, had more severe depressive and anxious symptoms and a lower sense of competence and mastery, felt less happy, and had more health problems, less family support, and more feelings of loneliness.

There is little evidence related to trajectories of depressive disorders among dementia caregivers. A study by Joling et al. (2012) reported that, after 18 months, 24.8% of 725 at-risk caregivers developed depression, with 58% of them showing high levels of depressive symptoms at all points of assessment. In addition, several cohort studies have shown that increases in caregiver depressive symptoms over time are related to factors associated with the person with dementia, the caregivers themselves, and the context. The severity of behavioral and psychological symptoms, as well as more time since the diagnosis of dementia, has been associated with higher levels of caregivers' depression over time (Cheng, 2017; O'Rourke et al., 2010).

A relevant dimension to understanding depressive symptomatology in caregivers of people living with dementia is gender. It is known that women are more likely to carry out the duties of caregiving. In addition, there is current evidence suggesting that female caregivers of people living with dementia are at higher risk for depression and have worse mental health outcomes overall (Verma & Anand, 2012; Watson et al., 2019; Xiong et al., 2020).

Although different perspectives have been proposed to address gender differences relative to mental health in caregivers, such explanations are linked to traditional gender role expectations. Stress and coping theory have shown the main evidence relative to differences between male and female caregivers. It has been reported that female dementia caregivers experience higher impacts from caregiving, as well as a larger effect on their depressive symptoms and somatic activity, which, in turn, has been explained by their inefficient use of coping styles (Pillemer et al., 2018). However, so far, evidence about the role of coping strategies by gender is limited and sometimes contradictory (Sharma et al., 2016). Additionally, literature also shows that women who provide care for their spouses are at higher risk of presenting depressive symptoms, which are more likely to appear near the end of the caregiving trajectory (Kaufman et al., 2018; Schulz & Sherwood, 2008).

Given this background, Sharma et al. (2016) proposed that the impact of gender may be mediated by other variables such as sociodemographic characteristics of patients and caregivers, as well as the sociocultural context. For example, specifically focusing on Latin America and the Caribbean, with their unique particularities in confronting dementia compared to the European scenario (Baez & Ibáñez, 2016), it can be noted that there are structural/systemic problems that contribute to the difficulties that dementia caregivers face in terms of prevention and promotion of mental health. Among such obstacles, the following have been mentioned: a scarcity of mental health facilities, cultural barriers and socioeconomic vulnerabilities, and shortage of formal long-term care (Ibáñez et al., 2021; Parra et al., 2018). All of this has placed most of the burden on informal care (Thrush & Hyder, 2014) and consequently led, in this group, to a higher vulnerability to experiencing depressive symptoms.

10.4 Management of Depressive Symptoms Among Dementia Caregivers

An early diagnosis improves the prognosis and effective management of mental health disorders. The WHO Mental Health Gap Action Program (mhGAP) recommends a combination of both antidepressant drugs and psychosocial interventions to address moderate to severe disorders (World Health Organization, 2011). Depression among caregivers of people living with dementia is managed with the same treatments available in primary and specialist care (NICE guideline, 2018). There are, however, specific interventions for dementia caregivers that have shown to be cost-effective with long-term effects in reducing depressive symptoms (Livingston et al., 2020a).

10.4.1 Psychoeducational Programs

Psychoeducational interventions have shown the most positive results in reducing depression symptoms among caregivers (Chien et al., 2011; Lee et al., 2020; Liu et al., 2017; Piersol et al., 2017). A recent systematic review compared the efficacy of remotely delivered interventions offering information (determined by the professional with the participant having a passive role), training (practical skills to manage the burden of care with an active role of caregivers) and support (participants discuss and share feelings, problems, or issues related to caring with peers or professionals), or a mixture of these. When compared to usual treatment, waiting list, or attention control, any of the above interventions have little or no effect on depressive symptoms (SMD = −0.05; 95% CI = −0.22 to 0.12). However, compared to a control group with only information, remotely delivered interventions involving training, support, or both had a small effect on caregivers' depressive symptoms (SMD = −0.25; 95% CI = −0.43 to −0.06; $I_2 = 53\%$) (González-Fraile et al., 2021).

10.4.2 Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) has had the largest amount of evidence and has shown significant effects to reduce depressive symptoms among caregivers (Lee et al., 2020). CBT aims to empower people and promote self-agency, by working on automatic and dysfunctional thoughts (Hopkinson et al., 2019). In the case of caregivers, the principal outcomes are to change dysfunctional thoughts about caregiving and behavioral activation that enhances self-care strategies including leisure activities (Losada et al., 2011).

CBT has shown effectiveness in reducing depressive symptoms among caregivers of people living with dementia (Cheng et al., 2019). In a meta-analysis carried out by Hopkinson et al. (2019) including 25 randomized controlled trials (RCTs) published between 1996 and 2016, moderate quality of evidence was found for the effectiveness of CBT to reduce depression among caregivers. The authors reported statistically significant improvements of depression symptoms immediately after completing the intervention (standardized mean differences (SMD) = −0.34; 95% CI = −0.47–0.21; $p < 0.001$) and after up to 3 months of follow-up (SMD = −0.99; 95% CI = −1.35–0.64; $p < 0.001$). The authors also reported that brief versions (up to eight sessions) and longer versions (more than eight sessions) significantly improved caregivers' depressive symptoms.

Similarly, Sun et al. (2022) conducted a meta-analysis that aimed to compare CBT formats. They included 37 RCTs published between 2000 and 2021, obtaining standardized mean differences (SMD) and conducting a rank analysis based on P-scores to compare different formats to control groups. Higher P-score indicated a higher probability of a specific format being the best intervention. They found no significant differences between the formats of CBT. However, compared to control groups (no intervention or treatment as usual), CBT delivered over the Internet (SMD = −1.45; CI = −2.31, −0.28), telephone (SMD = −1.28; CI = −1.78, −0.53), and individual (SMD = −1.19; CI = −2.29, −0.31) reduced depressive symptoms and had the higher probabilities of being the best treatment for caregivers ($P_{\text{Internet}} = 0.811$; $P_{\text{telephone}} = 0.803$; $P_{\text{individual}} = 0.771$; $P_{\text{group}} = 0.440$; $P_{\text{combine}} = 0.334$; $P_{\text{control}} = 0.107$).

Finally, low-intensity CBT, which includes the delivery of the intervention in a short format or by a nonspecialized therapist, has shown effectiveness in reducing depressive symptoms among caregivers. Even though the effect size is smaller than the one found for traditional CBT, this format might be useful for countries with fewer resources for highly trained therapists (Kaddour et al., 2019).

10.4.3 Mindfulness-Based Interventions

Mindfulness interventions are based on meditative exercises, like meditation or yoga, to connect people with the present while helping them be aware of their experiences (thoughts, feelings, body sensations) and accept them. Mindfulness-based interventions (MBIs) are combinations between psychological therapies and mindfulness practices (Zhang et al., 2021). The most recognized ones are mindfulness-based cognitive therapy (MBCT) and mindfulness-based stress reduction (MBSR) (Han, 2021). Acceptance and commitment therapy (ACT) is also considered an MBI, but it will be reviewed separately in the following section.

MBIs have shown positive results to help caregivers with depression (Cheng & Zhang, 2020). Liu et al. (2017) reviewed seven RCTs focused on MBIs for dementia caregivers. The authors reported small heterogeneity across studies ($I_2 = 7\%$) and, compared with control groups, mindfulness training significantly decreased caregivers' depressive symptoms (SMD = −0.58; 95% CI = −0.79 to −0.37). Moreover, Cheng et al. (2020) analyzed 131 studies (RCTs and quasi RCTs) published between 2006 and 2018, including nine MBI studies. They converted the SMD to Hedges to correct for small samples bias. The authors found that MBIs were effective in reducing depressive symptoms ($g = 0.58$; $k = 7$; $N = 258$). Similarly, Han (2021) carried out a meta-analysis of 15 RCTs published between 1966 and 2021. From them, 11 were exclusively for caregivers with dementia and 4 had caregivers of other chronic conditions. The study analyzed the effectiveness of MBIs including MBCT, MBSR, ACT, and other forms of mindfulness. The authors reported that the effect of MBIs on reducing depressive symptoms was related to the type of control groups. At immediate posttest, a large effect was found when compared to passive control groups (SMD = 1.21; 95% CI = 0.67, 1.75), and a medium effect was found when compared to active control groups (SMD = 0.60; 95% CI = 0.39, 0.80).

10.4.4 Acceptance and Commitment Therapy

ACT is part of the contextualistic approaches of CBT, but it does not completely fit into traditional categories because of its flexibility in integrating mindfulness (Hayes, 2004). It addresses topics like feelings, values, or spirituality within specific contexts using techniques to overcome avoidant behaviors and thoughts while keeping the person in the present instead of focusing on the past or future experiences (Hayes, 2004).

According to ACT theory fundaments, psychological problems are rooted in six processes: (1) experiential avoidance, (2) cognitive fusion or controlling behavior through rigid verbal use, (3) loss of contact with values, (4) inaction produced by unalignment between behavior and values, (5) loss of contact with the present moment, and (6) conceptualized self, judging one's thoughts and emotions (Hayes, 2004; Hayes et al., 2006; Pachana & Laidlaw, 2014). Therefore, ACT's clinical aim is to reach behavioral flexibility to adapt and accept difficult scenarios. It focuses on helping people to solve problems by validating and accepting their experiences (feelings, thoughts, and behaviors) and connecting them with their values in life (Márquez-González et al., 2014). Rigidly believing the content of our thoughts, feelings, and body sensations, disconnected from our immediate experiences with the environment, creates avoidant behaviors and dysfunctional coping mechanisms and ultimately an unalignment between values and meaning of life. Therefore, ACT works with the client's use of language to redefine the problem and potential solutions (Hayes, 2004).

ACT has shown a moderate size effect and quality of evidence to reduce depression among the general population (Bai et al., 2020) and family caregivers of children, people with cancer or in palliative care, and people living with dementia (Han et al., 2020).

In the case of dementia caregivers, ACT aims to change the ideas or verbal rules related to caregiving (Pachana & Laidlaw, 2014). ACT has gained notice to support dementia caregivers because of the challenges of caring for a relative with multiple needs and progressive levels of dependency (Losada et al., 2015). Most dementia caregivers think about their relatives as completely dependent; therefore, they focus their lives to become the perfect caregiver. They usually reject help and avoid engaging in leisure activities or using their time to take care of themselves, including seeking health support. They also experience confronted feelings for their relatives (love, pain, frustration, tiredness, anger) and, consequently, feelings of guilt (Márquez-González et al., 2014). So far, ACT effectiveness for dementia caregivers' depression has been evaluated in two RCTs. Losada et al. (2015) carried out an RCT with 135 dementia family caregivers in Madrid, Spain. They designed a specific ACT intervention for caregivers that was compared to a minimal treatment condition. The intervention improved depressive symptoms immediately after the intervention (time by treatment effect estimate = 10.47; $p < 0.001$), but these differences did not remain at 6-month follow-up (time by treatment effect estimate = 3.48; $p = 0.196$). The authors also compared ACT with CBT for depressive symptoms. They did not find significant differences from baseline to posttreatment or from baseline to follow-up. Similarly, Márquez-González et al. (2020) conducted an RCT with 92 dementia caregivers. They were allocated to functional analysis-guided modular intervention (FAMI), ACT, CBT, or control group (CG) with 2 hours of psychoeducation workshop. The authors found that there was a higher decrease in depressive symptoms among the three treatment conditions compared to CG ($p < 0.005$), and this improvement was maintained in time (6-month follow-up).

There were no significant differences between FAMI, ACT, and CBT to treat caregivers' depression ($F_{(4, 78)} = 0.250$; $p = 0.909$). These promising results should, however, be further explored because of their attrition rate and sample sizes.

10.4.5 Other Non-pharmacological Interventions

Due to their easy access during the daytime and their adaptability, telephone- and computer-delivered interventions have been developed to support caregivers of people living with dementia. Telephone counseling and face-to-face technology-based counseling are effective interventions to address mental health issues among dementia caregivers (Teahan et al., 2020; Waller et al., 2017; Zhu et al., 2021). However, the effectiveness of both technological systems, used separately or combined, to reduce depressive symptoms, has had inconsistent results, and the quality of the studies has been rated as low or moderate. Thus, their impact still needs to be verified (Teahan et al., 2020; Waller et al., 2017; Zhu et al., 2021).

Physical exercise interventions have been widely recommended because of the number of RCTs that had reported statistically significant effects on reducing depressive symptoms and other mental health issues. However, the internal validity of their evidence makes it difficult to determine the quality of those results (Cuthbert et al., 2017).

Finally, multicomponent interventions have been developed to support family caregivers. Recently, Cheng and Zhang (2020) did not find advantages of multicomponent interventions over single interventions. However, the Strategies for Relatives (START) program, a multicomponent intervention for dementia caregivers, showed to be cost-effective for reducing depressive symptoms with an effect lasting from after the intervention up to 5 years. START is a manualized intervention delivered by graduate psychologists with no clinical training, which is key in health systems with a low rate of clinical specialists (Knapp et al., 2013; Livingston et al., 2013; Livingston et al., 2020b).

10.5 Conclusion

The relationship between caregivers' mental health and the quality of life and prognosis of people living with dementia has led to the inclusion of caregivers in dementia policies and national care plans (Livingston et al., 2020a). Comprehensive management of dementia usually encompasses psychoeducation, training, and counseling in coordination with mental health-care interventions. Linking caregivers with support networks is essential for helping them, and it has been considered among different dementia national plans in Europe and countries in other regions (Tokovska et al., 2021). In addition, exchanging experiences with people living with dementia and other relatives has improved caregivers' mental health, including the reduction of depressive symptoms (Carter et al., 2020). Evidence confirms the use of non-pharmacological interventions to manage caregivers' depressive symptoms (González-Fraile et al., 2021), especially CBT, and mindfulness-based programs (Cheng et al., 2019; Han, 2021; Hopkinson et al., 2019; Kaddour et al., 2019; Liu et al., 2017; Sun et al., 2022). ACT has shown promising results; however, more research is needed to find out whether its effects are long-lasting and cost-effective (Losada et al., 2015; Márquez-González et al., 2020). Other interventions have been analyzed including social peer support groups, exercise, and counseling or a combination of all. Evidence does not support dyadic or multicomponent interventions over single-component interventions (Cheng & Zhang, 2020).

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