Impact of the pandemic on dementia care and caregivers: a qualitative study

Abstract

Background: Physical distancing measures to limit contagion in the Covid 19 pandemic made it difficult to care for older persons with dementia. Non-essential home visits were prevented and family caregivers took over most of their care. The aim of our study was to describe the lived experience of peoples living with dementia caregivers during the pandemic regarding the care provided and the person cared for.

Methods: A qualitative phenomenological design was used. Participants were recruited using purposeful sampling. Informants were selected from primary health care centres, day centres and a community mental health unit. The study participants comprised 21 caregivers. Semi-structured in-depth interviews by telephone were used and field notes were collected from the researchers. A thematic analysis was conducted. The criteria used to control trustworthiness were credibility, transferability, dependability, and confirmability.

Results: Three main themes and six related sub-themes were identified: 1) care for the person with dementia during the pandemic, including lockdown, associated with difficulties in coping with restrictions, deterioration in health and the impact of the closure of health and social resources; 2) health and social care provided to people with dementia after the disruptions and the care received from primary care prior to hospital or residential admission; and 3) the caregiver's perspective on the effects of the psycho-emotional impact, and coping strategies adopted in caring.

Conclusions: Interventions for people with dementia should be planned in order to prevent the worsening of their health and cognitive status, while also developing programmes to prevent stress and alleviate caregiver burden in case of health crises.

Keywords: dementia; older person; Covid-19; nursing; caregiver; quarantine; qualitative research

INTRODUCTION

In late 2019, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was detected as the causative agent of COVID-19 (World Health Organization, 2020). In 2020, almost 80% of COVID-19 deaths occurred among people aged 65 years and older with multiple chronic conditions (Centers for Disease Control and Prevention, 2020), while 46% of Covid-19 deaths occurred in nursing homes, with premorbid conditions and advanced age considered risk factors for COVID-19 mortality (Bonanad et al., 2020; Comas-Herrera et al., 2020).

Among the control measures employed, the countries implemented mass lockdowns and quarantines in order to establish social distancing (Hellewell et al., 2020). Similarly, many countries implemented physical distancing measures in order to contain the speed of virus transmission, reduce the chances of health systems collapsing and reduce mortality (Azevedo et al., 2021), only allowing flexibility for certain jobs or emergency situations (Nussbaumer-Streit et al., 2020). These isolation measures limited non-essential home visits or even prohibited them in facilities where the older persons were institutionalized (Carbone et al., 2021; Hanna, Giebe, et al., 2022). Previous studies have shown that measures for social distancing, lack of social interaction and lack of physical closeness had an adverse impact on the well-being of PLwDs (peoples living with dementia) and their caregivers (Abbasi, 2020; Chu et al., 2020; Velayudhan et al., 2020).

PLwDs were at increased risk of fatal outcomes from the COVID-19 outbreak, due to their vulnerability to the disease and the indirect effect of the pandemic on social and medical support (Brown et al., 2020). PLwDs may also have been affected by the changes in routine imposed by social isolation, experiencing increased burdens and negative impacts on their mental health (Brown et al., 2020). Under normal conditions, family caregivers assume a significant burden in the care of their relative with dementia (Wimo et al., 2017) presenting an increased risk of physical and psychosocial health problems (Abreu et al., 2020). In fact, several international studies have identified caregiver stress in the context of the pandemic. In Italy, Altieri & Santangelo (2021) identified a heavy burden experienced by caregivers, along with an increase in depression and anxiety, despite their high levels of resilience. In Greece, Tsapanou et al. (2021) added that the most affected domains in PwDs (peoples with dementia) were communication, mood, movement and compliance with the new measures, while their caregivers experienced a large increase in their psychological and physical burden due to limited means of support. In Portugal, Borges-Machado et al. (2021) associated the increase in caregiver burden and loss of well-being with the physical and cognitive worsening of people with neurocognitive disorders in their care, as they became more dependent on daily living activities. In Argentina, Cohen et al. (2020) highlighted the increase in stress among caregivers, especially in severe cases of dementia, due to the lack of paid caregiver support during lockdown. Finally, in India, Vaitheswaran et al. (2020) highlighted the concern among caregivers of dementia patients regarding immediate needs posed by the pandemic, as opposed to other long-term needs related to home care, caregiver training and relief services.

Apart from the care burden referred to by the relatives of patients with dementia indicated by research carried out in different countries, it is necessary to continue developing studies from a qualitative perspective. These will help us understand to what extent the restrictions on mobility and social isolation implemented in Spain during the Covid 19 pandemic influenced the care of people with dementia and their family caregivers. The aim of our study was to describe the lived experience of PLwDs caregivers during the pandemic regarding the care provided and the person cared for.

MATERIAL AND METHODS

Design

The qualitative phenomenological method was adopted, based on the study of people's experience and how they interpret it (Korstjens & Moser, 2017). Phenomenology seeks to understand how individuals construct their vision of the world based on the experience of other people (Giorgi, 2003), in our case related to the impact of measures adopted during the pandemic and care for patients with dementia. In addition, phenomenology focuses on the study of phenomena as they appear in order to reach an essential understanding of human experience (Carpenter and Suto, 2008; Norlyk and Harder, 2010).

Research Team

Prior to the study, the positioning of the researchers was established through briefing sessions that addressed the theoretical framework of the study, their beliefs and their motivation for the research (Carpenter & Suto, 2008) (Table 1). The research team consisted of five nursing professionals of whom four were female. One of them was a primary care nurse and the remaining four were university lecturers and researchers in the field of nursing with experience in qualitative research. None of them had any previous relationship with the study participants.

Sampling strategies and participants

The study was carried out in the Autonomous Community of Cantabria (Spain). The informants were selected from primary health care centres, day centres and a community mental health unit. The criteria for inclusion were: a) being a family caregiver of a PLwDs; b) having been a caregiver during the COVID-19 pandemic; c) not suffering from pre-existing psychological disorders, and d) being willing to take part in the study. Sampling and data collection continued until redundancy of information was achieved, at which point no new information emerged from the data analysis (Carpenter & Suto, 2008; Creswell & Poth, 2018; Moser & Korstjens, 2018).

Data collection

Data were collected through semi-structured qualitative interviews following a script of questions developed according to the study objective and the literature published in the context of the pandemic to date (Table 2). Open-ended questions were used to elicit information on specific topics of interest (Moser & Korstjens, 2018). Field notes were taken, topics of interest were identified, and clarifications were sought from caregivers (Creswell & Poth, 2018; Carpenter & Suto, 2008). Data were collected via telephone between February and August 2022. Only one interview was conducted per participant. The interviews were conducted in Spanish, audio-recorded and transcribed by a professional service. They had an average duration of 34 minutes (ranging from 12 to 63 minutes).

Rigour criteria

The Guba & Lincoln criteria for guaranteeing trustworthiness were followed (Korstjens and Moser, 2017). The Consolidated Criteria for Reporting Qualitative Research were followed (Tong et al., 2007). The techniques performed are described in Table 3 (O'Brien et al, 2014; Korstjens and Moser, 2017).

Ethical considerations

The project was approved by the Ethics Committee for Research with Medicines (CEIm) of Cantabria (Spain) with the internal code INNVAL 20/12 and the approval of the participating centres was obtained. Convenience sampling was carried out to select family caregivers in Primary Care Centres, Day Centres and one Mental Health Unit located in the community. The study was presented to the heads of the participating centres and their written authorization was obtained for the study. Subject recruitment was carried out with the help of healthcare and social professionals at the different centres, who selected possible participants. Caregivers were contacted by telephone on two separate occasions. The purpose of the first contact was to offer information about the study and invite them to participate, answer any possible questions and arrange the most convenient day and time for the next meeting according to their availability. Data collection was carried out in the second contact, previously collecting informed consent orally by audio recording.

Data analysis

A thematic analysis was conducted, which involved: 1) identifying words, sentences and metaphors in the text; 2) reducing the data to units of meaning; 3) grouping units into clusters with meanings in common; and 4) identifying emerging themes. The researchers first analysed the interviews separately, then the results were grouped together and agreed upon (Moser & Korstjens, 2018). The data analysis was conducted manually and no computer software was used.

RESULTS

A total of 21 PLwDs caregivers participated in the study. One potential informant did not participate due to lack of time and adequate conditions for conducting the interview. The profile of the participants was female (n=18, 85.7%), with an average age of 60.52 years (SD 10.14) and mostly married (n=17, 81%), and living with the person being cared for in just over half of the cases (n=13, 61.9%). The average age of the PLwDs was 86.24 years (SD 8.43), most of whom were mothers (n=12, 57.1%) and less frequently spouses (n=4, 19.1%). They had been suffering from dementia for a mean time of 5.71 years (SD 2.97). The participants had been caregivers for between 1 and 15 years. Most (n=12) had been caring for five years or less, followed by periods of between six and ten years (n=7). Time spent caring ranged from three to 24 hours a day, with most (n=11) spending between 11 and 20 hours a day.

Most of the carers relied on the Day Centre as a formal support resource, as the only resource or combined with paid carers. In six cases, they did not have resources to help them with care and of those, four were 24-hour caregivers. In relation to the impact of the pandemic, the vast majority of respondents (80.9%) stated that it had affected them in their role as caregivers, in just over half of the cases (62%) it had affected the PLwDs, and in nearly half of the cases (47.6%) it had affected the care they offered (Table 4). Three main themes were identified (Table 5) which are presented below along with accompanying quotes (Table 6).

Theme 1. PLwDs care during the pandemic

Sub-theme 1.1. Management of the PLwDs due to COVID-19 related knowledge and changes in daily routines

Some caregivers identified difficulties during the pandemic including lockdown in managing PLwDs associated with their cognitive state, such that they were neither aware of nor understood the implications of the pandemic for their daily lives, despite the seriousness of the problem. These included adopting and following preventive measures against the risk of contagion, such as the use of masks, keeping a safe distance and the need to limit social contacts. After lockdown and a gradual return to normality, some PLwDs showed difficulties in returning to their pre-pandemic daily routines. For other caregivers, the pandemic was not experienced as an unpleasant situation as it did not affect the care for PLwDs and their daily routine was not altered, even during lockdown, seeing as how before the pandemic, they rarely left their home.

Sub-theme 1.2. Deterioration in the health status of the PLwDs

Lockdown affected the physical condition of the PLwDs, especially the deterioration of mobility and loss of autonomy, limiting or requiring help with moving around after the return to normality. In some cases, the confinement affected the PLwDs emotionally and they became aware of the pandemic, sometimes requiring the prescription of drugs in order to stabilize them. However, there were caregivers who expressed doubts as to whether the deterioration was due to lockdown or to the evolution of the disease itself.

Caregivers who relied on a day centre as a formal support resource before the pandemic highlighted the negative impact of the loss of daily routines on PLwDs due to its temporary closure, as well as the interruption in activities they regularly undertook in the centres as part of their treatment.

Theme 2. Health and social care during the pandemic

Sub-theme 2.1. Health services in primary care

Where caregivers needed assistance for their family members, their assessment of care revolved around access to health professionals. In some situations, face-to-face home-based care was maintained as normal during the pandemic. However, the closure of health centres to normal activities meant that the alternative was telephone health care, which in some cases was assessed as sufficient and positive, and in others as negative due to difficulties in establishing communication and therefore being left unattended and with a feeling of abandonment. In other cases, the alternative was referral to hospital for care and in some situations, the carer resorted to contracting private health care in order to guarantee care in case of need.

Other caregivers expressed feeling fortunate and satisfied with the system and the health care received, grateful to their assigned health care professionals, highlighting their personal commitment despite the difficulties in the normal functioning of the healthcare system due to the pandemic.

Sub-theme 2.2. Admission to hospital or residential care

In some cases, caregivers experienced institutionalization of their relatives in residential care or hospitalization during the pandemic.

After admission to the residence, following the protocols, isolation in the relative's room for the first few days and the consequent absence of face-to-face visits meant that the only alternative was telephone contact with the relative or communication with the staff at the institution. The hardship and suffering of these circumstances was felt not only by the caregivers but also by the family member, given the change in their environment where even the staff's protective equipment was unpleasant for a person recently admitted to an institution. Safety measures led to new dynamics which affected hospital admission and even communication with the health staff.

Theme 3. The caregiver's perspective

Sub-theme 3.1. Psycho-emotional impact

The loss of formal and informal resources to support caregiving, especially during lockdown, overwhelmed some caregivers physically and psychologically, leading to fatigue and feelings of loneliness, fear and worry about continuing to care for their family member in the face of possible health problems in the new health and social circumstances. The feeling of loneliness was a recurring theme in the experience of caregiving during the pandemic. Caring in solitude without the possibility of a break for other social or leisure activities came to be seen as imprisonment, accompanied by negative feelings such as loneliness and anguish.

Additionally, caregivers described their concern and fear of the possibility of their family member becoming infected with COVID-19, so that extreme adherence to health measures became obsessive, with stress and anxiety triggered by their sense of responsibility as caregivers.

Fear of the possibility that they themselves could become infected and transmit the disease to their relative was also noted in the caregivers, including feelings of remorse in the event of such a situation occurring. Some caregivers even reported situations of panic, stress or anxiety. In addition to this, there was concern about the state of neglect in which their relative would be left should they themselves become infected and fall ill.

Mainly during lockdown, there was a recognition of accumulated stress as a result of the buildup of negative emotions, which they took out on other cohabiting family members. These negative effects did not extend to all caregivers. Due to differences in the family circumstances, some caregivers did not experience major changes during lockdown.

Sub-theme 3.2. Coping strategies adopted

Caregivers adapted to the difficulties of caring for their relative; they coped with the psycho-emotional impact by distancing themselves emotionally, normalizing the risk of contagion, distracting themselves and taking medication. By distancing themselves emotionally, caregivers withdrew from the care they had been giving to their relative. Other caregivers downplayed the importance of the contagion by normalizing the situation; they took it as a risk inherent to the contact and care for the family member. In other cases, they distracted themselves with other activities, being able to redirect their attention. Leisure activities with their children helped them to cope with caring for the relative. The stress felt by some caregivers as a result of the pandemic led to an increase in pharmacological treatment for anxiety on some occasions.

DISCUSSION

This study aimed to describe the impact of the pandemic on PLwDs care and the caregiver during the Covid 19 pandemic. Our results showed that the pandemic presented additional challenges to caregivers of family members with dementia beyond those of the disease itself. PLwDs were a particularly susceptible group not only to SARS-CoV-2 infection and its effects, but also to the impact of measures taken worldwide in order to control the spread of the virus. Caregivers of family members with dementia faced numerous difficulties in ensuring continuity of care during the pandemic.

In our study, PLwDs caregivers describe how their family members were not really aware of the pandemic, most likely due to their cognitive impairment. Mok et al. (2020) agreed that cognitive impairment and neuropsychiatric symptoms made it difficult for PwDs to understand and comply with protective measures, such as wearing masks and maintaining physical distance. At the same time, in our study, caregivers highlighted that, at times, lockdown was not an unpleasant experience for the PLwDs to the extent that most basic needs were covered. In this case the dementia itself was already limiting their lives and therefore the restrictions adopted during the pandemic were not as severe as the existing ones. In their study, Talbot & Briggs (2021) argued that PLwDs felt safe and secure in their home, as it provided a respite from daily stress and created opportunities for success.

In our study, mobility restrictions contributed to sedentary lifestyles and social isolation impacting the lives of PLwDs, previous studies (Brown et al., 2020; Manca et al., 2020; Mok et al., 2020) have claimed that restrictions in many countries had significant neuropsychiatric consequences for PLwDs. Manca et al. (2020) described how social restrictions exacerbated aggression and agitation in PLwDs, which can become chronic and make their care more difficult. Therefore, it is possible that social restrictions could have an irreversible impact on PLwDs, increasing their morbidity and mortality (Numbers & Brodsey, 2005).

In our study, with the interruption of activities due to lockdown, PLwDs experienced a lack of stimulation, and with it a loss of autonomy and capabilities despite caregivers trying to stimulate them with alternatives in their homes. Once the pandemic subsided and care could be recovered in day centres, there were caregivers who were reluctant to allow their relatives to attend for fear of contagion. Here, it is important to bear in mind the theory of the shrinking world of Duggan et al. (2008), where PLwDs, in our case motivated by caregivers, reduce the number of places where they feel comfortable, resulting in patterns of anxiety that become subject to treatment (Brittain et al., 2010). Disruption of social activities, which are closely linked to PLwDs in social and health care settings, has an impact on their identity, social inclusion and well-being (Brittain et al., 2010; Duggan et al., 2008).

Our findings reveal the changes in health services during the pandemic, both in hospital care and, above all, in primary care for PLwDs. In the latter, three models of care coexisted: 1) face-to-face care in the home of the PLwDs, 2) telephone care and 3) referral to hospital. In their studies, Tousi (2020) and Mok et al. (2020) highlighted the inability of the system to deal with non-urgent patients, such as cognitive disorders or dementia. Parmar et al. (2021) added that caregivers of relatives with dementia encountered difficulties and deficiencies due to a lack of human resources and support. In our study, the face-to-face care of PLwDs in their homes focused on the control of baseline pathologies, highlighting the leading role of the nurse, as well as their limitations and dependence on the doctor. In their study, Fragkiadaki et al. (2023) argued that during the first wave of COVID-19, face-to-face medical visits were limited and even avoided, and telemedicine was proposed as an alternative, although it did not develop adequately. In our study, the use of telemedicine was via telephone, with no use of videoconferencing, most likely due to a lack of digital literacy among caregivers. Previous studies have included remote telephone consultations in primary care in the UK prior to the pandemic (Brant et al., 2016) and were rated as satisfactory by both the doctor and the patient (McKinstry et al., 2010). In the case of PLwDs caregivers, videoconferencing would have been a feasible resource in order to ensure continuity of care (Laver et al., 2020).

The strain that PLwDs caregivers experienced due to the loss of formal support as they provided continuous care during the pandemic is notable, having a significant psychological and emotional impact. Our findings are consistent with previous studies (Brown et al., 2020;

Carcavilla et al., 2021; Greenberg et al., 2020) where PLwDs caregivers faced double stress: on the one hand, the psychological impact of the pandemic, in addition to lockdown and social restrictions; and on the other hand, the stress associated with the demands of caring for the PLwDs. Moreover, seeing as informal caregivers of PLwDs were already experiencing chronic stress prior to this crisis, which increased the risk of suffering from a variety of physical and emotional problems, especially anxiety and depression (Pinquart & Sörensen, 2003; Schulz & Sherwood, 2008) the impact identified in our study would be exacerbated by the previous baseline situation. Our results are in line with previous studies, where PLwDs caregivers experienced anxiety, stress and an additional burden in their daily lives (Tsapanou et al., 2021).

PLwDs caregivers highlighted the following personal coping strategies: 1) emotional distancing, which allowed them to dissociate themselves from caregiving; 2) normalizing the risk of contagion, which helped them to bear it as something inherent to caregiving; 3) distraction, which redirected attention to leisure activities so as not to focus on caregiving. In their study, Rising et al. (2022) identified reading, cooking or attending to household chores as serving to combat depression; and/or 4) using medication to meet the demands of caregiving. In their study. In their study, Hoel et al. (2021) highlighted how technology was able to preserve social contact during the pandemic, lessening the negative effects of restrictions. In situations other than our own, the practice of faith amongst religious caregivers in order to cope with the pandemic and its restrictions is noteworthy (Giebel et al., 2022). Britt et al. (2023) highlighted the benefits of religion and spirituality as being associated with improved mental health and decreased psychological distress. Hanna et al. (2022) highlighted the role of pre-pandemic family support networks in the face of the stress and rapid lifestyle changes that occurred. A good family support network lessened caregiver burden by relying on other family members for practical and emotional support. (Hanna, Giebel, et al., 2022).

This study has several limitations. Firstly, although the results cannot be generalized, they can be applied to situations with similar characteristics. Secondly, the data collection was conducted through telephone interviews so that the collection of non-verbal information was limited and it was not possible to contrast verbal and non-verbal information. The use of telephone interviews to collect data might have influenced the willingness of participants to share their personal experience. Finally, when interpreting the results, it is necessary to take into account the diverse characteristics of the caregivers and the care they provided, as well as the degree of deterioration secondary to dementia. This diversity of care profiles and contexts at least partly explains the diversity in the lived experience of caregivers during the pandemic when it comes to the care they provided and the person they cared for.

CONCLUSIONS

This study shows how limitations in mobility due to the risk of infection, together with the disruption and changes in social and health care during the pandemic, had an impact on PLwDs and their family caregivers, with important consequences for daily life and well-being. Furthermore, our results reveal differences in the impact that the pandemic had on caregivers, PLwDs and the carrying out of care duties. In this regard, it is necessary to take into account the varied profiles of our participants and the fact that their lived experience can at least be partly explained by the status of the PLwDs, the characteristics of the care administered, such as amount of time dedicated to care, the use of formal resources for care, the family member's healthcare needs during the pandemic and the strategies adopted by caregivers to deal with it.

RELEVANCE FOR CLINICAL PRACTICE

The results of this study should help to increase the care for older persons with dementia, especially if they lack support outside the home and are socially isolated, as was the case during the pandemic. The care needs of older persons with dementia living at home have increased during the pandemic, highlighting the importance of continuity of nursing care. There is a need to strengthen support for family caregivers of older persons with dementia during health crises such as that experienced during the pandemic.

DECLARATION OF CONFLICTING INTERESTS

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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REFERENCES

Abbasi, J. (2020). Social Isolation - The Other COVID-19 Threat in Nursing Homes. *JAMA*, *324*(7), 619-620. https://doi.org/10.1001/jama.2020.13484

Abreu, W., Tolson, D., Jackson, G. A., & Costa, N. (2020). A cross-sectional study of family caregiver burden and psychological distress linked to frailty and functional dependency of a relative with advanced dementia. *Dementia*, *19*(2), 301-318. https://doi.org/10.1177/1471301218773842

Altieri, M., & Santangelo, G. (2021). The Psychological Impact of COVID-19 Pandemic and Lockdown on Caregivers of People With Dementia. *American Journal of Geriatric Psychiatry*, *29*(1), 27-34. https://doi.org/10.1016/j.jagp.2020.10.009

Azevedo, L., Calandri, I., Slachevsky, A., Graviotto, H., Vieira, M., Andrade, C., Rossetti, A., Generoso, A., Carmona, K., Pinto, L., Sorbara, M., Pinto, A., Guajardo, T., Olavarria, L., Thumala, D., Crivelli, L., Vivas, L., Allegri, R., Barbosa, M., ... Caramelli, P. (2021). Impact of Social Isolation on People with Dementia and Their Family Caregivers. *Journal of Alzheimer's Disease*, *81*(2), 607-617. https://doi.org/10.3233/jad-201580

Bonanad, C., García-Blas, S., Tarazona-Santabalbina, F., Díez-Villanueva, P., Ayesta, A., Sanchis Forés, J., Vidán-Austiz, M., Formiga, F., Ariza-Solé, A., & Martínez-Sellés, M.

(2020). Coronavirus: la emergencia geriátrica de 2020. Documento conjunto de la Sección de Cardiología Geriátrica de la Sociedad Española de Cardiología y la Sociedad Española de Geriatría y Gerontología. *Revista Española de Cardiología*, *73*(7), 569-576. https://doi.org/10.1016/j.recesp.2020.03.027

Borges-Machado, F., Barros, D., Ribeiro, Ó., & Carvalho, J. (2020). The Effects of COVID-19 Home Confinement in Dementia Care: Physical and Cognitive Decline, Severe Neuropsychiatric Symptoms and Increased Caregiving Burden. *American Journal of Alzheimer's Disease & Other Dementias*, *35*, 1-9. https://doi.org/10.1177/1533317520976720

Brant, H., Atherton, H., Ziebland, S., McKinstry, B., Campbell, J. L., & Salisbury, C. (2016). Using alternatives to face-to-face consultations: A survey of prevalence and attitudes in general practice. *British Journal of General Practice*, *66*(648), e460-e466. https://doi.org/10.3399/bjgp16X685597

Britt, K. C., Richards, K. C., Radhakrishnan, K., Vanags-Louredo, A., Park, E., Gooneratne, N. S., & Fry, L. (2023). Religion, Spirituality, and Coping During the Pandemic: Perspectives of Dementia Caregivers. *Clinical Nursing Research*, *32*(1), 94-104. https://doi.org/10.1177/10547738221115239

Brittain, K., Corner, L., Robinson, L., & Bond, J. (2010). Ageing in place and technologies of place: The lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health and Illness*, *32*(2), 272-287. https://doi.org/10.1111/j.1467-9566.2009.01203.x

Brown, E., Kumar, S., Rajji, T. K., Pollock, B., & Mulsant, B. (2020). Anticipating and Mitigating the Impact of the COVID-19 Pandemic on Alzheimer's Disease and Related Dementias. *American Journal of Geriatric Psychiatry*, *28*(7), 712-721. https://doi.org/10.1016/j.jagp.2020.04.010

Carbone, E., Palumbo, R., Di Domenico, A., Vettor, S., Pavan, G., & Borella, E. (2021). Caring for People With Dementia Under COVID-19 Restrictions: A Pilot Study on Family Caregivers. *Frontiers in Aging Neuroscience*, *13*, 652833. https://doi.org/10.3389/fnagi.2021.652833

Carcavilla, N., Pozo, A. S., Gonzalez, B., Moral-Cuesta, D., Roldan, J. J., Erice, V., & Remirez de Ganuza, A. (2021). Needs of Dementia Family Caregivers in Spain during the

COVID-19 Pandemic. *Journal of Alzheimer's Disease*, *80*(2), 533-537. https://doi.org/10.3233/JAD-201430

Carpenter, C., & Suto, M. (2008). *Qualitative research for occupational and physical therapists: a practical guide*. Wiley-Blackwell Publishing.

Chu, C. H., Donato-Woodger, S., & Dainton, C. J. (2020). Competing crises: COVID-19 countermeasures and social isolation among older adults in long-term care. *Journal of Advanced Nursing*, *76*(10), 2456-2459. https://doi.org/10.1111/jan.14467

Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. (2020). Living with dementia: increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics*, *32*(11), 1377-1381. https://doi.org/10.1017/S1041610220001593

Comas-Herrera, A., Zalakaín, J., Lemmon, E., Henderson, D., Litwin, C., Hsu, A., Schmidt, A., Arling, G., & Fernández, J. (2020). Mortality associated with COVID-19 in care homes: international evidence. In *International Long-term Care Policy Network.*

Creswell, J., & Poth, C. (2018). *Qualitative Inquiry and Research Design: Choosing among Five Approaches* (4th ed.). Sage.

Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of early dementia on outdoor life: A "shrinking world"? *Dementia*, *7*(2), 191-204. https://doi.org/10.1177/1471301208091158

Fragkiadaki, S., Kontaxopoulou, D., Stanitsa, E., Angelopoulou, E., Pavlou, D., Šemrov, D., Colnar, S., Lustrek, M., Blažica, B., Vučica, I., Matković, R., Vukojevic, K., Jelicic, A., Guzzi, P. H., Martinović, V., Medina, A. P., Piccoli, G., Menon, M., Kozetinac, S., ... Papageorgiou, S. G. (2023). How Well Did the Healthcare System Respond to the Healthcare Needs of Older People with and without Dementia during the COVID-19 Pandemic? The Perception of Healthcare Providers and Older People from the SI4CARE Project in the ADRION Region. *Geriatrics*, *8*(21), 1-13. https://doi.org/10.3390/geriatrics8010021

Giebel, C., Ivan, B., & Ddumba, I. (2022). COVID-19 Public Health Restrictions and Older Adults' Well-being in Uganda: Psychological Impacts and Coping Mechanisms. *Clinical Gerontologist*, *45*(1), 97-105. https://doi.org/10.1080/07317115.2021.1910394

Giorgi, A. P., & Giorgi, B. M. (2003). The descriptive phenomenological psychological method. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (243–273). American Psychological Association. https://doi.org/10.1037/10595-013

Greenberg, N., Wallick, A., & Brown, L. (2020). Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychological Trauma: Theory, Research, Practice, and Policy*, *12*(12(S1)), S220-S221. https://doi.org/10.1037/tra0000793

Hanna, K., Giebe, C., Tetlow, H., Ward, K., Shenton, J., Cannon, J., Komuravelli, A., Gaughan, A., Eley, R., Rogers, C., Rajagopal, M., Limbert, S., Callaghan, S., Whittington, R., Butchard, S., Shaw, L., & Gabbay, M. (2022). Emotional and Mental Wellbeing Following COVID-19 Public Health Measures on People Living With Dementia and Carers. *Journal of Geriatric Psychiatry and Neurology*, *35*(3), 344 -352. https://doi.org/10.1177/0891988721996816

Hanna, K., Giebel, C., Butchard, S., Tetlow, H., Ward, K., Shenton, J., Cannon, J., & Komuravelli, A. (2022). Resilience and supporting people living with dementia during the time of COVID-19; A qualitative study. *Dementia*, *21*(1), 250-269. https://doi.org/10.1177/14713012211036601

Hellewell, J., Abbott, S., Gimma, A., Bosse, N. I., Jarvis, C. I., Russell, T. W., Munday, J. D., Kucharski, A. J., Edmunds, W. J., Funk, S., & Eggo, R. M. (2020). Feasibility of controlling COVID-19 outbreaks by isolation of cases and contacts. *The Lancet. Global Health*, *8*(4), e488-e496. https://doi.org/10.1016/S2214-109X(20)30074-7

Hoel, V., Ambugo, E. A., Steinert, L., Schultz, T., & Wolf-Ostermann, K. (2021). Technology-driven dyadic interaction in caregiving. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *17* (*Supp.1*, e050637). https://doi.org/10.1002/alz.050637

Korstjens, I., & Moser, (2017). A. Series: practical guidance to qualitative research. Part 2: context, research questions and designs. *Eur J Gen Pract*; *23*(1): 274–279

Laver, K., Liu, E., Clemson, L., Davies, O., Gray, L., Gitlin, L., & Crotty, M. (2020). Does Telehealth Delivery of a Dyadic Dementia Care Program Provide a Noninferior Alternative to Face-To-Face Delivery of the Same Program? A Randomized, Controlled Trial. *American Journal of Geriatric Psychiatry*, *28*(6), 673-682.

https://doi.org/10.1016/j.jagp.2020.02.009

Manca, R., De Marco, M., & Venneri, A. (2020). The Impact of COVID-19 Infection and Enforced Prolonged Social Isolation on Neuropsychiatric Symptoms in Older Adults With and Without Dementia: A Review. *Frontiers in Psychiatry*, *11*(October), 585540. https://doi.org/10.3389/fpsyt.2020.585540

McKinstry, B., Hammersley, V., Burton, C., Pinnock, H., Elton, R., Dowell, J., Sawdon, N., Heaney, D., Elwyn, G., & Sheikh, A. (2010). The quality, safety and content of telephone and face-to-face consultations: A comparative study. *Quality and Safety in Health Care*, *19*(4), 298-303. https://doi.org/10.1136/qshc.2008.027763

Mok, V. C. T., Pendlebury, S., Wong, A., Alladi, S., Au, L., Bath, P. M., Biessels, G. J., Chen, C., Cordonnier, C., Dichgans, M., Dominguez, J., Gorelick, P. B., Kim, S. Y., Kwok, T., Greenberg, S. M., Jia, J., Kalaria, R., Kivipelto, M., Naegandran, K., ... Scheltens, P. (2020). Tackling challenges in care of Alzheimer's disease and other dementias amid the COVID-19 pandemic, now and in the future. *Alzheimer's and Dementia*, *16*(11), 1571-1581. https://doi.org/10.1002/alz.12143

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *European Journal of General Practice*, *24*(1), 9-18. https://doi.org/10.1080/13814788.2017.1375091

Norlyk, A., & Harder, I. (2010). What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies. Qualitative Health Research, 20(3), 420-431.

Numbers, K., & Brodaty, H. (2021). The effects of the COVID-19 pandemic on people with dementia. *Nature Reviews*, *17*(2), 69-70. https://doi.org/https://doi.org/10.1038/s41582-020-00450-z

Nussbaumer-Streit, B., Mayr, V., Dobrescu, A. I., A., Chapman, A., Persad, E., Klerings, I., Wagner, G., Siebert, U., Christof, C., Zachariah, C., & Gartlehner, G. (2020). Quarantine Alone or in Combination with Other Public Health Measures to Control COVID-19: A Rapid Review. *Cochrane Database of Systematic Reviews*, *4*, 1-45. https://doi.org/10.1055/a-1164-6611

Parmar, J., Anderson, S., Dobbs, B., Tian, P. G. J., Charles, L., Triscott, J., Stickney-Lee, J., Brémault-Phillips, S., Sereda, S., & Poole, L. (2021). Neglected Needs of Family Caregivers during the COVID-19 Pandemic and What They Need Now: A Qualitative Study. *Diseases*, *9*(4), 70. https://doi.org/10.3390/diseases9040070

Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *58*(2), 112-128. https://doi.org/10.1093/geronb/58.2.P112

Rising, K. L., Salcedo, V. J., Amadio, G., Casten, R., Chang, A. M., Gentsch, A., O'Hayer, C. V., Sarpoulaki, N., Worster, B., & Gerolamo, A. M. (2022). Living Through the Pandemic: The Voices of Persons With Dementia and Their Caregivers. *Journal of Applied Gerontology*, *41*(1), 30-35. https://doi.org/10.1177/07334648211036399

Schulz, R., & Sherwood, P. (2008). Physical and Mental Health Effects of Family Caregiving. *The American Journal of Nursing, 108(9 Suppl), 23-27.*, *108*(9 Suppl), 23-27. https://doi.org/https://doi.org/10.1097/01.NAJ.0000336406.45248.4c

Talbot, C., & Briggs, P. (2021). 'Getting back to normality seems as big of a step as going into lockdown': the impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age and Ageing*, *50*(3), 657-663. https://doi.org/10.1093/ageing/afab012

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349-357. https://doi.org/10.1093/intqhc/mzm042

Tousi, B. (2020). Dementia Care in the Time of COVID-19 Pandemic. *Journal of Alzheimer's Disease*, *76*, 475-479. https://doi.org/https://doi.org/10.3233/JAD-200461

Tsapanou, A., Papatriantafyllou, J. D., Yiannopoulou, K., Sali, D., Kalligerou, F., Ntanasi, E., Zoi, P., Margioti, E., Kamtsadeli, V., Hatzopoulou, M., Koustimpi, M., Zagka, A., Papageorgiou, S. G., & Sakka, P. (2021). The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. *International Journal of Geriatric Psychiatry*, *36*(4), 583-587. https://doi.org/10.1002/GPS.5457

Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., Sargunan, S., & Venkatesan, S. (2020). Experiences and Needs of Caregivers of Persons With Dementia in India

During the COVID-19 Pandemic-A Qualitative Study. *American Journal of Geriatric Psychiatry*, *28*(11), 1185-1194. https://doi.org/10.1016/j.jagp.2020.06.026

Velayudhan, L., Aarsland, D., & Ballard, C. (2020). Mental health of people living with dementia in care homes during COVID-19 pandemic. *International Psychogeriatrics*, *32*(10), 1253-1254. https://doi.org/10.1017/S1041610220001088

Wimo, A., Guerchet, M., Ali, G.-A., Wu, Y.-T., Prina, A. M., Winblad, B., Jönsson, L., Liu, Z., & Prince, M. (2017). The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's and Dementia*, *13*(1), 1-7. https://doi.org/10.1016/j.jalz.2016.07.150

World Health Organization. Dementia. World Health Organization (WHO). Avalilable at: https://www.who.int/news-room/fact-sheets/detail/dementia . Accessed July 22, 2023,

World Health Organization. Coronavirus Disease (COVID-19) Pandemic. Available at: https://www.who.int/emergencies/diseases/novel-coronavirus-2019 . Accessed July 23, 2023.

Table 1. Positioning of the researchers

Theoretical Framework The researchers based their approach on an interpretive paradigm. This paradigm is based on the assumption that human beings construct their own social reality and that knowledge is built through increasingly nuanced reconstructions of individual experiences.
Beliefs The lockdown and social distancing measures imposed during the pandemic, which were applied to the general population, did not take into account the particular needs of dementia patients and their family caregivers. This lockdown could have an impact on caregivers and caregiving performance.
Motivation for the Research To gain insight into the care provided to dementia patients through the first-hand experience of their caregivers. To describe and understand the caregivers' views on aspects they consider relevant to their needs, difficulties and impact on care and their role as caregivers during the pandemic.

Table 2. Question guide

Research Area	Questions
Impact of the COVID pandemic on the health of the person being cared for	How has the situation experienced during the pandemic influenced the person you care for? To what extent did it affect their health, behaviour, symptoms...?
Impact of the COVID pandemic on caregiver and caregiving performance	How did you experience the restrictions adopted during the pandemic (prevention measures, social isolation, lockdown...) as a caregiver? In your experience caring for your relative, did you experience any changes in the way you did things before the pandemic?
Health and social care during the pandemic	How did you experience the health and social care received during the pandemic (health centres, hospital, day centres)? What was that care like?

Table 3. Trustworthiness criteria.

Criteria	**Application procedures**
Credibility	Investigator triangulation: each data source was analysed. Thereafter, team meetings were held during which the analyses were compared, and themes were identified. Triangulation of data collection methods: including semi-structured interviews, and researcher field notes.
Transferability	In-depth descriptions of the study performed, providing details of the characteristics of researchers, participants, circumstances, sampling strategies, and the data collection and analysis procedures.

Dependability	Audit by an external researcher: an external researcher assessed the study research protocol, focusing on aspects concerning the methods applied and the study design.
Confirmability	Investigator triangulation, data collection triangulation. Researcher reflexivity was encouraged via the previous positioning, performance of reflexive reports and by describing the rationale behind the study.

Table 4. Caregiver, PLwD, care, and impact of the pandemic

ID	**Caregiver**				**PLwD**			**Characteristics of care**			**Impact of the pandemic**		
	Age	Gender	Marital status	Living with the cared person	Age	Tie	Years with dementia	Years	Hours /day	Formal Resources	On the PLwD	On the caregiver	On care
01	63	F	Married	0	95	Mother	5	5	20	No	No	Yes	No
02	48	F	Single	0	76	Mother	5	5	18	a	No	Yes	Yes

03	63	F	Married	1	93	Mother	9	9	4	a	No	Yes	No
04	53	F	Married	1	73	Mother	2	2	24	No	No	Yes	No
05	65	F	Married	1	93	Father	1	1	8	No	Yes	No	No
06	73	F	Married	0	79	Husband	12	6	17	e	Yes	Yes	Yes
07	56	F	Married	1	88	Mother	4	4	8	a	Yes	Yes	Yes
08	39	F	Married	0	91	Grandma	5	5	14	c	Yes	Yes	Yes
09	42	F	Married	0	87	Mother -in-law	4	15	24	No	No	Yes	No
10	63	F	Married	0	90	Mother	4	4	24	No	No	No	No
11	69	M	Married	1	92	Mother	5	5	12	d	No	No	No
12	74	F	Married	0	78	Husband	4	4	18	a	Yes	Yes	Yes
13	59	F	Single	0	84	Mother	12	12	15	c	Yes	Yes	Yes
14	70	F	Married	0	85	Husband	8	8	16	b	Yes	Yes	No
15	67	M	Married	0	64	Wife	5	5	18	b	Yes	Yes	Yes
16	47	F	Married	1	82	Mother-in-law	3	3	5	e	No	Yes	No
17	54	F	Married	0	88	Mother	7	7	24	No	Yes	Yes	Yes
18	73	F	Widower	1	97	Mother	8	8	10	c	Yes	Yes	No
19	65	F	Married	0	93	Father	4	4	18	b	Yes	Yes	No
20	66	F	Single	0	96	Mother	9	9	20	b	Yes	Yes	Yes
21	62	M	Married	1	87	Mother	4	6	3	c	Yes	No	Yes

Gender: F: Female, M: Male
Living with the cared person: 0:Yes, 1:No
Formal resources: ^{a} Paid caregiver; ^{b} Day Centre; ^{c} Paid caregiver and Day Centre; ^{d} Dependency Care Caregiver; ^{e} Dependency Care Caregiver and Day Centre

Table 5. Themes and sub-themes identified

Theme	**Sub-theme**
1. PLwD care during the pandemic	1.1. The management of the PLwD due to COVID-19 related knowledge and changes in daily routines
	1.2. Deterioration in the health status of the PLwD

2. Health and social care during the pandemic	2.1. Health services in Primary Care
	2.2. Admission to a hospital or a nursing home
3. Caregiver's perspective	3.1. Psycho-emotional impact on the caregiver
	3.2. Coping strategies adopted

Table 6. Narratives of themes

THEME 1. PLWD CARE DURING THE PANDEMIC
Sub-theme 1.1. Management of PLwD due to COVID-19 related knowledge and changes in daily routines

Not being aware of the pandemic because of the disease*: "She could not understand because, although she saw it on television, she was unable to grasp how serious the pandemic was (...) she, I tell you, was not really aware of what was going on".* (ID 2)

Difficult management due to cognitive difficulties in understanding lockdown: *"Then the lockdown began and of course, as his short-term memory was already damaged, he forgot that he couldn't go out. So the first two weeks were a war of 'you can't go out, you can't go out, you can't go to see your friend, you can't'. "Well, I'm going to buy bread". "You can't, I've already bought it, you can't go out, I don't want you to..."* (ID 13).

More difficult to manage at home during lockdown: "*Before lockdown you had to be with her, I tell you that when she was walking, you took her out for a walk, you had to be very careful and keep the keys in your pocket because she would run away, and during lockdown the same thing, worse, you couldn't go out with her and it was bad, because of course, she didn't understand why...".* (ID 17)

Not understanding the use of the mask: *"the mask thing was a drama (...) Well, a drama, the mask... "she has to wear a mask", she has the mask, she has masks at home but she doesn't want to wear them, because she's fine and she doesn't need to wear them, she's never worn them, why does she have to wear them? (...) And well, then we had the same fight as always".* (ID 11)

Rejecting the use of masks and keeping a safe distance: *"And that, the mask thing. 'It's just that this...'. Of course, well, when we were locked up, nothing, but then we had to wear a mask. 'Oh, to hell with the mask, it's silly, it's useless...'"* (ID19).

Not accepting the safety distance and the limited contact*: "Because when he returned from lockdown to the day centre, as all the regulations had changed, it was terrible for him. In the sense of the instructions he was asked to follow, such as, for example, not to sit in certain places, because of the safety distance. They only had to tell him that he couldn't sit in a chair for him to sit in that chair. He had a terrible time because he couldn't understand why he couldn't sit there (...). He was doing terribly because he couldn't understand why he couldn't sit there".* (ID 19)

Impact on the condition of the patient due to the closure of the day centre and difficulties in returning to routines: "*She was affected by not going to the day centre, which she liked. I could see she was less interested in going out, because she didn't like going for a walk in the wheelchair and she would get angry".* (ID 18)

Difficulty in returning to normality: *"There was a terrible drop in everything, physically and psychologically, because even when they started to let us go out in the street, well, he didn't want to go out. It was a struggle to get him out (...)*". (ID 19)

No management difficulties: *"As she was at home and was looked after and saw the three of us and all that, she wasn't unhappy or anything (...) she read her newspaper, she watched TV, she dozed there on the couch and no, she didn't feel bad (...)"* (ID 18).

No change in routines due to the pandemic: *"During the lockdown, there was no difference in our daily routine, we were practically here the whole day, we went out very little, I haven't noticed much difference".* (ID 9)

Sub-theme 1.2. Deterioration in the health status of the PLwD

Physical impairment and assistance in moving around: *"He's been in a wheelchair since the pandemic started. Before, he would take my arm, but when we got locked up, he couldn't hold himself up and I couldn't take him out of the house (...) my husband deteriorated more and I had to put him in a wheelchair".* (ID 12)

Loss of autonomy: "*(...) he went out every day, he took the car, he went to the where the pensioners gather, he came to the village, but well, he stayed at home and hasn't been the same, his character has changed, apart from the depression he had before, he was better, but he came and went, he went out, he came in, now nothing, he doesn't want to do anything".* (ID5)

Psychological impact: *"It's affected him emotionally. Knowing that there are a lot of people who are having a hard time was psychologically damaging. He was aware of the pandemic".* (ID 15)

Cognitive impairment: *"In the pandemic specifically her dementia was not as bad as it is right now, right now it's worsened in the last four or five months, it's been downhill (...), the worsening has been terrible, and with the pandemic even more so".* (ID2)

Prescription of drugs to stabilize: "*They gave her a pill to calm her down so she wouldn't be aggressive".* (ID17)

Deterioration due to the disease vs. the pandemic: *"We did everything for him, we helped him dress. My father's always read a lot, during the lockdown he continued reading, but he'd drop the book on the floor, he'd read the same page again, he'd start reading again anywhere and he didn't know if he was repeating it or not. Was that because of the lockdown, I don't know"*. (ID19)

Negative impact on his condition due to the closure of the day centre: *"During the pandemic they closed the day centre and the lockdown affected him a lot. Once he was locked down, he stayed here at home sitting down a lot, all day long. I frequently noticed that he could walk less and less, that he talked less and less... I would ask him something and his answer would be completely unrelated. He wasn’t in his normal state of mind, not like when he was in the day centre. His capacities were diminished".* (ID 6)

Affected by the loss of routines after closure of the day centre: *"She was very upset when they took away the day centre, very upset, because my mother is already at a point where she has to maintain a strict routine, because as soon as the routine is broken for any reason, she is very upset for a week".* (ID 13)

Affected by the closure of the day centre and not being able to attend the stimulation workshops: *"It affected her a lot. The day centre and the stimulation workshops were fundamental and she no longer had them. On an oral level, on a psychomotor level above all, that is to say, on the level of oral responses and mobility. When my mother went to the day centre, well, she already had quite advanced Alzheimer's, and thanks to the stimulation workshops, I noticed (...). Then at a motor level, although I tried to stimulate her, she gradually began to lose even more of the psychomotor skills she had for getting around the house. It was very noticeable".* (P20)

THEME 2: PLWD HEALTH CARE DURING THE PANDEMIC

Sub-theme 2.1. Health services in primary care

Face-to-face medical care. “*During the lockdown when the doctor had to come to see my mother, I had no problems or complaints about the system.”* (ID 10)

On-site nursing care. "*They’ve been treating an ulcer that he got, the nurse came no problem, we have the health centre here and they’ve been attending to him without any problem, during the pandemic as well*” (ID 3)

Health care via telephone without problems. “*They have, of course, consulted me over the phone, when I have had to consult them for my father or for prescriptions or whatever, with no problem".* (P7)

Difficulties establishing telephone communication: *"As a system it was terrible, because you would call the health centre and you could wait hours, literally hours, for them to answer the phone".* (ID 13)

Lack of health care due to lack of access to health professionals. *"In the middle of lockdown I asked for help, you couldn't go to the outpatient clinic in person, they wouldn't pick up the phone and if they did, my family doctor couldn't be reached, the nurse was swamped with work and I needed someone to guide me on how to treat my mother (...). So I had nowhere to go".* (ID 20)

Perception of abandonment. *"You feel abandoned. My mother has a slight fever and it's all on me. On top of that you call the doctor and you can't go and get her checked out, and I felt alone".* (P17)

Referral to hospital as an alternative: *"Now it's the same, if she doesn't have a very high fever they won't come and if she has a very high fever, it’s ‘Don't call me, take her to the hospital’".* (P17)

Privately guaranteeing home medical care in case of need: “*So I’ve hired a service called the Night Angels… it costs 26 euros. I call these people any time and they come to see my mother and treat her (...). And it’s sad that you have to pay for health insurance to say I have the security of knowing that a doctor will come to see her if I need one. It's sad, but that's the way it is.”* (P17)

Feeling fortunate for the health care received: *"Well, I'll tell you that I've had 10 out of 10 consultations, they haven't been cancelled.... Well, when I say I, I mean my mother. My mother has had lots of consultations, I can tell you, very, very many, very many and I have been extremely lucky".* (ID 4)

Satisfaction with the health system: *"I can only say good things, I can only say good things about the health system, only good things, because I’ve always felt supported, cared for, well, I’m very happy with the health system I have".* (ID14)

Personal gratitude to the assigned professionals for their professional involvement: *"Regarding my doctor, my parents' doctor, my parents' nurse, she is a goddess. I have nothing but gratitude, I mean, they’re always there, my parents' nurses (...) the nurse ended up giving me her personal mobile phone number so that if I needed something and I couldn't contact her I could call her directly. That's why I tell you, in a bad system, as people I’d give them a 10, but only because I can’t give them a 12".* (ID 13)

Sub-theme 2.2. Admission to hospital or residential care

Suffering during the isolation of the relative in residence: *"She was admitted in June and in August there was a COVID outbreak, which meant that all visits were stopped, you couldn't see her, they had to keep them isolated in the rooms, you could only contact the staff, because she was in a* *room and you couldn't understand her when it came to talking.... so it was a bit like living the whole pandemic in its purest form"* (ID 8).

Hardship of admission to the nursing home during the pandemic: *"It was a very bad time for her, she was isolated in the room for 14 days, alone, and then they came in with PPE. So it was very hard to go from being at home to being in the residence in those conditions (...) she went in there, a room with no one, alone and that was not her home, that was very hard, for her and of course for the others as well. She had a phone, we called her on the phone so that... I don't know, to be a bit closer, so that she could see that... and sometimes she cried (...) she wanted to go out, she wanted to leave, she didn't want to be there (...) she was in the room alone, in an unknown place and then when those people came in, it wasn't that a person came in and smiled at her and told her that nothing was wrong, they came in wearing that protective equipment, that was very hard. And then afterwards, I mean, when we went to see her and so on, she wasn't happy*". (ID 18)

A bad experience in their mother's admission to hospital: *"Fortunately she was only admitted for one day, but it was a bad experience, she looked at me with eyes like 'where have you brought me, where am I?' You take them away from the place they know..."*. (ID 3)

Interpersonal distance in the hospital and the effect on health communication: *"The doctor who attended her as she came into the room said to me: 'Go over there'. She would send me to the corner and I couldn't hear what she was saying, because of course, she spoke softly and I can't hear well, and I said: 'But I can't hear her from here'"*. (ID18)

THEME 3. THE CAREGIVER'S PERSPECTIVE

Sub-theme 3.1. Psycho-emotional impact

Physical and psychological overload of care: *"With the lockdown, I was very tired to move him, even physically because I couldn't sleep, so the ulcers that had started to appear on his buttocks wouldn't get better; in short, it affected me a lot, I needed external help for his care. Not on a psychological level, but on a physical level."* (ID 20)

Fear and loneliness in care: *"It's a hard illness, in itself it's very hard, but the lockdown was not only hard, it was fear, fear because you felt alone, you felt powerless, you saw that you couldn't ask anyone for help, because no one could get in there*". (ID 17)

Concern about the need for care: *"I was a bit worried that something would happen, that we would get sick, because they wouldn't take care of you in the hospital. I was afraid that something related to health would happen to us"*. (ID19)

Caring alone with no social life. "*More loneliness, you could only socialize with people at home, at home I had my husband, my daughter and so on but I don't know how to tell you, you miss talking to more people, having visitors, sharing, I don't know, a different life".* (ID 1)

Caring without rest. *"The lockdown made everything a bit more acute, I was alone, I had no escape route in any sense; otherwise you would go out, go for a walk, be with a friend, but you were locked in your own hell so to speak, you had no incentive of any kind, I was more alone than usual*". (ID 8)

Care as incarceration. *"Because I've been limited in what I can do. I was locked down all day with him. Anguished, unable to talk or anything. I could only talk on the phone, because I was locked down all day... my children comforted me a lot because I couldn't talk to him here"* [her husband with dementia]. (ID 12).

Obsession with contagion: *"During the lockdown, we only went out shopping, to the pharmacy, on errands, banks and home, we were not with anyone, only by phone. I changed my shoes, my clothes, I put them in the washing machine, I cleaned everything, it was crazy, really, I sprayed alcohol sprays on the soles of my shoes and left them in the street, washing my hands. It was an odyssey, my son said I was paranoid, obsessed, I said I was being careful".* (ID 9).

Panic, stress or anxiety about contagion: *"I had horrendous panic about going out and bringing the disease with me. I was nervous, I was sad, it was a very stressful situation, a lot of anxiety, fear, helplessness, mixed feelings, but all negative".* (ID 2)

Sense of responsibility: *"I was obsessed with not bringing home the disease, I couldn't afford to, the responsibility to my mother is very big*". (ID 4)

Fear of catching and transmitting the disease to the PLwD: *"At the beginning we were all afraid of passing it on to older people, because of everything, because of age, because my mother does not breathe well, she smoked a lot and well, a bilateral pneumonia is difficult to manage, and especially at the beginning there was also a lot of ignorance, but we didn't know how to deal with the virus".* (ID 21)

Remorse in the face of contagion: *"My greatest fear has been for her, out of remorse of conscience, that you go out, get it and bring it back; in the end she's the weak one".* (ID 9)

Panic, stress or anxiety due to contagion: *"We are the ones who have had the worst time... I had terrible panic about going out, even if it was to go shopping and possibly bringing the disease with me. So I was nervous, I was sad, it was a very stressful situation (...). A lot, a lot of stress, a lot of anxiety, a lot of fear, a lot of impotence, they were mixed feelings but all negative, all anxious because* *it created the anxiety of saying: ‘My God, what am I going to do if I bring it back and I have to take her to hospital?’. So it was... it was very, very stressful, very sad".* (ID 2)

Fear and worry about catching it: *"The fear was not of catching it, but for her, if I caught it, who would take care of her, it was me and my husband who went out to work. If one of us falls, I have to continue taking care of her, I can't depend on anyone".* (ID 9)

Tensions unloaded on the family: *"I lived through it with tiredness, depression and bad moods; my son told me that they were not to blame and I ended up taking it out on them. I agreed with them, there came a time when you exploded, it was hard, complicated, I smoked like a lorry driver. I would get out of bed, open my eyes and say ‘another whole day’. I don't know how to explain it, sometimes I didn't even feel like cooking".* (ID 17)

Experience as a carer without changes. *"Living through the pandemic without major changes: we didn't think we had a bad time either, I imagine that those who were single or so would have had a worse time, but we didn't really... we have coped well and we have endured".* (ID18)

Sub-theme 3.2. Coping strategies adopted

Adapting to difficulties: *"I have a great capacity for resilience, as they say nowadays, adapting to difficulties. So, well, that's what it was".* (ID 19).

Emotional distancing: *"It was very difficult for me, not taking care of her so much, it took a lot out of me psychologically, I have had to distance myself a little, although I feel very sorry for her, but it’s a feeling of psychological effort that sucks you in. Before, I used to go to work, I would come here, I distracted myself in other ways... it’s reached a point where I stay at home reading, doing something else so as not to spend so much time with her".* (ID 3)

Normalizing the situation: *"I have never thought about COVID, I have half-normalized it, I had to hug her to move her from the bed to the chair. If I had been infected I would have infected her, I can't avoid contact with her, what should I use, a screen, I’ve never been afraid of COVID, I was aware that if I caught it she was going to get it".* (ID 8)

Distraction with alternative activities: *"Now you think about it and it was hard during the lockdown, but having children made it easier to cope. I would paint my daughter’s face, she would paint mine and my grandmother would paint mine while she was watching us; at siesta time it was your escape, you would go down to the garden, have a barbecue there or jump with water balloons and it was your moment of escape".* (ID 9)

Tackling anxiety with medication: *"The pandemic has stressed me out a lot, I have treatment for anxiety and they had to increase the dose, I went shopping, I came home, I washed the packages, because after I touched it, I took it to my mother"*. (ID 2)