The Effects of COVID-19 Stress on the Quality of Life and Well-Being of Informal Caregivers of Persons with Dementia

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Abstract

Objective. The main objective of this study was to measure the extent of the relationship between COVID-19 Stress (CS) and both Quality of Life (QOL) and Well-Being (WB) in informal caregivers (ICs) of persons with dementia (PWD). The current gap in literature suggests that little is known about the IC experience throughout the novel and evolving COVID-19 pandemic. **Methods.** Participants were recruited both online Canada-wide and via the Bruyère Research Institute (BRI) between December 2021 and April 2022. The study employed a mixed-method approach and captured quantitative data via a self-report online survey using validated scales to measure COVID Stress (CSS), Dementia Caregiver QOL (C-DEMQOL), Carer Burden (ZBI-22), and Role Captivity. Qualitative data was collected via four open-ended questions which concluded the survey, to gather further information on the experiences of ICs throughout the pandemic. The statistical analysis employed for this study was Pearson's r for correlation. Thematic analysis was employed to interpret qualitative data. **Results.** No significant results were found between CS and both QOL and WB, though significant associations were found between specific scale and subscale measures for QOL and WB. Thematic analysis revealed three main themes within the qualitative data: (1) *increased burden on caregivers*, (2) *diminished quality of care for care recipients*, and (3) *lack of support and consideration by policy makers for caregivers*. The impact that the findings of this study can have are substantial, as it will begin the process of documenting the impact of the novel COVID-19 pandemic on ICs of PWD and, more specifically, within the Canadian demographic. This will be able to address the current gap in literature and more tentatively, provide data to advocate for informed policy making.

Keywords: Informal caregivers of PWD, COVID-19 Stress, Quality of Life, Well-being, Pandemic, Dementia

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Abbreviations Used Throughout This Manuscript

ADL: Activities of daily living

ADRD: Alzheimer’s disease and other related dementias

BPSD: Behavioural and psychological symptoms of dementia

C-DEMQOL: Dementia caregiver quality of life

CS: COVID Stress

CSS: COVID Stress Scales

CT: Centeredness Theory

IC/ ICs: Informal caregiver/ informal caregivers

LTCF: Long-term care facility

PI: Primary investigator

PWD: Person with dementia/ Persons with dementia

QOL: Quality of life

WB: Well-being

ZBI-22: Zarit Burden Interview (22 question format)

The Effects of COVID-19 Stress on the Quality of Life and Well-Being of Informal Caregivers of Persons with Dementia

In late 2019, an acute respiratory infection known as the novel coronavirus disease (COVID-19) was first identified and in March 2020, was declared as a global pandemic by the World Health Organization (Jenkins et al., 2021; World Health Organization, 2020). The onset of the COVID-19 pandemic has disrupted many crucial support services offered by global health care systems, which may have consequences on informal caregivers (ICs) of persons with dementia (PWD); a population that has often been known to face serious emotional, social, physical, and financial vulnerabilities in pre-pandemic times (Bussè et al., 2022; Quach et al., 2021). The COVID-19 pandemic has been widely regarded as a phenomenon of isolation, with several increased stresses within the general global population (Cohen, 2020). More specifically, it has been referred to as the "geriatric emergency of 2020" (Altieri and Santangelo, 2021). Altieri and colleagues (2021) highlight the extreme uncertainty that has characterized this pandemic and its consequences on ICs of PWD, which consider limited access to vital supports due to government-imposed lockdowns and public health protocols. Research highlights that the mental and physical well-being of both caregivers and care recipients is greatly affected by loneliness and social isolation (Altieri and Santangelo, 2021; Greenberg et al., 2020). Given the fact that informal caregiving for PWD can already have severe consequences of burden and role captivity, which is associated with feelings of isolation (Ringer et al., 2020), it is important to understand how the COVID-19 pandemic interacts with these compounding factors to impact the current QOL and WB of individual caregivers. Studies by Tsapanou and colleagues (2020) report increased physical and psychological burden for PWD and their caregivers, with increased worries that entire care systems will collapse due to caregivers possibly experiencing threats to their own well-being throughout this time. Taking actionable measures to conduct foundational research on the experiences of this population can expedite the process of implementing appropriate interventions to promote caregiver well-being, which in turn can also lead to higher quality of life (QOL) and well-being (WB) outcomes of those being cared for (Schumann et al., 2019). It has already been suggested by research that quite often the needs of ICs are overlooked by healthcare professionals (Bressan et al., 2020). Therefore, the thrust of a global health crisis warrants a critical examination of current caregiver states.

Informal Caregiving in the Context of Dementia

Impact on the Canadian Health Care System

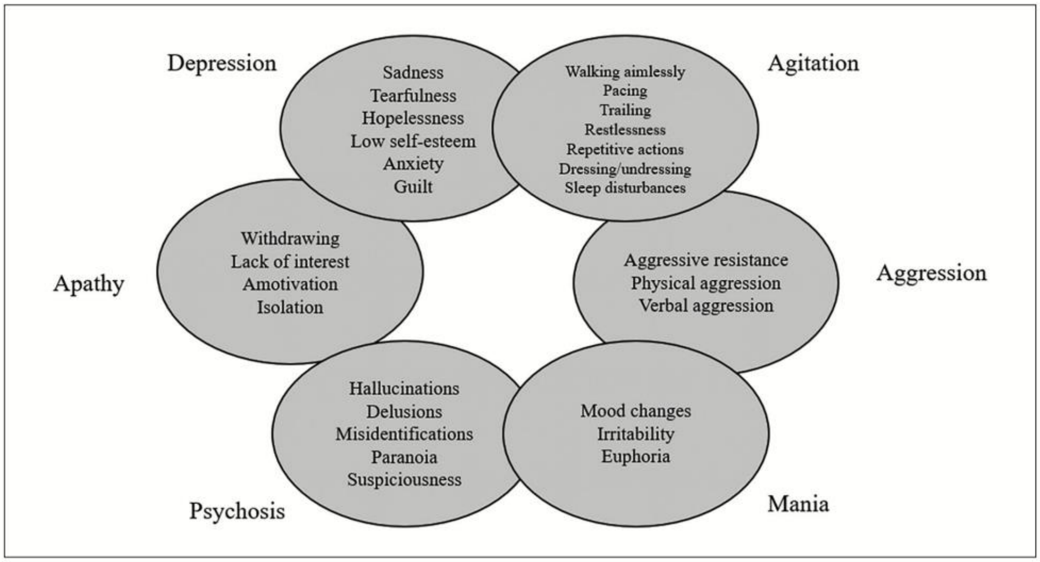
Informal caregiving in the context of dementia refers to unpaid voluntary care or support for a PWD that is made possible by individuals who are usually either a family member, friend, and/or neighbour (Khayatzadeh-Mahani and Leslie, 2018). In Canada alone, data suggests that 70%-90% of care at home for the elderly is provided in an informal context through these personal and caring relationships (Khayatzadeh-Mahani and Leslie, 2018). These individuals are known to be the backbone of homecare services for PWD; providing necessary emotional and social support, along with a wide-ranging list of complex nursing and clinical care tasks which include numerous activities of daily living (ADL) that are instrumental and/or basic in nature (Smith-Carrier et al., 2018). Informal caregiver contributions notably facilitate the sustainability of formal care systems (Khayatzadeh-Mahani and Leslie, 2018), with their economic contribution in Canada estimated at $25 billion per year (Hollander et al., 2009). As a result, it has been evidenced that the demands of informal caregiving for PWD, specifically, could possibly lead to decreased QOL outcomes for the caregiver if the role is maintained longer-term (Ruisoto et al., 2019). Previous studies have reported that caregivers of older adults with dementia experienced increased exacerbation of care-related stress compared to non-dementia caregivers, characterized by an intensification of the role due to conditions and increased feelings of captivity in their role (Bertrand et al., 2006). Bertrand and co-authors (2006) highlight through their own studies and by thorough examination of the literature that grouping caregivers within a homogenous group is likely to overestimate or underestimate caregiver relationships to stress; citing that caregivers of those with Alzheimer’s disease or related dementias often report higher stress and care recipient challenges compared to non-dementia caregivers due to specific physical and emotional demands related to dementia diagnoses. Stall and colleagues (2019) bring attention to informal caregiving being assessed as a key issue in dementia care by the World Health Organization due to its impact on sustaining national economies and optimizing the QOL of PWD. As Bressan and colleagues (2020) argue, the well-being, health, and quality of life of this population and the role they play in sustaining care systems should be a public health priority.

Managing Comorbidities and BPSD in PWD

Alzheimer’s disease or related dementias (ADRD) are characterized as both chronic and progressive diseases that impact cognitive, psychological, behavioural, physical, and social function (Harris and Titler, 2022). Harris and Titler (2022) purport that older PWD are more susceptible to a variety of behavioural and psychological symptoms of dementia (BPSD) due to cognitive impairment that often informs their overall perceptions and reactions differently. PsychDB (2022) reports that 90% of PWD will develop BPSD, with symptoms that may include but are not limited to delusions, hallucinations, aggression, screaming, restlessness, wandering, depression, and anxiety. It has been suggested that managing BPSD has its own set of challenges based on medication often having an adverse impact on older adults with dementia and limited community resources that employ non-pharmacologic interventions (Harris and Titler, 2022). The literature confirms that BPSD results in increased caregiver burden, decreased QOL, rapid cognitive decline in PWD, and increased financial burden (PsychDB, 2022). The literature also notes that the prevalence of comorbidities in PWD is quite high (Dementia statistics hub, 2022; Liu et al., 2019). As per Harris and Titler (2022), who referenced the work of McShane (2000), BPSD include agitation, aggression, mania, psychosis, apathy, and depression. Therefore, ICs of PWD are faced with high care demands which pose substantial physical and emotional health risks for them (Altieri and Santangelo, 2021; Cipolletta et al., 2021; Harris and Titler, 2022; Liu et al., 2019; Pongan et al., 2021). The figure below provides a more detailed illustration of how some of these symptoms may manifest in PWD.

Figure 1

Behavioural and Psychological Symptoms of Dementia (BPSD)



Note. As adapted by Harris and Titler (2022) from McShane (2000).

As noted above, the needs of informal caregivers of PWD are often overlooked by healthcare professionals and, due to the intense physical and emotional demands of their roles, this increases their likelihood of requiring healthcare services themselves (Bressan et al., 2020). Furthermore, a difficult-to-navigate care system (Smith-Carrier et al., 2018) and a projected increase of PWD in the decades to come (Manuel et al., 2016), paired with the thrust of a novel pandemic, indicates a potentially troublesome trajectory for informal caregivers.

COVID-19 Stress

In his work on the psychology of pandemics, which was published weeks before the reported global outbreak of COVID-19, Taylor (2020) brings attention to the uncertain, confusing, and often panic-inducing nature that characterizes a pandemic. Taylor (2020) notes that this uncertainty and confusion floods various domains of consideration, from both the odds and seriousness of becoming infected in earlier stages, to questioning whether a pandemic is truly over in later stages; acknowledging that a pandemic can potentially come in several waves. Taylor (2020) also speaks to possible misinformation regarding prevention and management that may add to confusion and uncertainty. Taylor’s (2020) work acknowledges the myriad of potential psychosocial stressors that must also be considered in a pandemic that include, but are not limited to, health threats to oneself and loved ones, service and routine disruptions, social isolation, personal financial hardship, and shortages of essential medical and food supplies. The experience of COVID-19 has been no exception.

Emerging literature recognizes that the COVID-19 pandemic has had an adverse psychological impact within the general global population that has intensified due to the prolonged isolation of quarantine measures, and can be observed through symptoms of post-traumatic stress, anxiety, and anger related to the pandemic (Brooks et al., 2020; Sánchez-Teruel et al., 2022). Jenkins et al. (2021) highlight that overall, Canadian populations are currently facing declining mental health and coping skills as a result of the pandemic. Furthermore, they report that vulnerable populations within the Canadian demographic that were already exposed to health, social, and/or structural inequities pre-pandemic were at higher risk for deterioration of mental and emotional health (Jenkins et al., 2021).

Research from the Angus Reid Institute (2020) states that 50% of the 1900+ Canadians they surveyed in April 2020 reported a worsening of their mental health throughout the pandemic, with 10% overall describing that their mental health had worsened “a lot”. This same study confirmed that based on the individuals surveyed, Canadians were most likely to identify as worried (44%), anxious (41%), bored (30%), yet also grateful (34%) when thinking about their experience throughout the COVID-19 pandemic (Angus Reid Institute, 2020).

Brooks et al. (2020) acknowledge that, while quarantine in certain cases may be a more effective option than no quarantine at all, depriving individual liberties for public health policy is a contentious matter that needs careful attention. Brooks et al. (2020) suggest that clarity in communication and the information disseminated regarding the pandemic, finding meaningful activities in quarantine, availability of essential supplies, and reinforcing a sense of altruism are a few ways to promote well-being throughout the isolating factors of the pandemic.

Informal Caregivers Throughout the COVID-19 Pandemic

Compounded Challenges

As expressed by Cipolletta et al. (2021), the pandemic and the associated lockdowns were unfamiliar experiences that only amplified existing problems associated with caregiving for a PWD. It has been documented that ICs of PWD have historically experienced a multitude of challenges in their role, which only became further compounded by the pandemic (Cipolletta et al., 2021; Harris and Titler, 2022). Those living with dementia have been recognized as more vulnerable to contracting Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) for reasons beyond old age and medical comorbidities (Mok et al., 2020; Sánchez-Teruel et al., 2022). The results of a study done by Taneska (2021) show that ICs experienced exacerbated BPSD of their care recipients throughout COVID-19, while managing limited access to facilities and their care recipient, along with a fear of becoming infected and transmitting the virus to their care recipient.

Social Distancing, Lockdown, and Public Health Protocol: The Evolution of BPSD

Not only must caregivers of PWD manage the cognitive decline of their care recipients in undertaking daily activities throughout non-pandemic times, the COVID-19 pandemic has also introduced potential challenges in PWD comprehending, executing, or recalling implemented public health measures such as wearing masks or social distancing (Mok et al., 2020). Furthermore, PWD dependency on others for basic activities of daily living poses a direct challenge to caregivers realistically being able to implement many physical distancing protocols (Mok et al., 2020). This has not only created an increased workload and scope of care provided by ICs throughout the pandemic, but brought to light a multitude of personal pandemic-related stressors that have a potentially compounding effect on their QOL and overall wellness. Meanwhile, changes in living conditions have brought about new rules for social functioning, characterized by lockdown measures and the suspension of support and care systems; evidencing a link between the evolution of BPSD in PWD and its consequences of poorer mental health on their caregivers (Pongan et al., 2021).

Service Disruptions and Loss of Social Support

Recent data suggests that the rise of the COVID-19 pandemic has provided a bold reality check that there are many gaps in social welfare that hinder access to proper care and support for PWD and their caregivers (Tsapanou et al., 2020). Greenberg et al. (2020) state that restrictions of community-based supports due to the pandemic have a significant impact on the emotional and physical well-being of an IC of an older adult with dementia. With many anxieties surrounding the potential collapse of care systems in the face of this global crisis, the physical and psychological burden of caregivers for PWD has notably been on the rise (Tsapanou et al., 2020). Service disruptions associated with the COVID-19 pandemic introduced a potential increase in the care responsibilities of ICs, particularly with mandatory medical tasks that they may not have felt adequately trained or equipped to take on (Greenberg et al., 2020). Wong and colleagues (2021) observed that caregiver stress was compounded by diminished social services throughout the pandemic, with the cessation of daycare services notably leading to higher caregiver stress and challenges with mood and functional decline in PWD. Maffioletti and colleagues (2021) confirm that social isolation is a risk factor for dementia and puts both PWD and their caregivers at risk, while other literature reports that an IC's perception of social connection and access to social supports can be a protective factor that promotes resilience (Altieri and Santangelo, 2021; Sánchez-Teruel et al., 2022).

Observed Deterioration

Research done by Tsapanou et al. (2020) reported a significant overall decline in older PWD as an effect of COVID-19, with the domains of mood, communication, movement, and compliance with newly imposed measures as most affected. The literature also points to lockdown measures as having exacerbated mental health outcomes in ICs of PWD, with individuals with lower levels of resilience being presented as more vulnerable to an increase of adverse symptoms (Altieri et al., 2021). A study by Hwang and colleagues (2021) found that quarantine likely led to increased caregiver burnout, with post-traumatic stress symptoms, confusion, and/or anger as reported psychological outcomes due to in-home confinement and reduced social and physical activity to cope. The same study by Hwang and colleagues (2021) reported an increase in caregiving duties and financial burden due to quarantine, which may have increased anxiety-related symptoms in caregivers. Meanwhile, Masterson-Algar and colleagues (2021) conducted a scoping review that highlighted nine studies reporting adverse outcomes on apathy, anxiety, agitation/aggression, and depression on PWD throughout the pandemic. Many studies confirm that the COVID-19 pandemic and lockdown measures have had negative physical and psychological consequences on ICs of PWD (Altieri and Santangelo, 2021; Hwang et al., 2021; Masterson-Algar, 2021; Tsapanou et al., 2020).

Long-Term Care Considerations

Prins et al. (2021) suggest that even when PWD enter a long-term care facility (LTCF), many of their ICs continue being an integral part of their regular care. The involvement of these ICs in caring for PWD living in LTCFs also influences factors related to their own mental health, possibly contributing to positive emotional and relational outcomes (Prins et al., 2021). It is important to consider the potential impact that lockdown and visitor restriction may have had in the IC's ability to ensure relationship continuity with the PWD and provide various types of support, which may have negative mental health consequences on PWD and their caregivers (Prins et al., 2021).

Quality of Life (QOL)

Literature by Farina et al. (2020) emphasizes the multifaceted construct of the term Quality of Life in research, which embodies the culture and value systems an individual lives in and their perception of their position within this context and in relation to their aspirations, standards of living, expectations, and concerns. Providing care for a PWD is known to impact all domains associated with QOL which includes but is not limited to physical, psychological, social, and economic areas of consideration (Daley et al., 2018; World Health Organization, 2021). Brown and colleagues (2019) suggest that generic models of QOL are unlikely to adequately capture the complexity of caring for a PWD. This realization encouraged their work to develop the C-DEMQOL tool, which was constructed to attend to nuances unique to the experiences of ICs of PWD, as it pertains to their QOL (Brown et al., 2019). The constructs of the scientifically validated C-DEMQOL tool consider carer responsibilities and personal needs, carer well-being, carer role and relationship with the PWD, feelings about the future, and carer support (Brown et al., 2019). Farina et al. (2020) purport that there is currently mixed evidence about the relationship between QOL and severity of cognitive impairment in PWD however, they acknowledge that to-date, the less researched field of carer QOL suggests that there is often no association found between these two variables. Rather, the data emerging on carer QOL tends to point to carer burden and depression, along with behavioural problems, as factors more consistently associated with lower QOL in caregivers of PWD (Farina et al., 2020). The study conducted by Farina et al. (2020) concluded that factors such as carer burden play a more critical role in poorer carer QOL and that the severity of impairment of the PWD does not automatically relate to lower carer QOL scores. However, Farina et al. (2020) acknowledge that an indirect effect between disease severity and QOL may occur through increasing carer burden and depression. Brown et al. (2019) also point to aspects of personal fulfillment in the caregiving role which could potentially strengthen one’s sense of self and their relationship with their care recipient, and possibly contribute to increasing a caregiver’s QOL.

Well-Being (WB)

Within the Context of Dementia

The concept of well-being, when associated with dementia, has been conceptualized through a variety of lenses without a solid consensus on its precise definition (Miller et al., 2019). Miller et al. (2019) highlight that researchers within the dementia context are likely to employ measures of QOL and depressive symptoms, in some cases in combination with other measures, to represent physical and mental health aspects of one’s well-being. Miller et al. (2019) speak of more than one construct being helpful to provide a comprehensive definition of well-being within the context of dementia. Miller et al. (2019) hint at caregivers’ assessment of their care recipient’s diagnosis often being more negative than the PWD’s assessment of their own diagnosis, and that the anticipation of an impending decline in the PWD could also adversely impact caregiver well-being.

Carer Burden and Role Captivity as Proxy Measures for Well-Being

Bressan et al. (2020) note that the vital role of ICs of PWD and their associated responsibilities increase their risk of becoming an “invisible second patient” due to emotional and physical stressors associated to caregiver burden, such as depression, physical illness, depleted social networks, low QOL, and financial challenges. It has been suggested that caregivers of PWD are also likely to experience burden to a higher degree than other caregivers, partly due to the anticipatory grief associated with the typical onset and evolution of dementia symptoms (Cipolletta et al., 2021). A pre-pandemic study conducted by Ringer and colleagues (2020) employed thematic analysis to identify sub-themes of caregiver burden for ICs of PWD, which were characterized by fatigue and poor sleep, physical toll including exacerbation of an existing injury or condition, feeling overwhelmed by work and responsibilities, isolation and role captivity. The same pre-pandemic study recorded insufficiency of supports, while acknowledging that caregivers were already accessing a variety of supports through government and personal networks (Ringer et al., 2020). Increased caregiver burden is associated to caregivers of PWD, as 98% of those with ADRD exhibit BPSD, which can also influence cases of elder abuse, increased health care costs, and premature transitions to long-term care (Harris and Titler, 2022; Stall et al., 2018). Research has highlighted the likeliness of increased burden on caregivers of PWD, noting that there are often comorbidities with dementia diagnoses that point to behavioural issues or depression, which can also have adverse consequences on the care provided and the conditions in which it is provided in (Greenberg et al., 2020). A study by Bussè and colleagues (2022) reported negative outcomes for PWD and their caregivers due to social isolation brought on by the pandemic, while also highlighting the prevalence of caregiver burden even in a non-pandemic context due to psychologically and physically stressful tasks. A study by Tsapanou and colleagues (2020) reported increases in burden within their study sample, with 64.7% reporting a serious increase in physical burden and 80% reporting a serious increase in psychological burden, while also noting the effect of limited support sources throughout the pandemic.

The concept of role captivity is described as the involuntary assumption of the caregiver role (Alspaugh et al., 1999; Givens et al., 2014; Pearlin et al., 1990). Furthermore, a study by Alspaugh et al. (1999) concluded that a powerful predictor for assessing chronic risk for clinical depression in caregivers of PWD is caregivers' feelings of captivity in their role. Pearlin et al. (1990) share that role captivity is an intrapsychic strain, which is supported by Alspaugh et al.'s (1999) assessment that role captivity is a subjective stressor which differs from objective stressors related to a care recipient's behavioural challenges. Furthermore, supportive literature from Givens et al. (2014) is clear in distinguishing that the concept of role captivity is separate from the challenges one faces in the required caregiving tasks. Rather, role captivity focuses on the sense of self of the caregiver, as activities of caregiving create changes that come to symbolize the life and identity of the individual (Pearlin et al., 1990). Research by Harris and Titler (2022) suggests that increased reliance on caregivers throughout the pandemic often affected caregivers' degree of independence, which hinders a collaborative dynamic within the care partner dyad.

Dyadic Considerations

Findings from Harris and Titler (2022) postulate interconnectedness between the experiences of care recipients with ADRD and their informal caregivers, which are consistent with theories of interdependence which substantiate the dynamically interactive and interdependent nature of the health, wellness, and behaviours of the dyad. Research maintains the significance of viewing the care recipient and caregiver relationship as a partnership, as opposed to a one-directional relationship, and asserts the notion that health care providers should be attuned to the complex needs of the dyad (Harris and Titler, 2022; Miller et al., 2019).

The Rise of Virtual Care Options and Virtual Connection Throughout the Pandemic

The onset of the pandemic introduced creative and novel approaches for PWD and their caregivers to access certain health care services and social networks through technology-based interventions, in lieu of face-to-face meetings (Masterson-Algar et al., 2021). Ho-yin Lai and colleagues (2021) recognize that telehealth offered through video conference platforms was associated with improved resilience and well-being throughout the pandemic to both PWD and their caregivers, as opposed to telephone interventions alone. Observations by Hwang and colleagues (2021) shed light on protective coping strategies that assisted in managing stress throughout the pandemic, which included virtual church services, telephone calls, and television game shows. A study by Wong et al. (2021) reported the adverse consequences of the cessation and decrease of crucial day programs on PWD and their ICs, and urges for ongoing development of online interventions as an alternative option in delivering social stimulation to PWD and providing caregiver support. Additionally, concerns have been presented with virtual options replacing face-to-face social activities and support services, with the argument that they should instead serve simply as a supplement to PWD and their caregivers in these circumstances (Masterson-Algar et al., 2021). Masterson-Algar and colleagues (2021) also acknowledge the aging demographic typically associated with PWD and their caregivers, which may present challenges in accessing language, perception, and cognitive function related to the use of advanced technology. Similarly, Harris and Titler (2022) conclude that though at-home support strategies should be prioritized throughout this time, these strategies should not rely on internet access, as a significant portion of this population reported lacking digital access at home.

Meaning-Making and Resilience

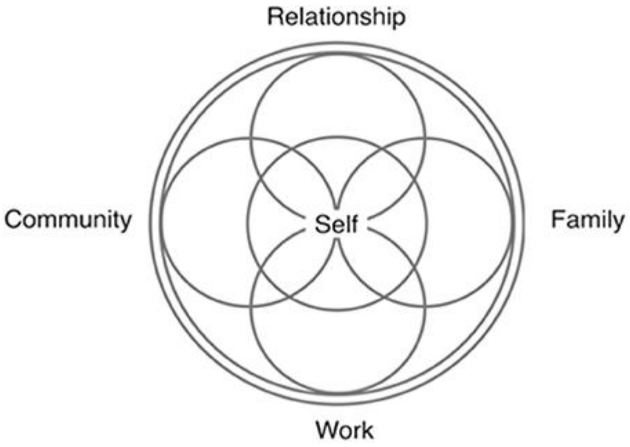
It is also beneficial to note the positive aspects that are associated with the role of caregiving, where individuals reported a sense of pride and purpose that was directly related to the activities assumed by the caring role (Grover et al., 2017). The study by Taneska (2021), mentioned earlier, also acknowledges that the pandemic has resulted in more free time for caregivers to attend to their care recipients. A study conducted by Cipolletta et al. (2021) reported that social connection was integral in overall resilience by providing motivation for care recipients while also providing caregivers with an opportunity to receive practical and psychological support. In a study by Tulloch et al. (2022), ICs reported unexpected benefits throughout the pandemic which included the ability to develop closer relationships with their care recipient, family, and even paid caregivers; with the desire to continue this closeness post-pandemic. Additionally, Tulloch et al. (2022) recognize that the flexibility and creativity required throughout the pandemic to adjust perspectives, behaviours, and attitudes can contribute to meaning-making experiences for caregivers. Even for ICs whose care recipient is in a LTCF, research has noted that their involvement in care can have positive outcomes on their mental health, which includes emotional incentives such as personal growth, appreciation for their role, and relationship strength (Prins et al., 2021).

Centeredness Theory (CT) in Psychology: A Paradigm for Well-Being at a Systems Level

Centeredness Theory (CT), developed by Bloch-Jorgensen and colleagues (2018), is a relatively novel paradigm in Western psychology which conceptualizes well-being through a systems approach to self-actualization; the ability for an individual to realize their full potential. These systems include the five life domains of self, relationship, family, work, and community, with the self being a central and internal measure among the other four exogenous domains, as illustrated in Figure 2 (Bloch-Jorgensen, 2015; Bloch-Jorgensen et al., 2018). The study conducted by Bloch-Jorgensen and colleagues (2018) explored the constructs and psychometric properties of their novel CT scale, inspired by CT theory, which was created to measure well-being using constructs of centeredness. Their research validated the psychometric properties of the CT scale by measuring it against existing well-being and mental health measures, along with confirming internal consistency and reliability (Bloch-Jorgensen et al., 2018).

Figure 2

The Five Domains of Centeredness Theory



Note. This figure was created by Bloch-Jorgensen et al., Frontiers in Psychology, 2018. Copyright by Bloch-Jorgensen, Cilione, Yeung and Gatt. Their work is an open-access article distributed under the terms of the Creative Commons Attribution License (CC BY). This figure illustrates the five domains posited by Centeredness Theory.

CT maintains a heuristic model of mental balance and is grounded in an open-systems approach which suggests that all five life domains are interconnected and that balance or imbalance in one particular domain will have an impact on whether other domains are balanced or imbalanced (Bloch-Jorgensen et al., 2018). The homeostatic need to achieve balance provides the theoretical framework for CT, which is based on achieving balance between one's inner state and outer environment (Bloch-Jorgensen et al., 2018). Bloch-Jorgensen et al. (2018) suggest that promoting balance between the self and exogenous domains, as well as within domains, is achieved when meaningful goals exist in all five domains and balance is achieved within and between all domains through congruent thoughts and behaviours that align with one's personal values.

Self

Bloch-Jorgensen et al. (2018) define the self by the subdomains of inspiration, contentment, adaptability, and awareness. Their validated measure considers each subdomain and its interrelationship with the other subdomains that comprise the Self measure (Bloch-Jorgensen et al., 2018). According to Bloch-Jorgensen and colleagues (2018), high Self scores indicate a strong sense of self and personal identity, while also assessing the degree to which an individual is hopeful for their future and works actively toward meaning-making through intrinsically rewarding goals. When contemplating the literature regarding role captivity and its intrapsychic and subjective qualities, a strong sense of self can be a powerful predictor in reducing the likelihood of this phenomenon in a caregiver (Alspaugh et al., 1999; Givens et al., 2014; Pearlin et al., 1990). Furthermore, as Prins and colleagues (2021) add, personal growth experienced in the caregiving role can serve as an emotional incentive that could foster resilience.

Relationship

Bloch-Jorgensen et al. (2018) describe the domain of Relationship through the four subdomains of attentiveness, enrichment, connection, and understanding. They purport that the domain of relationship identifies the degree to which an individual is able to relate intimately and maintain both deep and rich connection with another (Bloch-Jorgensen et al., 2018). Bloch-Jorgensen and colleagues (2018) state that optimal Relationship scores suggest that the individual finds significant meaning and satisfaction in their relationship(s). In referencing theories of interdependence and interconnectedness, research suggests that a dynamically interactive partnership in the caregiving and care receiving relationship contributes to increased overall well-being (Harris and Titler, 2022; Miller et al., 2019). Furthermore, as Prins and colleagues (2021) add, relationship strength experienced in the caregiving role can serve as an emotional incentive that could further develop resilience.

Family

Bloch-Jorgensen et al. (2018) conceptualize the domain of Family through the four subdomains of care, participation, communication, and receptiveness. Bloch-Jorgensen and colleagues (2018) argue that a strong Family score is indicative of a cohesive sense of family and familial belonging and, similar to the Relationship domain, is also able to measure the ability that an individual has to foster meaningful bonds. Furthermore, they contend that high scores in this domain are representative of tenacity, self-control, the ability to be responsive in emotionally challenging situations, and the ability to optimize meaning-making opportunities that mutually strengthen bonds (Bloch-Jorgensen et al., 2018). Given that many informal caregivers are family members (Khayatzadeh-Mahani and Leslie, 2018), this speaks to the importance of strength in both the dyadic relationship (Harris and Titler, 2022; Miller et al., 2019), as well as the family unit and extended family as an overall system of support to foster resilience (Cipolletta et al., 2021; Tulloch et al., 2022). Additionally, Tulloch et al. (2022) credit caregiver flexibility and creativity to the development of meaning-making experiences in their caregiving interaction with family members with dementia throughout the pandemic.

Work

Bloch-Jorgensen et al. (2018) illustrate the domain of Work through the four subdomains of innovation, supportiveness, engagement, and accountability. Bloch-Jorgensen and colleagues (2018) state that a strong Work score demonstrates that an individual is both an active and productive contributor in the workplace, while also indicating the degree to which an individual finds their work filled with meaningful and purposeful activity. The role of an informal caregiver, though unpaid and voluntary, is work filled with complex nursing and clinical care tasks, as well as necessary emotional and social support (Smith-Carrier et al., 2018); contributing to the sustainability of formal care systems (Khayatzadeh-Mahani and Leslie, 2018), with an estimated $25 billion dollar economic contribution in Canada alone (Hollander et al., 2009). Grover and colleagues (2017) highlight the positive impacts on the caregiving role that contribute to well-being, which involved individuals reporting a sense of pride and purpose that was directly related to the activities assumed by the caring role. Furthermore, as Prins and colleagues (2021) add, appreciation for the caregiving role can serve as an emotional incentive that could contribute to the development of resilience.

Community

Bloch-Jorgensen et al. (2018) define Community through the four subdomains of confidence, sympathy, empathy, and sensitivity. Bloch-Jorgensen et al. (2018) contend that the Community score considers a group of people either living in the same place and/or unified by a common interest. They elaborate by suggesting that this could include one’s local community, wider community, and the world as a body of nation states unified by common interest and amplified by unprecedented accessibility to information through media, internet, and international travel (Bloch-Jorgensen et al., 2018). Research highlights the importance of community in supporting a caregiver’s emotional and physical well-being in their highly demanding role (Greenberg et al., 2020), whether it is care through community-based health and care support services (Greenberg et al., 2020; Tsapanou et al., 2020) or social supports that provide a sense of connection to both caregivers and care recipients (Altieri and Santangelo, 2021; Sánchez-Teruel et al., 2022). As noted by Cipolletta et al. (2021) earlier, social connection was a general predictor of overall resilience; providing motivation for care recipients while also giving caregivers an opportunity to be supported in their role through both practical and psychological support.

Reframing Stress, Mindfulness, Awareness, and Formulating Meaningful Goals

Bloch-Jorgensen and colleagues (2018) cite the ability to reframe stress, be mindful, cultivate awareness, and formulate meaningful goals as mechanisms which assist in enhancing each system and ensuring that a fit which complements intrinsic goals is both created and maintained between the self and exogenous environments. Furthermore, they imply that with centeredness, each domain may expand and be mastered, and one can achieve higher states of well-being and self-actualize by incorporating these skills together (Bloch-Jorgensen et al., 2018). Similarly, and as aforementioned, literature by Tulloch et al. (2022) recognizes that the ability to be flexible and creative in adjusting perspectives, behaviours, and attitudes can foster resilient qualities in caregivers throughout this time.

The Medicine Wheel: An Enduring Symbol and Concept of Well-Being

Given that Centeredness Theory is considered a relatively novel paradigm for well-being within Western psychology, it is worthy to note that many principles regarding the holistic nature of well-being and the importance of balance to achieve well-being have historically been present within the traditional teachings of the medicine wheel (Gray, 2012). The medicine wheel remains a longstanding symbol and concept of well-being among various, though not all, Indigenous nations; aiding to visualize and verbalize cultural values and beliefs regarding overall health, over several generations (Gray, 2012). The four quadrants of the medicine wheel represent spiritual, physical, emotional, and mental elements of the self (Murdoch-Flowers et al., 2019). While Indigenous teachings regarding the medicine wheel are vast and vary from nation to nation, approaches to health are attributed to holistic living via balance between all elements found on the wheel (Montour, 2000). Individuals who strive to live in balance with the medicine wheel are thought to be happy, productive, and embody the spiritual capacity to share, care, trust, and respect others (Murdoch-Flowers et al., 2019). Traditional Indigenous healing cites that when there is a lack of balance between the four quadrants, this is both the cause and effect of poor health (Murdoch-Flowers et al., 2019).

The Evolving Nature of the Pandemic and the Need for Continued Research

Research conducted by Tsapanou et al. (2020) confirms that the pandemic threatens the mental and physical health of caregivers, and that the evolution of the virus warrants continual data collection to address the matter. Due to the evolving nature of the pandemic, the significance of ongoing exploration of the experiences of ICs of PWD and their care recipients has been emphasized to better understand their unique experiences and needs (Harris and Titler, 2022). A study by Pongan et al. (2021) depicts the upsurge in COVID-19 cases and likeliness of new lockdowns being enacted, which suggests that there is an ongoing need for research to reflect the progression of the impact of the COVID-19 pandemic on ICs of PWD as time goes on. It has been suggested that additional research is required on the experiences of caregivers to bridge gaps between ICs of PWD, their care recipients, community-based supports, clinicians, and researchers (Harris and Titler, 2022).

According to a recent study by Bacsu et al. (2021), they concluded that a significant gap in research exists to address the impact on COVID-19 from the perspective of caregivers of dementia. It has been noted that such research is required to provide evidence-informed data to influence policy making aimed to support these individuals throughout this global crisis (Bacsu et al., 2021). Specifically, Bacsu and colleagues (2021) identify PWDs as among the most vulnerable to the pandemic when contemplating factors such as social isolation and hospitalization, and highlight caregiver challenges throughout the pandemic within the domains of finances, mental health, and lack of formal supports/care options that point to areas of policy which may require immediate consideration to improve the overall QOL of this population. Daley et al. (2018) confirm that studies on ICs' QOL and WB are under-researched and would benefit from an exploration of the caring role, weight of responsibility, and conflict within the role. Greenberg et al. (2020) stress the importance and relevance of continued research on the effects of the pandemic on caregiving for PWD in these unprecedented times. Additionally, the literature highlights how vulnerable this care system was prior to the pandemic and the increased potential that it has to collapse in the face of a global pandemic, where reports of increased physical and psychological caregiver burden are on the rise (Bussè et al., 2022; Cipolletta et al., 2021; Greenberg et al., 2020; Harris and Titler, 2022; Tsapanou et al., 2020).

The Current Study

This study plans on addressing the aforementioned gap in literature by conducting a self-report study which will be executed in two parts, via a concurrent mixed-method approach. The aim of the present study is to explore if a relationship exists between COVID-19 pandemic stress in ICs of persons with dementia (PWD) and their quality of life (QOL) and well-being (WB). The research question that guided our proposed observation was *Does an association exist between COVID-19 Stress and both Quality of Life and Well-Being in caregivers of PWD?* Due to the findings presented in the aforementioned research, which suggests certain caregiver consequences both prior and in the face of the global pandemic, we hypothesized that a negative correlation would exist between COVID-19 Stress and both QOL and WB. We also predicted that the qualitative results would speak to this correlation. Current literature was examined to develop sub questions relevant to the qualitative domain that would be able to speak to aspects of caregiver QOL and WB, in relation to COVID-19 stresses. Furthermore, considering Bloch-Jorgensen et al.'s (2018) Centeredness Theory, the presence of pandemic-related stressors in the unique role of informal caregivers of PWD may impact the five interconnected life domains and their respective subdomains, which could indicate domain and subdomain imbalances that could potentially affect the overall well-being of the individual. The impact of the coronavirus (COVID-19) pandemic has brought about a global shift in daily functioning, introducing a novel model of lockdown and social distancing measures via strict worldwide public health interventions. Being a relatively unprecedented phenomenon in more recent history, the effects of these novel interventions have changed the face of social exchanges, social support, and access to many once regularly provided in-person social services. More specifically, its direct impact on our caregiving communities is worth considering in greater detail.

Methods

Participants

Ethical approval for this study was obtained on November 3rd, 2021, by the REB at Saint Paul University in Ottawa, Ontario, under REB protocol # 1360.16/21 (see Appendix A). Twenty participants who identified as informal caregivers of PWD belonging to the Canada-wide region were recruited for this study throughout December 2021 to April 2022. Recruitment was done via purposive sampling to best capture the population being studied. Individuals were invited by the primary investigator (PI) and the thesis director to participate voluntarily via mass emailing to Canadian community networks associated with dementia-related care/supports, such as the Alzheimer's Society of Canada (see Appendix B) and The Dementia Society, and sharing a link to the Qualtrics-based study on relevant pages of social media outlets such as Facebook (see Appendix C) and SPU Intranet. Individuals who initiated contact with the PI or the thesis director and expressed interest in participating were provided with a link to the survey, which contained a short series of pre-screening questions to ensure that the individuals met participant criteria.

Due to challenges with recruitment which are associated to aspects of the ongoing pandemic, a substantial portion of the recruitment was achieved through the Bruyère Research Institute (BRI), and was facilitated by the Research Coordinator of the Clinical Trials Research Unit. Prior to beginning work with BRI, the PI and thesis director submitted an application for ethical approval to the Bruyère Research Ethics Board (BREB), which was successfully approved on February 1st, 2022, under BREB protocol #M16-21-060 (see Appendix D). The Research Coordinator was then responsible for mining the BRI database for eligible participants who had previously agreed to be contacted for research purposes. The Research Coordinator then contacted eligible individuals by telephone. Individuals who expressed interest to the Research Coordinator at BRI about participating in the current study were provided with the PI's contact information. Once prospective participants initiated contact with the principal investigator, the PI provided them with a link to the survey, which contained a short series of pre-screening questions to ensure that the individuals met participant criteria. Informed consent was obtained from all participants prior to engaging with the study (see Appendix E). The ethical guidelines and approved psychometric assessments applicable to Saint Paul University (affiliate of the University of Ottawa) and The University of Ottawa were followed.

All eligible participants who successfully completed both the quantitative and qualitative portions of the survey received a $25 Amazon gift card upon the study's completion. Funding for honorariums was generously provided by the Graduate Student Support Program at Saint Paul University under code 1350.E.2/21, upon approval of the funding application submitted by the PI.

Inclusion Criteria

To reduce the possibility of Type I error, participants had to meet the criteria of being in a primary informal (unpaid) caregiver role for at least 2 years, to better assess the impact of pandemic stress on the QOL and WB of ICs. Participants were required to be 18+ in age and their care recipients had to meet the qualifications for an official diagnosis of dementia, along with being dependent on support of the IC for activities/tasks related to daily living.

Exclusion Criteria

Primary ICs who offered less than an average of 10 hours of direct contact per week were excluded from participation in the study, as they may not accurately represent the population studied.

Measures

This study employed a mixed-methods design with the intention of gaining both quantitative and qualitative data to determine if a correlation exists between COVID-19 stress and both QOL and WB in ICs of PWD.

Quantitative Instruments

Demographic Questionnaire. The demographic questionnaire was a self-developed survey aimed to capture the following variables: *Age, Gender, Sex*, *Race and Ethnicity of the Care Giver, Race and Ethnicity of the Care Recipient, Employment Status*, *Household Income, Relationship to Care Recipient, Cohabitating/Not Cohabitating with the Care Recipient, Hours per week providing care, and Years providing care to the care recipient.* Please refer to appendix F for the demographic questionnaire.

COVID Stress Scales (CSS). Taylor et al. (2020) developed a 36-item validated scale that is directly applicable to the novel assessment of COVID-19 related stress, as it pertains to identifying individuals experiencing pandemic-related distress who are in need of mental health services. A factor analysis has confirmed that there are five scales within the questionnaire that evaluate various aspects of COVID-related stress and anxiety symptoms (Taylor et al., 2020). The CSS were developed and first validated in North America (Canada *N=3479*; United States *N=3375*), with indication of reliability and validity, while also determining inter-correlation of all scales (Taylor et al., 2020). A factor analysis determined a 5-factor solution, indicating that each factor corresponded to one of the six scales present in the CSS, with two subscales loading onto a single factor (Taylor et al., 2020). The scales measured apply to the following 5 factors of assessment: *(1) Danger and contamination fears, (2) Fears about economic consequences, (3) Xenophobia, (4) Compulsive checking and reassurance seeking, and (5) Traumatic stress symptoms about COVID-19* (Taylor et al., 2020). Please refer to appendix G for the COVID Stress Scales.

Zarit Carer Burden Inventory (ZCBI). Zarit et al. (1980) developed a 29-item self-report scale on a four-point Likert scale to measure Caregiver Burden of PWD. In this study, the ZBI-22 will be employed, which is a revised version of the ZCBI that contains 22 items on a five-point Likert scale to assess many aspects of caregiver burden, ranging from behavioral and functional impairments of the individuals they are providing care for to the impact of caregiving upon various domains of the caregiver’s life (Springate and Tremont, 2014). It employs a five-point ordinal scale of *0- never; 1- rarely; 2- sometimes, 3 - quite frequently; and 4- nearly always* (Ballestros et al., 2012). A high internal consistency of α=0.90 has been associated with the questionnaire, with individual items being added to reach a total score which ranges from 0-88, with higher scores being reflective of increased caregiver burden (Farina et al., 2020). A study by Whitlatch et al. (1991) reports that a factorial analysis of the ZBI-22 scale produces two subscales of burden, role strain (α=0.81) and personal strain (α=0.80). The ZBI-22 is among one of the most frequently used questionnaires to assess caregiver burden in a subjective manner (Yu et al., 2020). Please refer to appendix H for the ZBI-22 scale.

C-DEMQOL Dementia Caregiver Quality of Life Questionnaire. Brown et al. (2019) developed a 30-item questionnaire characterized by 5 subscales that measure Quality of Life for caregivers of PWD: *(1) Meeting personal needs, (2) Carer Wellbeing, (3) Carer-patient relationship, (4) Confidence in the future, (5) Feeling Supported.* In their study, the C-DEMQOL demonstrated high reliability and validity across several demographic dimensions, with a total score of ω=0.97, indicating its usefulness in assessing overall QOL in a variety of contexts (Brown et al., 2019). Factor analysis done by Brown et al. (2019) also confirmed reliability and validity of sum scores of the five subdomains of the C-DEMQOL. A study done by Daley et al. (2018) prompted the development of the conceptual framework for assessing QOL in caregivers of PWD, as domains specific to the conditions of ICs of PWD were not typically found in general assessments of QOL. Please refer to appendix I for the C-DEMQOL questionnaire.

The Role Captivity Scale. Pearlin et al. (1990) created a brief 3-item caregiver assessment, with a reported reliability of α = 0.83, regarding the degree of entrapment that they experience in their role. Response categories range from (4) *very much*, (3) *somewhat*, (2*) just a little*, (1) *not at all* (Pearlin et al., 1990). The scale developed by Pearlin et al. (1990) asks the following questions: how much do you (a) wish you were free to lead a life of your own? (b) feel trapped by your relative's illness? (c) wish you could just run away? Please refer to appendix J for the Role Captivity scale.

Total Quantitative Questions

The quantitative portion of our study contained 91 questions; 36 which belonged to the CSS measure (refer to appendix G), 22 which belonged to the ZBI-22 measure (refer to appendix H), 30 which belonged to the C-DEMQOL measure (refer to appendix I), and 3 which belonged to the Role Captivity measure (refer to appendix J).

Qualitative Data Collection

Four open-ended questions with prompting examples were added to the final portion of the online survey, to capture the thematic experiences of ICs throughout the COVID-19 pandemic. In considering Bloch-Jorgensen and colleagues' (2018) Centeredness Theory and its holistic and systems-based approach, these questions aimed at exploring emotional, psychological, physical, financial, and socio-cultural themes, based on participants' experience in a caregiving role throughout the COVID-19 pandemic. Please refer to appendix K for the qualitative survey.

The first question was asked to assess the current need for care-related supports and to assess if there was a notable decrease in support since the onset of the pandemic, which may have increased stress. Given what the aforementioned literature has suggested about the cessation and decline of services and its impact on this population, this would be an important area to consider (Altieri and Santangelo, 2021; Greenberg et al., 2020; Maffioleti et al., 2021; Sánchez-Teruel et al., 2022; Tsapanou et al., 2020). The second question addressed participant perceptions of the quality of government-based COVID-19 initiatives made available to them in their role, in relation to a realistic estimation of the various and unique challenges they face as caregivers throughout a pandemic. As Bacsu et al. (2021) highlight, a collaborative approach to developing more in-depth knowledge on this population throughout the pandemic would benefit more informed approaches. Similarly, Masterson-Algar et al. (2021) note existing gaps in policy as a barrier to adequately supporting this population throughout the pandemic. The third question was aimed at capturing the level of risk and resiliency participants may be experiencing throughout this time, which also helps provide pertinent information regarding QOL and WB. When contemplating CT theory by Bloch-Jorgensen and colleagues (2018), it would be important to assess if there are significant factors in the caregiver experience that may affect their ability to maintain balance throughout various systems that impact their overall well-being. Similarly, Cipolletta et al. (2021) speak of protective factors that provide motivation for care recipients while also providing caregivers with an opportunity to receive practical and psychological support from a greater network, which impacts the overall resilience of the caregiver. The fourth question facilitated the exploration of current gaps in support throughout the pandemic, along with assessing which areas of support require immediate attention, to be able to sustain caregiver QOL and WB, and the contributions that they currently make to health care infrastructure. As noted above, taking a collaborative approach to inform current knowledge on the experiences of this population throughout the pandemic would be beneficial to truly understanding the current needs of informal caregivers of PWD.

Procedure

The survey was generated by the PI on the Qualtrics platform, a credible web-based software program used to create research surveys and generate data-related reports. In addition to iterative reviews by both the PI and the thesis director, the Qualtrics program also offered the *ExpertReview* feature, which provided an additional internal assessment of the survey; highlighting potential survey issues while suggesting methods to optimize survey quality and engagement.

An e-mail invitation containing a link to the Qualtrics survey was disseminated by the PI or the thesis director to participants who initiated contact to take part in the study. The Qualtrics survey began with a set of pre-screening questions to ensure participant eligibility. The survey then continued by obtaining informed consent, which then led the participant to the demographic questionnaire and the quantitative portion of the survey, once informed consent was received. The survey concluded with four open-ended questions to collect qualitative data relevant to the study at hand. Each open-ended question included prompting examples to facilitate participant focus on the themes being explored, along with the option to answer in up to 200 words per question. Participants had the option to perform the survey on any day of the week and at any time. The survey took approximately 30 minutes to complete; varying slightly from participant to participant based on personal requirements and preferences. The surveys were stored on an encrypted USB to ensure confidentiality and safe storage of data.

Once the study was complete, a report was generated in the Qualtrics system to extract eligible data onto a separate Excel document, which was extensively reviewed and prepared prior to being inputted into the Statistical Package for the Social Sciences (SPSS) v28 software system for statistical analysis. Extrapolated data and thematic transcripts were stored on an encrypted USB and placed in a secure location. Participant names and contact information were also stored on an encrypted USB, separately from the extrapolated data and thematic transcripts. Extrapolated quantitative data was identified with internally adapted numerical coding and transcripts were identified by internally adapted thematic coding. Individual names were never directly associated with both the quantitative and qualitative data collected. All personal information and electronic data were associated with a code and kept in a separate file on an encrypted USB key, which was stored in a secure location.

Preliminary Score Conversion

COVID Stress Scales. Inputting the CSS measure developed by Taylor et al. (2020) into the Qualtrics platform and exporting the data from the Qualtrics platform for analysis automatically assigned numerical values of 1 through 5 on the 5-point scale responses, due to the design of the software. Prior to data analysis, all scores related to the CSS were exported to a separate Excel file and subject to a manual conversion in order to assign the numerical values of 0 through 4 to responses on a 5-point scale, in order to comply with the score system and interpretations as developed by Taylor et al. (2020). The process of converting these scores was simple, as it required each question's individual value, as reported by the respondent, to be subtracted by 1 point. The conversion of scores did not manipulate any of the individual responses in any way and solely adjusted the scoring system to adhere with the original design of the measure. The score conversion was initiated by the PI and presented to the thesis director for checking, which was done in a collaborative and iterative process to ensure accuracy prior to being imputed in the SPSS file for data analysis.

ZBI-22 Scale. Inputting the ZBI-22 measure developed by Zarit et al. (1980) into the Qualtrics platform and exporting the data from the Qualtrics platform for analysis automatically assigned numerical values of 1 through 5 on the 5-point scale responses, due to the design of the software. Prior to data analysis, all scores related to the ZBI-22 were exported to a separate Excel file and subject to a manual conversion to assign the numerical values of 0 through 4 to responses on a 5-point scale, in order to comply with the score system and interpretations as developed by Zarit et al. (1980). The process of converting these scores was simple, as it required each question's individual value, as reported by the respondent, to be subtracted by 1 point. The conversion of scores did not manipulate any of the individual responses in any way and solely adjusted the scoring system to adhere with the original design of the measure. The score conversion was initiated by the PI and presented to the thesis director for checking, which was done in a collaborative and iterative process to ensure accuracy prior to being imputed in the SPSS file for data analysis.

C-DEMQOL Scale and Role Captivity Scale. Inputting both the C-DEMQOL measure developed by Brown et al. (2019) and the Role Captivity measure developed by Pearlin et al. (1990) into the Qualtrics platform and exporting the collected data from the Qualtrics platform to SPSS for analysis required no score conversions. The assigned numerical values from Qualtrics were already aligned with the initial score systems and interpretations developed.

Quantitative Data Analysis

Due to the correlational nature of this study, Pearson's correlation coefficient, also known as Pearson's r, was employed to measure if a relationship exists between COVID-19 stress and both QOL and WB in caregivers of PWD. Analyses were carried out through the Statistical Package for the Social Sciences (SPSS) v28 and a threshold of $\alpha = 0.05$ was assumed as the statistical significance level. To test the hypothesis of this study, bivariate correlations were used to determine whether an inverse relationship was present between COVID-19 stress and both QOL and WB. We predicted that the results would support the study's initial hypothesis of an inverse relationship between COVID-19 stress and both QOL and WB. Given that this is a novel area of research and little is known about the impact of the pandemic on caregivers of PWD, additional correlations were run to analyze associations between the COVID Stress subscales in relation to all other scales and subscales, Quality of Life and Burden scales and subscales, Burden and Role Captivity scales and subscales, and QOL and Role Captivity scales and subscales**.** The PI and thesis director were cognizant of the possibility of increasing type 1 error when running additional correlations therefore, results were interpreted with caution.

Qualitative Data Analysis

The qualitative section of our study incorporated thematic analysis according to the six-phase guide by Braun and Clarke (2006) to inform the process of extracting relevant themes and coding. The first phase of thematic analysis is known as *Familiarizing yourself with your data*, which requires the researcher to engage in transcribing the data, if necessary, and taking an iterative approach to reading the data; noting down emerging ideas (Braun and Clarke, 2006). The second phase proposed by Braun and Clarke (2006) is *Generating Initial Codes*, which entails examining the entire data set to code compelling features of the data in a systematic fashion. The third phase within the study done by Braun and Clarke (2006) is *Searching for themes*, which requires assembling codes to extract potential themes and sorting relevant data according to each potential theme. The fourth phase of thematic analysis is *Reviewing themes,* which involves verifying if the emergent themes are convergent with coded extracts (Level 1) and the entire data set (Level 2), which requires the researcher to create a detailed ‘map’ of the thematic analysis conducted (Braun and Clarke, 2006). According to Braun and Clarke, 2006, the fifth phase of thematic analysis is *Defining and naming themes,* which refers to an iterative approach in analysis to further refine the specific data of each theme; reviewing the overall narrative that emerges from the analysis, along with generating precise definitions and names for each theme observed. The last phase of thematic analysis, according to Braun and Clarke, 2006, is *Producing the report*, which is the culminating window for the process of analysis. This phase is characterized by selecting evocative and captivating extracts, followed by a thorough analysis of these extracts; relating their pertinence to the research question and literature at hand, in order to produce an academically structured report of the analysis.

Additionally, a MA-level social sciences graduate with apt qualitative research experience was recruited as a research assistant to ensure inter-coder reliability. A multiple-review process, especially between steps 4 and 5 of Braun and Clarke's (2006) framework was employed between the research assistant, PI, and clinical psychologist/researcher supervising the project to primarily reduce the risk of any errors in coding themes and sub-themes. Multiple phases of collaborative analysis also ensured that the emergence of new findings and insights would not be overlooked.

Given that the qualitative questions contained overlapping themes about the experiences of ICs throughout the pandemic, it is likely that oversaturation of themes may have been present if the final analysis was formatted to present the themes and sub-themes extracted per question. To address potential redundancy and ensure succinct final analyses, all qualitative data were analyzed thoroughly to generate codes to extract general themes and sub-themes which emerged from the totality of the responses, while also maintaining awareness of these responses in the context of the question they belonged to. As witnessed in their work in assessing the needs of ICs of PWD, Ringer et al. (2020) also opted for an analysis which drew upon common themes that emerged from their semi-structured interviews with participants.

Results

Sample Characteristics

Out of the 20 participants engaged with our study, 50% of participants identified as the husband/wife of the PWD and 70% of these caregivers identified as both female and women. Many of the caregivers we surveyed were between the ages of 50 and 78, with a mean age of

54.3 years old. A total of 80% of all participants reported currently living with their care recipient, which suggested that it may be more challenging for them to find time for themselves and their individual needs. A total of 65% of all participants reported providing more than 20 hours of care weekly, with 40% of all participants reporting 50+ hours of weekly care. Results suggest that many of the participants are relatively new to their caregiving role, as 80% of participants reported that they have been in their primary caregiver role between 2-5 years.

In terms of annual income, 60% of participants that engaged with our study had a household income between $75,001 and $175,000. Only 3 participants (15%) were found to be between the $25,001-$50,000 annual household income bracket, while 5 participants (25%) were found to be between the $50,001 and $75,000 income bracket. The mean income score was 4.05, suggesting that the mean income of participants was within the range of $75,001-$100,000. In terms of employment status, 65% of participants reported currently being unemployed. This may suggest that they are retired and are receiving some sort of pension. Meanwhile, 60% of our participants reported having a bachelor’s degree, while 20% reported being a college or trade school graduate. One individual reported having a doctoral and professional degree (5%), while another individual indicated that they did some undergraduate studies with no degree (5%), followed by another reporting being a CEGEP graduate (5%), and finally one individual preferred not to state their level of education (5%).

A total of 20% of participants identified as BIPOC. In terms of ethnicity and/or ethnic origins, our participants self-identified as the following: African (5%), Caribbean (2.5%), European (32.5%), Latin, Central, and/or South American (7.5%), North American Indigenous (10%), Other North American (22.5%), Other (10%), and Prefer not to say (10%). Participants reported currently residing in Ontario (85%), British Columbia (5%), Manitoba (5%), and

Québec (5%). Of the individuals we surveyed, 60% did not consider themselves to be religious or spiritual.

A total of 55% of care recipients were identified as both male and man, while 45% of care recipients were identified as both female and woman. The sample reported that 20% of care recipients identified as BIPOC. In terms of ethnicity and/or ethnic origins of the care recipient, the sample reported the following: African (5%), Caribbean (5%), European (30%), Latin, Central, and/or South American (5%), North American Indigenous (10%), Other North American (27.5%), Oceanic (2.5%), Other (10%), and Prefer not to say (5%).

Main Statistical Analysis

The quantitative portion of our study contained 91 questions; 36 which belonged to the CSS measure, 22 which belonged to the ZBI-22 measure, 30 which belonged to the C-DEMQOL measure, and 3 which belonged to the role captivity measure. In total, we anticipated 1,820 individual responses, given that we had 20 participants. We reported a total of 1,818 responses upon a missing values assessment, which indicated that in total, only 2 responses were missing. One missing response was from participant 7 to question 30 of the CSS. The other missing response was from participant 13 to question 9 of the ZBI-22. We determined that these responses are missing completely at random (MCAR), as outlined in the literature (Buuren, 2021). The approach that we determined best suited this outcome was a mean interpretation, as missing responses were minimal and there was no more than one missing value in our data set within each associated question (Buuren, 2021). Given our efforts to screen for accuracy and plausibility in previous stages, we were confident that our initial analysis of minimum and maximum values further strengthened the value calculated for the mean.

Preliminary Data Screening

A total of 82 participants were recorded in this study. Of those, 27 responses were excluded for not having directly met the geographical location criteria (there were responses from various American states, England, Kenya, Nigeria, Venezuela, and Singapore). Additionally, 35 responses were excluded on the basis of undisclosed geographical location, which was due to a variety of factors such as an incomplete eligibility screening, missing consent and/or prematurely abandoning the survey. This study was clearly presented as a Canadian study and these requirements were outlined in the screening questionnaire, as well as the informed consent and advertising of the study. Being mindful of the gift card incentive for this online study, strict measures adhering to inclusion/exclusion criteria were taken in doing a preliminary data screening to avoid the use of random data in our study. Twenty participants' data were used for analysis; approximately 55% of these participants were recruited directly from the BRI database.

Preliminary Accuracy and Plausibility Check

Both the PI and the thesis director worked in tandem to screen for accuracy of data from the data exported from Qualtrics and the data being imputed into the SPSS file for analysis by isolating and comparing values for demographics and measures in a collaborative and iterative manner. No discrepancies in data transmission were detected. The data were also screened for outliers by examining minimum and maximum values to evaluate the overall plausibility of the data collected.

Value Conversion and Mean Calculation For Qualitative Demographics

Both question 19 (*How many hours per week, on average, do you spend caring for this individual?*) and question 20 (*How many years have you been a primary caregiver for this* *individual, specific to their dementia-related needs for tasks/activities associated with daily living?)* of the demographic questionnaire were asked to capture the numerical values relative to their respective areas of interest. In the Qualtrics survey format, the response portion for these questions was a blank field for participants to freely type in their responses in alphabetical characters and/or numerical values, as opposed to selecting from a set of numerical values included in the response portion.

The PI and thesis director determined that a blank field may capture the values more accurately and succinctly, as there was a likelihood of high variance in the responses. This may have posed a challenge to predicting a set of values for participants to select from. As a result of the use of a blank field, there were three qualitative responses within these questions that went beyond the spelling of a numerical value (i.e.: twenty for the value 20), and required a conversion system to assign numerical values for statistical purposes.

This process was done collaboratively between the PI and the thesis director by familiarizing themselves with the data and generating initial codes to interpret the content within the qualitative data then, through an iterative process, ensuring that the coding was consistent between both raters. A numerical value was then assigned based on the generated codes, as agreed upon by both the PI and thesis director. There were also 3 responses where a range of numerical values were given (i.e.: 12-15 hours). In this case, the mean value was calculated in order to facilitate statistical analyses.

Our sample as a whole presented with slight COVID Stress (*M*= 39.4000, *SD*= 38.43710), as per the validation study done by Taylor et al. (2020). In terms of QOL, our sample as a whole reported mostly good, closely approaching satisfactory scores (*M*= 88.1500, *SD*= 15.59107), as per the validation study done by Brown et al. (2019). In terms of Carer

Responsibilities and Personal Needs, the first subscale within the QOL category, our sample generally reported satisfactory scores (*M*= 19.9500, *SD*= 4.48946). In terms of Carer Well-Being, the second subscale within the QOL category, our sample as a whole reported satisfactory scores (*M*= 18.6500, *SD*= 5.17357). In terms of Carer Role, the third subscale within the QOL category, our sample generally reported mostly good scores (*M*= 13.6500, *SD*= 3.34467). In terms of Feelings About the Future, the fourth subscale within the QOL category, our sample as a whole reported satisfactory scores (*M*= 18.9000, *SD*= 4.14094). In terms of Carer Support, the fifth subscale within the QOL category, our sample generally reported mostly good scores on a spectrum that is closely approaching satisfactory scores (*M*= 17.0000, *SD*= 4.90971). Our sample as a whole presented with moderate to severe burden, though the mean score appears to be at the lower end of the spectrum within this category, indicating that overall it presented as more moderate than severe (*M*= 41.4000, *SD*= 15.94200), as per the validation study done by Zarit et al. (1980). In terms of Personal Strain, the first subscale within the Burden category, our sample as a whole reported rarely, approaching the sometimes category (*M*= 21.7500, *SD*= 7.27559). In terms of Role Strain, the second subscale within the Burden category, our sample as a whole reported sometimes (*M*= 11.9500, *SD*= 5.78087). In the category of Role Captivity, our sample as a whole reported feeling somewhat captive in their role as a caregiver (*M*= 6.9000, *SD*= 2.55260), as per the validation study done by Pearlin et al. (1990). Please refer to Table 1 below.

Table 1

Mean Scores for COVID Stress, QOL, and WB (Burden and Role Captivity)

	N	Mean	Std. Deviation
CSS Total	20	39.4000	38.43710

CSS Sum1	20	17.8000	11.62846
CSS Sum2	20	5.3500	7.41460
CSS Sum3	20	5.2000	7.25186
CSS Sum4	20	6.1500	7.11022
CSS Sum5	20	4.9500	6.98476
Burden Total	20	41.4000	15.94200
BurdenSum1PS	20	21.7500	7.27559
BurdenSum2RS	20	11.9500	5.78087
QOL Total	20	88.1500	15.59107
QOL Sum1	20	19.9500	4.48946
QOL Sum2	20	18.6500	5.17357
QOL Sum3	20	13.6500	3.34467
QOL Sum4	20	18.9000	4.14094
QOL Sum5	20	17.0000	4.90971
Role Captivity	20	6.9000	2.55260

Note. CSS=COVID Stress Scales. Burden=Zarit Burden Interview (ZBI-22). QOL= Dementia Caregiver Quality of Life Questionnaire (C-DEMQOL). Sum= Subscale number.

Our findings suggest that statistically, a significant correlation between COVID-19 stress and both QOL and WB does not appear to exist. Our bivariate correlational analysis indicated that the association between COVID Stress totals and QOL totals were not found to be significant, as the findings were $r(19)=.121$, p .611. Both Burden and Role Captivity totals, which comprised the measure for WB, were also subject to a bivariate correlational analysis with

COVID Stress totals. The association between COVID Stress totals and Burden totals were not found to be significant, as our findings were *r*(19)=.297, *p* .203, while the association between COVID Stress totals and Role Captivity totals were not found to be significant, as our findings were *r*(19)=-.291, *p* .213. Therefore, we failed to reject the null hypothesis in this statistical analysis. Please refer to Table 2 below for these figures.

Table 2

Correlations

		Burden Total	Burden Sum1 PS	Burden Sum2 RS	QOL Total	QOL Sum 1	QOL Sum 2	QOL Sum 3	QOL Sum 4	QOL Sum 5	Role Captivity
CSS Total	Pearson Correlation	0.297	0.337	0.303	0.121	0.280	0.303	-0.181	0.266	-0.292	-0.291
	Sig. (2-tailed)	0.203	0.147	0.194	0.611	0.232	0.194	0.444	0.257	0.212	0.213
	N	20	20	20	20	20	20	20	20	20	20
CSS Sum1	Pearson Correlation	0.244	0.297	0.246	0.039	0.187	0.191	-0.204	0.166	-0.251	-0.205
	Sig. (2-tailed)	0.299	0.204	0.295	0.871	0.429	0.419	0.389	0.485	0.286	0.387
	N	20	20	20	20	20	20	20	20	20	20
CSS Sum2	Pearson Correlation	0.287	0.305	0.299	0.133	0.339	0.355	-0.203	0.287	-0.364	-0.276
	Sig. (2-tailed)	0.220	0.191	0.201	0.575	0.144	0.125	0.391	0.219	0.114	0.239
	N	20	20	20	20	20	20	20	20	20	20
CSS Sum3	Pearson Correlation	0.136	0.140	0.157	0.078	0.202	0.176	-0.140	0.186	-0.185	-0.314
	Sig. (2-tailed)	0.568	0.557	0.508	0.744	0.392	0.458	0.556	0.431	0.435	0.177

	N	20	20	20	20	20	20	20	20	20	20
CSS Sum4	Pearson Correlation	0.384	0.440	0.379	0.144	0.292	0.384	-0.199	0.312	-0.341	-0.269
	Sig. (2-tailed)	0.094	0.052	0.099	0.544	0.211	0.095	0.400	0.181	0.142	0.252
	N	20	20	20	20	20	20	20	20	20	20
CSS Sum5	Pearson Correlation	0.392	0.443	0.391	0.228	0.362	0.397	-0.100	0.371	-0.272	-0.375
	Sig. (2-tailed)	0.087	0.050	0.088	0.334	0.116	0.083	0.675	0.107	0.247	0.103
	N	20	20	20	20	20	20	20	20	20	20
Burden Total	Pearson Correlation	1	.969**	.976**	.864**	.790**	.854**	.524*	.813**	0.079	-.666**
	Sig. (2-tailed)		0.000	0.000	0.000	0.000	0.000	0.018	0.000	0.742	0.001
	N	20	20	20	20	20	20	20	20	20	20
Burden Sum1 PS	Pearson Correlation	.969**	1	.919**	.776**	.773**	.789**	0.429	.757**	-0.004	-.554*
	Sig. (2-tailed)	0.000		0.000	0.000	0.000	0.000	0.059	0.000	0.985	0.011
	N	20	20	20	20	20	20	20	20	20	20
Burden Sum2 RS	Pearson Correlation	.976**	.919**	1	.844**	.768**	.837**	.522*	.761**	0.100	-.699**
	Sig. (2-tailed)	0.000	0.000		0.000	0.000	0.000	0.018	0.000	0.674	0.001
	N	20	20	20	20	20	20	20	20	20	20
QOL Total	Pearson Correlation	.864**	.776**	.844**	1	.760**	.787**	.723**	.868**	0.427	-.790**
	Sig. (2-tailed)	0.000	0.000	0.000		0.000	0.000	0.000	0.000	0.060	0.000
	N	20	20	20	20	20	20	20	20	20	20
QOL Sum1	Pearson Correlation	.790**	.773**	.768**	.760**	1	.665**	0.405	.705**	-0.072	-.671**

	Sig. (2-tailed)	0.000	0.000	0.000	0.000		0.001	0.076	0.001	0.764	0.001
	N	20	20	20	20	20	20	20	20	20	20
QOL Sum2	Pearson Correlation	.854**	.789**	.837**	.787**	.665**	1	0.388	.681**	-0.002	-.549*
	Sig. (2-tailed)	0.000	0.000	0.000	0.000	0.001		0.091	0.001	0.993	0.012
	N	20	20	20	20	20	20	20	20	20	20
QOL Sum3	Pearson Correlation	.524*	0.429	.522*	.723**	0.405	0.388	1	.529*	0.388	-.590**
	Sig. (2-tailed)	0.018	0.059	0.018	0.000	0.076	0.091		0.016	0.091	0.006
	N	20	20	20	20	20	20	20	20	20	20
QOL Sum4	Pearson Correlation	.813**	.757**	.761**	.868**	.705**	.681**	.529*	1	0.189	-.698**
	Sig. (2-tailed)	0.000	0.000	0.000	0.000	0.001	0.001	0.016		0.425	0.001
	N	20	20	20	20	20	20	20	20	20	20
QOL Sum5	Pearson Correlation	0.079	-0.004	0.100	0.427	-0.072	-0.002	0.388	0.189	1	-0.328
	Sig. (2-tailed)	0.742	0.985	0.674	0.060	0.764	0.993	0.091	0.425		0.159
	N	20	20	20	20	20	20	20	20	20	20
Role Captivity	Pearson Correlation	-.666**	-.554*	-.699**	-.790**	-.671**	-.549*	-.590**	-.698**	-0.328	1
	Sig. (2-tailed)	0.001	0.011	0.001	0.000	0.001	0.012	0.006	0.001	0.159	
	N	20	20	20	20	20	20	20	20	20	20

Note. CSS=COVID Stress Scales. Burden=Zarit Burden Interview (ZBI-22). QOL= Dementia Caregiver Quality of Life Questionnaire (C-DEMQOL). Sum= Subscale number.

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Additional Statistical Analysis

COVID Stress Subscales in Relation to All Other Scales and Subscales

No significant correlations were found between the subscale domains of COVID Stress and both total scores of QOL and WB. Additionally, both Burden and QOL subscale domains were also subject to analysis with COVID-Stress total and subscale domain scores. No significant correlations were found, as depicted in Table 2.

Quality of Life and Burden

A significant negative correlation was found between QOL and Burden totals, with *r*(19)=.864, *p* <.001. This is depicted in Table 2. This implies that when individuals scored higher totals on our Quality of Life scale (which indicated poorer QOL), they tended to score higher totals on the Burden scale (which indicated higher burden).

QOL total and Burden Subscales. A significant negative correlation was found between QOL and Burden subscale 1: Personal Strain, with *r*(19)=.776, *p* <.001. A significant correlation was found between QOL and Burden subscale 2: Role Strain, with *r*(19)=.844, *p* <.001. These findings are listed in Table 2.

Burden total and QOL Subscales. A significant negative correlation was found between Burden and QOL subscale 1: Carer Responsibilities and Personal Needs, with *r*(19)=.790, *p* <.001. A significant negative correlation was found between Burden and QOL subscale 2: Carer Well-Being, with *r*(19)=.854, *p* <.001. A significant negative correlation was found between Burden and QOL subscale 3: Carer Role totals, with *r*(19)=.524, *p* .018. A significant negative correlation was found between Burden and QOL subscale 4: Feelings About the Future, with *r*(19)=.813, *p* <.001. No significant correlation was found between Burden and QOL subscale 5: Carer Support totals, with *r*(19)=.079, *p* .742. These figures are depicted in Table 2.

Burden and Role Captivity

A significant positive correlation was found between Burden and Role Captivity totals, with $r(19)=-.666$, p .001. This is captured in Table 2. This implies that when individuals scored higher totals on our Burden scale (which indicated higher burden), they tended to score lower totals on the Role Captivity scale (which indicated higher role captivity).

Role Captivity total and Burden Subscales. A significant positive correlation was found between Role Captivity and Burden subscale 1: Personal Strain totals, with $r(19)=-.554$, p .011. A significant positive correlation was found between Role Captivity and Burden subscale 2: Role Strain, with $r(19)=-.699$, p .001. These figures are depicted in Table 2.

QOL and Role Captivity

A significant negative correlation was found between QOL and Role Captivity totals, with $r(19)=-.790$, $p <.001$. This is noted in Table 2. This implies that when individuals scored higher totals on our QOL scale (which indicated poorer QOL), they tended to score lower totals on the Role Captivity scale (which indicated higher role captivity).

Role Captivity and QOL Subscales. A significant negative correlation was found between Role Captivity and QOL subscale 1: Carer Responsibilities and Personal Needs, with $r(19)=-.671$, p .001. A significant negative correlation was found between Role Captivity and QOL subscale 2: Carer Well-Being, with $r(19)=-.549$, p .012. A significant negative correlation was found between Role Captivity and QOL subscale 3: Carer Role totals, with $r(19)=-.590$, p .006. A significant negative correlation was found between Role Captivity and QOL subscale 4: Feelings About the Future totals, with $r(19)=-.698$, p .001. No significant correlation was found between Role Captivity and QOL subscale 5: Carer Support with totals, with $r(19)=-.328$, p .159. Please refer to Table 2.

Thematic Analysis

Qualitative analyses of our results appear to point to findings which support our initial hypothesis. In our collaborative analyses, employing Braun and Clarke's (2006) *Thematic Analysis* method, three main themes arose within the qualitative data from the findings on the experiences of caregivers of PWD throughout the COVID-19 pandemic, which included (1) *increased burden on caregivers*, (2) *diminished quality of care for care recipients*, and (3) *lack of support and consideration by policy makers for caregivers*. A series of sub-themes were also identified which reveal relevant considerations to the larger themes at hand, to capture a more comprehensive overview of the qualitative findings.

Theme 1: Increased Burden on Caregivers

The first theme which emerged from the thematic analysis of participant responses was the general experience of *increased burden on caregivers*. This was evidenced by the sub-themes within this domain which revealed (1) *diminished access to in-home support workers and cancelled day programs*, (2) *isolation of the caregiver*, and (3) *financial stress*.

Several participants reported experiencing changes in caregiver-related supports throughout the pandemic, which suggested that they experienced increased burden in their role as a caregiver throughout the pandemic. Some of these changes included diminished access to in-home support workers and cancelled day programs. Participant 15 expressed, "My husband's day away program was cancelled […]. The helper we have come in one afternoon a week has often had to cancel due to COVID lockdowns or COVID concerns."

This points to not only experiencing decreased supports in the caregiving role to execute necessary care-related tasks and social activities, along with the gaps that the caregiver had to manage as a result of this, but also a disruption to certain routines that a PWD may find difficult to adjust to, which could lead to a rise in BPSD due to abrupt changes and noticeable decreases in stimulating activity.

A decrease in outside supports points to another challenge experienced by caregivers throughout the pandemic, which is lack of respite time that is often available through in-home support workers and day programs. Participant 13 shared, "All support became virtual which placed more of my effort and time and did not allow for respite time that would be normal with day programs etc." This offers insight into the experience that while certain programs that offered respite were virtually adapted due to the global circumstances, in some cases the method of delivery posed a bigger obstacle to the caregiver and their ability to find rest and relief in these moments that were intended to provide the caregiver with that. It also potentially highlights the learning curve required to adapt to these modalities and newer technology, which could create an additional level of strain to both the caregiver and care recipient in an area meant to provide repose.

Meanwhile, participant 15 reported, "[…] I used to have an activity of some kind set up for my husband every week day, and for the most part it was all cancelled." This offers the opportunity to contemplate that activities that are intended for the well-being of the PWD also offer respite time for the well-being of the caregiver. Many participants commented on the lack of respite time throughout the pandemic due to the cessation and decrease of certain vital supports.

When considering increased burden on caregivers in general, the sub-theme of isolation of the caregiver also emerged prominently in our qualitative data. Participant 18 reported, "During the pandemic I definitely felt more isolated with a lot less resources. I felt very alone and trapped." It became evident that in addition to activities that provided stimulation for PWD and offered respite for caregivers, caregivers also felt isolated from in-person meetings aimed at providing social support to them in their role. Participant 19 expressed, “I missed Dementia Society in person support group meetings and activities.”

Participant 10 shared, “[…] Some [*family and friend get-togethers*] disappeared because of public health measures around gathering and isolation.” More briefly, participant 20 expressed feeling, “More isolated.” This draws attention to informal supports that are seen as beneficial to the well-being of the care dyad no longer being available due to social distancing and public health measures. Many respondents hinted at the loss of important social connection that potentially increased the experience of isolation for the caregiver throughout this time.

Another sub-theme that emerged within this larger theme was the financial burden on caregivers throughout this time. In particular, certain participants shared the experience of being in a position where they were actively working and caregiving, along with the strain that assuming significant financial responsibility may add to their role. Participant 18 shared, “Caregivers of Early Onset Alzheimer’s spouses are in a tough spot, they are not retired and suddenly need to balance working and caregiving. […] Factor in worrying about money and it is a terrible situation.”

Many participants highlighted financial concerns as being a challenge throughout the pandemic and an area of worry and/or uncertainty when they contemplate their future as a caregiver. Participant 8 shared, “[*Greatest challenge was*] Just trying to balance a FT job, trying to stretch my money as I spend thousands of dollars a month on travel to assist my family member […]”. Quite interestingly, participant 15 stated, “I am “lucky” in that my husband was hit by a car, and with the settlement he received I can afford to pay for extra care and assistance. I am being frugal with those funds as I know his care requirements will only increase from here.

[…]”. There was also attention brought to the pandemic limiting a caregiver’s ability to work, which ultimately impacted household finances. Participant 3 stated, “[*greatest challenge was*] not being able to work due to fear of contracting the virus.”

Theme 2: Diminished Quality of Care for Care Recipients

The second theme which emerged from the thematic analysis of participant responses was an observation of *diminished quality of care for care recipients*. This was evidenced by the sub-themes within this domain which revealed (1) *caregiver burnout,* (2) *isolation of the care recipient,* (3) *challenges in accessing healthcare,* (4) *diminished services (in-home and day programs).*

Many participants noted that they believe decreased quality of care was a significant challenge brought on by the pandemic. A prominent sub-theme that emerged in this area of observation was the burnout that caregivers were experiencing throughout this time. Participant 10 stated, “Not very hopeful that my care giving burden is going to ease in the near future. […] Can’t see there being any significant respite time available for a while. Long Term Care wait lists are years long.” Meanwhile, participant 14 shared, “I am now dealing with depression and anxiety. I feel as though I have given my “all” and am now physically and mentally depleted.”

In reflecting on their experiences throughout the pandemic, participant 15 expressed, “Disturbing things that have happened during the pandemic have affected me emotionally which has caused him to be unhappy.” Participant 10 continued their reflection, “[…] As burnout approaches the quality of care diminishes. Serious help only comes when there is a complete breakdown or crisis […]”.

In expressing aspects of burnout throughout their experiences, certain caregivers expressed uncertainty about their future as a caregiver, highlighting concerns for their own health which could pose future challenges to remaining a primary caregiver. Participant 13 detailed, “I cannot really know how things are going to develop. My care recipient and I could be each other[’]s care giver as I am a person living with Parkinson’s Disease. […] I am the primary caregiver and just cannot let my PD get in the way.” Meanwhile, participant 16 shared, “To date I remain in fairly good health for a senior, but should my situation change – problem as a care giver.”

In considering the caregiver burnout that was present throughout this time, participants also noted the isolation of the care recipient due to closures, lockdown, and public health measures as a significant challenge throughout the pandemic. Participant 3 expressed, “One of the greatest challenges was being indoors […]”. Similarly, participant 5 shared, “[…] when restaurants and stores were open I was able to take her out regardless of weather which makes a big difference to the elderly who are cooped up in their homes now.[…]”. Participant 17 added, “At the beginning of the pandemic the PSW’s were stopped for a while as well as the day programs. This made my father feel quite isolated and depressed.”

In considering the experience of isolation, it also became evident that many caregivers were able to note a decline in mood with their care recipient throughout this time. This suggests that not only were caregivers experiencing their own sense of loss throughout this time which increased their experience of isolation, but the experience of the care recipient’s isolation posed additional challenges to caring for an individual with decline in both cognition and mood.

Caregivers appeared to notice the significant impact that isolation had on the overall state of the care recipient, which contributed to the experience of decreased quality of care throughout this time. Participant 17 reported, “[…] I’m also concerned about his mental health and feeling isolated because of things like the day program being limited.” Similarly, participant 15 shared,

"[…] the pandemic has caused him to be isolated, which has affected his communication abilities; places to walk indoors have been closed which affected his physical wellbeing; people who would normally come in for care or assistance have been kept away […]".

Another sub-theme that arose for this observation was the challenges in accessing health care throughout the pandemic. Within this domain, participants also appeared to highlight the vulnerability of the current healthcare system. Participant 4 disclosed, "The greatest challenge there was [*was*] not going to the hospital and no medical professional available when needed." Participant 5 added, "[…] The other main issue of course is the strain on the healthcare system and outside caregiver support (public and private), which adds more strain to my support."

On a similar note, other participants worried that the pandemic may have another intense wave that will continue to create barriers in accessing necessary supports and further impact the healthcare system. Participant 18 expressed, "I worry that we will experience [*a*] COVID flare up […] which will result in less help. This disease already isolates caregivers even without a pandemic. I do think resources did their absolute best under difficult circumstances." Meanwhile, participant 8 detailed, "[…] Worried that other health is impacted as many procedures have been cancelled due to hospital staffing issues."

The last sub-theme that arose for this area of observation, which has been interwoven in the aforementioned sub-themes within this area of exploration, was the experience of diminished services both with in-home and day programs. In addition to the previous excerpts which support this finding, participant 5 also shared, "CLSC support (public) was sometimes spotty due to COVID-19 outbreaks among their personnel. This impacts Schedules and personnel changes which is distressing to the cared-for individual. Change is hard for dementia patients."

Theme 3: Lack of Support and Consideration by Policy Makers for Caregivers

The third theme which emerged from the thematic analysis of participant responses was a general experience of *lack of support and consideration by policy makers for caregivers*. This was evidenced by the sub-themes within this domain which revealed (1) *financial responsibility on the caregiver,* (2) *lack of available dementia-informed and/or dementia-caregiver informed formal programming and support*.

Several participants reported feeling not adequately supported and considered by policy makers throughout the pandemic. Certain participants shared their experience of feeling ignored yet expected to uphold the financial infrastructure of the care system by expending their own time and resources significantly; most often to the point where significant support would only be made possible once they are completely depleted. Participant 15 expressed, “I don’t feel seen at all. I think they [*policy makers*] take advantage of family caregivers and won't do anything to help until I break down because I save them a lot of money. […]” Similarly, participant 10 shared, “Homecare has been ignored and needs attention. Caregivers are quietly caring for a vast number of people at no expense to the government. Don’t think they are in a hurry to spend any money on it.”

A second sub-theme that arose was a lack of available dementia-informed and dementia-caregiver informed formal programming and support. Our qualitative findings noted the sense of invisibility certain caregivers are experiencing regarding their needs throughout the pandemic. Participant 13 shared, “I don’t see any understanding of the things that I deal with or the real isolation that has been the norm for the last two years.” Notably, a lack of available programs in place to provide adequate support and ensure that caregivers were receiving the necessary respite time that they required was highlighted. Participant 15 stated, “[…] There is limited support available in the community, most of that went away during the pandemic and has not returned to previous levels."

Several participants pointed to more formal support and informed policy reform as a viable solution to better support them in their caregiving role throughout the pandemic. Participant 4 reported, "Needing other hands to help me. Changing to [*a*] more viable way." Similarly, participant 5 expressed, "Additional caregiver support to help her stay mobile and active is still needed." Meanwhile, participant 13 shared, "[…] assessments that try at least to understand the real needs of caregivers."

In addition to these requests, participants also frequently commented on the need for more funding and financial support to better assist them in their role. Participant 14 reported, "Respite, social programming and support for caregivers […]. Funding for respite care through the government." Similarly, participant 17 detailed, "Offering more days in a day program to allow my father to get out of the house more, counteract his boredom and isolation." Additionally, participant 3 shared, "I would want more support from charities."

Many participants also specifically drew attention to the need for more support for in-home caregiving options. Participant 15 shared, "I need more in home assistance, a few times every week where someone trustworthy can come in and ensure my husband is okay so I can get out into the community […] I need it to be easier to place my husband in assisted living for respite care, the paperwork and testing required is onerous on myself, the facility and my family doctor […] what if I have an emergency and need to place him quickly?[…] my sister lives with mental illness and I have had to travel to help her. I want to travel to see my daughter in Toronto. I want to get away to rejuvenate myself." Participant 20 simply stated, "[*wanting*] More support at home."

Certain participants highlighted wanting to keep their care recipient at home for as long as possible however, not feeling adequately supported to do so. This appears to have contributed to caregiver distress when it came to being able to access resources and feel supported in their role. Participant 18 reported, "[…] Little support is available, caregivers really have to source available resources. There needs to be more help for caregivers with spouses living at home [...]". Similarly, participant 5 shared, "In general, I feel that policy makers should consider that keeping patients in their home for as long as possible is far more advantageous than limiting in-home care and forcing families to place loved ones [...]".

Within this sub-theme, it was also evident that affordability of long-term care homes was a serious concern and also perhaps a motivation to increase more in-home support. Participant 10 voiced, "Homecare needs more funding, more "dementia trained" PSWs that are better paid. Care givers need more care hours. There needs to be affordable care homes for dementia patients." Participant 18 reported, "I would like to see more funding for in home help and for more day programs […] younger families need more support. The family should not have to bankrupt themselves when placing a loved one in long term care. I feel the future should definitely focus on keeping people in their own homes. Finally I see the whole system is very confusing and overlapping. It's a lot to navigate […]".

Certain participants shared that they are appreciative of the services and support made available throughout the pandemic by some organizations and private services. For example, participant 14 reported, "I don't feel caregivers are supported locally or nationally. I'm grateful for the support of the Alzheimer's society and our Primary Health Care Provider." However, as noted in the previous excerpt, they also expressed gaps in local and national policy that contributed to their feelings of being unsupported. In short, participant 4 shared, "I'm totally overwhelmed […]".

Discussion

Prior to conducting our research, we anticipated that individuals who had higher COVID Stress scores would yield lower QOL and WB scores. We expected that a negative correlation could point to a lack of appropriate pandemic-related supports in an area of informal care that has already faced many QOL and WB challenges prior to the pandemic, as documented in the literature. An empirical observation of this phenomenon could very well indicate that this population has experienced diminished QOL and WB due to burdening stressors related to the COVID-19 pandemic. In considering Centeredness Theory's open-systems foundation, imbalance in a particular domain of one's life is likely to influence other life domains and impact an individual's overall well-being (Bloch-Jorgensen et al., 2018). This would take into account what the current literature says about the impact that the global health crisis has had on the interruption of adequate government-funded caregiver support (Pongan et al., 2020), increased caregiver stress and anxiety related to COVID-19 (Mok et al., 2020), and the overall impact of these factors on general caregiver wellness (Bacsu et al., 2021). Based on a study done by Schumann et al. (2019), we also expected to see factors such as relationship to the caregiver and cohabitation as having an impact on QOL scores, as it has been suggested to dictate the level of captivity and responsibility associated to the role.

No Statistically Significant Association Between COVID Stress and Both QOL and WB

No statistically significant associations were found between COVID Stress and both QOL and WB. These results may have several implications. Firstly, it could very well be that there is no correlation between COVID Stress and both QOL and WB. However, current literature does seem to support a correlation (Altieri and Santangelo, 2021; Bacsu et al., 2021; Hwang et al., 2021; Masterson-Algar, 2021; Pongan et al., 2020; Tsapanou et al., 2020). Another consideration could be that the measure used to evaluate COVID Stress may be too general and is not structured to accurately capture the nuances within the dementia caregiver experience throughout the pandemic, thus obscuring this particular area of observation. If anything, this may point to a critical gap that brings attention to a need for dementia caregiver-specific scales to be developed to measure COVID Stress. As seen in studies surrounding QOL, the literature supported a need for dementia caregiver-specific tools to more adequately capture constructs relevant to the unique challenges faced by this very specific population (Brown et al., 2019; Daley et al., 2018). With the understanding that the COVID-19 pandemic is a relatively new phenomenon, and we cannot yet confirm that it has fully run its course, emerging studies continually recommend ongoing research to adequately grasp this area of study from a more longitudinal standpoint (Bacsu et al., 2021; Harris and Titler, 2022; Pongan et al., 2021; Tsapanou et al., 2020). It is important to note that the thrust of a global pandemic would call for the rapid development of measures and studies to document its acute impact, which is ongoing and ever-changing with various waves, reported strains of the virus, and emergency public health protocols. As the pandemic evolves, it is inevitable that studies and measures used to evaluate the experiences throughout this time will continue to expand as new information is gathered.

Given the continually evolving nature of the pandemic, it is also noteworthy to consider that there could have been challenges with self-reporting if participants consider current experiences primarily through a post-lockdown lens; perceiving these experiences much more positively when compared with the unprecedented intensity of previous waves of COVID and stricter public health measures. Our survey was live in a period where there was no lockdown,

lockdown, then no lockdown once again, with the last point being a period where restrictions loosened significantly and certain mandates were dropped. It is interesting to contemplate these moments from an experiential perspective and how this could potentially impact one's own perception of their current circumstances, after having vacillated through different levels of pandemic intensity and lockdown rather abruptly.

It is also crucial to note that recruiting participants throughout the pandemic had its challenges, despite help from Bruyère Research Institute, a large and credible research institution based in Ottawa, Canada. A higher sample size and increased diversity among participants could have possibly increased the power of the study. It appears as though many of the participants surveyed experienced their role throughout the pandemic with a certain degree of comfort when analyzing quantitative measures, which could point to socio-cultural and economic conditions that created more opportunities for receiving support in their role and having a greater appreciation for their role. These could be protective factors that mitigate COVID Stress. This could also influence their ability to be readily available to participate in such a survey, which may indicate that this may not be reflective of the general experiences within the majority of this population.

A Significant Correlation Between QOL and Burden

A significant correlation found between QOL and Burden totals provides confirmation of the inter-correlational qualities used to assess QOL and Burden, an aspect which comprised our WB measure. An inverse association was noted in this case. This supports the notion that when individuals typically reported a higher QOL, it is very likely that the level of burden they reported was low (Bressan et al., 2020; Daley et al., 2018). Bloch-Jorgensen et al.'s (2018) CT also supports the concept that overall well-being is achieved by maintaining balance within all life domains. Therefore, mitigating burden is likely to optimize quality of life.

A Significant Correlation Between Burden and Role Captivity

A significant correlation found between Burden and Role Captivity totals provides confirmation of the inter-correlational qualities of the proxy measures used to assess WB. A positive association was noted in this case. This supports the use of these two measures as a proxy for WB, an extension of quality of life, and supports the notion that when individuals typically reported higher burden, it is very likely that the level of role captivity they reported was higher (Alspaugh et al., 1999; Bressan et al., 2020; Pearlin et al., 1990; Ruisoto et al., 2019; Whitlatch et al., 1991; Zarit et al., 1980). Bloch-Jorgensen and colleagues (2018) maintain that CT views imbalance in one life domain as likely to influence imbalance in other life domains, which decreases overall well-being. Therefore, an increase in burden could likely influence an increase in feelings of role captivity, an emotional and subjective component of providing care, which could indicate decreased overall WB.

A Significant Correlation Between QOL and Role Captivity

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No Significant Correlation Between Burden and QOL Subscale 5: Carer Support

In our study, there did not appear to be an association between general Burden scores and Carer Support, a QOL subscale measure. This was the only subscale from the QOL measure that did not correlate with Burden scores. This could suggest that perceptions of and access to personal support systems and subjective approaches towards resiliency could have served as a protective factor, regardless of public supports for caregivers of PWD notably lost or diminished throughout the pandemic. This theory is also supported in the literature (Cipolletta et al., 2021; Daley et al., 2018; Sánchez-Teruel et al., 2022). This may imply that though a pandemic typically interrupts routines and can increase the personal responsibilities of a caregiver, a caregiver's attitudes towards other supports in their lives, such as family, friends, and support groups who offer significant value to their well-being as a caregiver, may be powerful enough to sustain them throughout times of sparse public health support and lockdowns.

No Significant Correlation Between Role Captivity and QOL Subscale 5: Carer Support

As with Burden scores, our study did not appear to find a significant association between general Role Captivity scores and Carer Support, a QOL subscale measure. This was the only subscale from the QOL measure that did not correlate with Role Captivity. As both Burden and Role Captivity were proxy measures for WB, this finding could suggest that perceptions of and access to personal support systems and subjective approaches towards resiliency could have served as a protective factor, regardless of public supports for caregivers of PWD notably lost or diminished throughout the pandemic. This theory is also supported in the literature (Cipolletta et al., 2021; Daley et al., 2018; Sánchez-Teruel et al., 2022). This may imply that although a pandemic typically interrupts routines and can increase the personal responsibilities of a caregiver, a caregiver's attitudes towards other relationships that offer significant value to their lives may be powerful enough to sustain them from feeling as though they are entirely captive in their caregiving role throughout times of sparse public health support and lockdowns.

Mostly Good Scores for Carer Role and Carer Support

Participants generally had mostly good scores for Carer Role, which indicates that participants generally valued their role and their relationship with their care recipient/partner. When consulting the literature, it is evident that a strong dyadic relationship suggests that the QOL and WB of each individual within the dyad is likely to be strong, when visiting theories of interdependence in the care partner dynamic (Harris and Titler, 2022). When a relationship is strong between care partners, this is likely to add value to the caregiving role (Daley et al., 2018; Harris and Titler, 2022). This could also reduce one-directional behaviour and attitudes toward the care recipient, which the literature has associated with less optimal QOL and WB in caring relationships (Harris and Titler, 2022; Miller et al., 2019). Additionally, mostly good scores for Carer Support also indicate that the caregiver generally had strong relationships outside of the dyad, regardless of the quantity of relationships, which added value and meaning to their role. Bloch-Jorgensen and colleagues (2018) present CT with four exogenous life domains and express that these domains impact one's self-perception and contribute to one's overall well-being. They purport that a strong sense of relationship, community, family, and work can contribute to a strong sense of self and purpose, which increases an individual's general well-being, despite challenges that may arise (Bloch-Jorgensen et al., 2018). Mostly good scores for both Carer Role and Carer Support could very likely be a protective factor that promoted resiliency throughout unprecedented times of the pandemic and COVID Stress. It is interesting to contemplate the possible impact on these scores if our sample generally had lower SES along with other influential socio-cultural factors, as decreased economic and socio-cultural privilege throughout a pandemic could place more stress and effort on accessing the basic necessities of survival, which may leave less time and energy to foster and develop these relationships, while also potentially creating more strain in the caregiving role.

Rarely Scores for Personal Strain

Though the caregiving role has its associated stresses, especially throughout a global pandemic, respondents generally felt that they rarely experienced personal strain when it came to quantitative measures associated with burden. Literature by Alspaugh and colleagues (1999) and Pearlin and colleagues (1990) mention subjective elements of caregiver stress that relate to carer thoughts and feelings about their caregiving. Therefore, in our study, though participants generally felt some objective role strain as it relates to measures of burden, it appears as though there were possibly mediating factors present which may have influenced the outcome when it came to personal strain. Reflecting on the aforementioned scores and interpretations related to Carer Role and Carer Support, it is quite possible that the outcome for Personal Strain was impacted to a certain degree by these factors.

Increased Burden on Caregivers

Our qualitative findings generated some initial curiosity in the analysis phase, as they provided additional considerations that may have been overlooked by focusing on the quantitative results alone. The opportunity to have participants speak freely about their experiences as a caregiver for a PWD throughout the pandemic offered rich insight into areas of interest that may have gone undetected due to more general constructs of measures for COVID Stress, which were not specifically informed of experiences of ICs of PWD throughout the pandemic.

The first theme that emerged from our qualitative analyses was increased burden on caregivers. Although the interpretation of the mean score for COVID Stress indicated slight COVID Stress, and an interpretation of the mean score for Burden indicated moderate burden, it appears as though the qualitative data indicates increased burden due to increased COVID-related stresses. A prominent sub-theme observed in this area was diminished access to in-home support workers, which was supported by reports that certain participants experienced frequent cancellations in regular services due to public health measures and COVID concerns. Studies by Tam et al. (2021) also report this phenomenon. Additionally, it was observed that trustworthy and consistent in-home assistance was lacking, which also limited participants' ability to engage with community outside of their homes. Studies have shown that caregiver independence and sense of self was important to achieving optimal QOL and WB scores (Alspaugh et al., 1999; Bressan et al., 2020; Pearlin et al., 1990; Ruisoto et al., 2019; Whitlatch et al., 1991; Zarit et al., 1980).

Additionally, the first sub-theme also included the cancellation of day program services offered by outside organizations. This was supported by reports that the switch to virtual care services demanded more time and effort from caregivers to navigate the delivery method of these services, which took away much needed respite time that normally came with day programs. These claims are also supported in literature by Maffioletti et al. (2021), who raised concerns that a switch to virtual activities could pose the risk of additional burden on caregivers, as the in-person options offered pre-pandemic were made available to ensure caregivers would be able to have a break and reduce their overall burden. As indicated in the literature, this population already tends to be aging, with age-related perceptual challenges, and often possesses limited knowledge of internet-based technology (Masterson-Algar et al., 2021; Wong et al., 2021).

Therefore, virtual options may require a steep learning curve and active caregiver involvement in an area that is intended to offer a caregiver respite time. Other participants commented on the experience of strain on the healthcare system and outside public and private caregiver supports, which notably added more strain on the support that the caregiver was able to provide in their role. Hwang and colleagues (2021) support these findings in their research as well.

The second sub-theme that emerged from our analysis of increased caregiver burden was the isolation experienced by the caregiver. Much like previous literature had mentioned (Cipolletta et al., 2021; Harris and Titler, 2022; Taneska, 2021), it was suggested by some participants that dementia already isolates caregivers and thus, a pandemic only further compounded these challenges. Certain participants reported increased isolation with limited resources compared to pre-pandemic times, which increased their sense of loneliness and captivity, as supported by emerging studies (Cipolletta et al., 2021; Maffioletti et al., 2021; Tam et al., 2021).

Lastly, within the theme of increased caregiver burden, a third sub-theme emerged, which was financial stress. Participants who were still employed acknowledged stresses related to trying to balance working and stretching financial resources to adequately care for their care recipient and the high financial costs associated to delivering care. Other participants commented on the decrease of family income throughout this unprecedented and unpredictable period, which impacted the QOL and WB of the caregiver, and worsened the condition of the care recipient. Hwang et al. (2021) confirm reports of increased financial burden for caregivers of PWD throughout the pandemic and research by Shooshtari and colleagues (2017) reports financial and economic security consequences for caregivers in general, which is associated to overall lower QOL and WB of caregivers due to financial burden.

Diminished Quality of Care for Care Recipients

The second theme that emerged from our qualitative analyses was diminished quality of care for care recipients. Although the interpretation of the mean score for COVID Stress indicated slight COVID Stress, and an interpretation of the mean score for Quality of Life indicated mostly good, closely approaching satisfactory, it appears as though the qualitative data expresses diminished quality of care due to increased COVID-related stresses. A prominent sub-theme observed in this area was caregiver burnout, which was supported by reports that caregivers were experiencing higher levels of depletion which impacted their quality of care and that the effects of the pandemic have had adverse emotional impacts on the caregiver, which in turn has affected the care recipient. Studies by Masterson-Algar and colleagues (2021) and Sánchez-Teruel et al. (2022) speak to this phenomenon as well.

A second sub-theme that emerged in the category of diminished quality of care for care recipients was isolation of the care recipient due to pandemic-related factors. This was evidenced by reports of PSW services being stopped at the height of the pandemic as well as day programs, which have yet to be restored to pre-pandemic capacities. This notably made care recipients feel more isolated and depressed. There were also concerns reported about the mental well-being of the care recipient due to loss of activities that increased feelings of isolation, which research by Harris and Titler (2022) and Maffioletti et al. (2021) also highlights.

When observing diminished quality of care for care recipients, a third sub-theme was noted, which pointed to challenges in accessing health care. Participants reported that accessing health care for their care partners was indeed more challenging throughout this period, as well as the services being difficult to navigate due to the unpredictable nature of the pandemic. This phenomenon is also noted in studies by Altieri and Santangelo (2021). There were also reports in our study that hospital and medically based services were limited, which also posed a significant challenge, since many of these services tended to be outside of the scope of care that the caregiver can confidently and competently provide to the care recipient. Research by Greenberg and colleagues (2020) also support this claim.

Lastly, in considering the emerging theme of diminished quality of care for care recipients, a fourth sub-theme was noted, which highlighted diminished services with both in-home support and day programs. Participants reported public supports being intermittent due to lockdown and COVID outbreaks among personnel. Certain participants recognized that abrupt changes posed challenges to the PWD, and that frequent schedule and personnel changes caused the PWD additional distress. Certain respondents also acknowledged how diminished support services impacted the BPSD of the PWD, notably in areas of mental and physical well-being. Similarly, studies done by Harris and Titler (2022) and Pongan et al. (2021) address the likelihood of increased BPSD in a PWD throughout the pandemic due to abrupt changes in living conditions and routines.

Lack of Support and Consideration by Policy Makers for Caregivers

The third theme that emerged from our qualitative analyses was lack of support and consideration by policy makers for caregivers. Although the interpretation of the mean score for COVID Stress indicated slight COVID Stress, and an interpretation of the mean score for the QOL subscale which measured Carer Support indicated mostly good on a spectrum that is closely approaching satisfactory scores, it appears as though the qualitative data expresses lack of support and consideration by policy makers in light of increased COVID-related stresses in their role as caregivers. A prominent sub-theme observed in this area was the financial responsibility on the caregiver, which was supported by reports that caregivers felt especially ignored in the realm of homecare. A study on PSW perspectives in Ontario, Canada by Breen and colleagues (2021) notes that provision of homecare has undergone longstanding reduction even in pre-pandemic times, though cost-effectiveness and desirability appear to make it a popular option among many caregivers. Bressan and colleagues (2020) purport that ICs of PWD who are providing care from home require access to individualized, structured, and timely formal care in order to optimize caregiver QOL and WB, as well as quality of care provided to the care recipient. Meanwhile, research by Harris and Titler (2022) acknowledges the challenges to in-home care for PWD and their caregivers prior to the pandemic, which have only become compounded by it.

Other responses highlighted the feeling of being taken advantage of by policy makers due to the financial contribution ICs make to overall health care infrastructure and their cost effectiveness on the health care system; stating that outside relief only felt possible in extreme situations that directly compromised the caregiver’s ability to provide care. Literature by Masterson-Algar and colleagues (2021) addresses poorer overall QOL experienced by both PWD and their caregivers as a result of the pandemic and associated policy responses. Respondents of our study were adamant about voicing their concerns for additional funding for homecare and day programs in order to be able to provide adequate care without having to deplete all of their finances, especially if the care recipient eventually had to be placed in long-term care. Research by Shooshtari et al. (2017) points to the financial burden associated with informal caregiving and its adverse impacts on QOL and WB, while research by Hwang et al. (2021) reports additional caregiving duties and worsening financial problems for caregivers of PWD throughout the pandemic.

The second sub-theme which emerged within the category of lack of support and consideration by policy makers for caregivers was a lack of available dementia-informed and/or dementia-caregiver informed formal programming and support. Participants reported feelings of hopelessness when contemplating receiving significant respite time throughout this period. Research by Wong et al. (2021) highlights that the pandemic prompted a need to develop alternative interventions to better support caregivers and provide PWD with social stimulation that could typically be accessed in-person prior to the pandemic. Other participants commented on the challenges they experience with navigating and organizing respite care, which included lengthy paperwork and approval times, and caused additional worry when contemplating the accessibility of placement services in emergency circumstances. Breen et al. (2021) reveal that even prior to the pandemic, ICs emphasized the importance of increased respite time as well as dementia-specific education. It is interesting to contemplate the compounding effects that a pandemic could have on this challenge.

Regarding our research, there were also comments made regarding the lengthy waitlists for long-term care options, along with expressing a need for more respite, social programming, and support for caregivers funded by the government. Stall and colleagues (2018) discuss that less optimal caregiver characteristics, such as caregiver distress, could predict placements in nursing homes for PWD, with relevant interventions to improve caregiver WB as a possible strategy to delay institutionalization. One participant expressed, “Private care facilities can't be trusted and are exorbitant in cost, while [*a*] dementia patient deteriorates quickly in strange and hospital-like surroundings”. Overall, inadequate in-home support appeared to be a prominent challenge outlined in our study, which limited participants’ ability to attend to other aspects of their lives outside of the home. Certain participants expressed the need for more accessible in-home care to better care for this population as their health declines, with a focus on keeping care recipients in their home for as long as possible, rather than restricting funding in this area and eventually forcing families to place loved ones due to limited support.

Another participant expressed, “Long term care facilities need a total overhaul: higher wages for paid care workers to improve quality [*of care*] and retain, different strategies to mix demographics and stop "warehousing" the elderly”. Research posited by Masterson-Algar and colleagues (2021) highlights a need for comprehensive policy development that moves beyond protectionism and removal of risk of the virus to this population in pandemic times, into areas which bring attention to, and support factors related to, QOL and protection from threats to the overall well-being of PWD and their caregivers.

It appears as though the qualitative portion of this study has provided an opportunity to highlight larger systemic challenges and gaps in program and policy making intended to support caregivers of PWD throughout the pandemic. Though many participants appeared to be managing relatively well when evaluating their experiences through quantitative measures, this may reveal aspects of their own resilience and protective factors that have allowed them to navigate in such a way; with an understanding that a global pandemic called for several adjustments and an expectation of diminished outside support for everyone. However, the qualitative data does well to investigate areas that may not have necessarily been able to be captured through the quantitative scales, as they focus on experiential and pandemic-specific questions, as they relate to feeling seen and supported in their caregiving role throughout a pandemic, as well as prospects for their caregiving role as we emerge from a global pandemic that has inevitably influenced the “new normal”. The qualitative questions also intentionally normalized feelings of loss, challenge, or worry as a result of the pandemic and could have made participants more at ease with sharing these experiences. It is possible that participants may have otherwise felt inclined to respond with more social desirability, given the fact that the pandemic is a globally shared experience which was unprecedented in recent history. Participants may have perceived airing grievances regarding aspects of their personal experiences as being highly critical of others throughout a period where many people were also equally affected by a pandemic. Therefore, normalizing challenges was seen as an essential element in presenting the qualitative questions to participants.

A larger question arises after qualitative data analyses: *how sustainable are these current conditions over a longer period of time?* Many of our participants were relatively new to the caregiving role and generally tended to have higher SES, which could have an influential presence on aspects of QOL and WB. However, more favourable financial conditions aside, there were still serious worries in the qualitative data regarding the feasibility of delivering care longer-term and being able to financially afford expenses related to the care recipient's conditions and care. Some participants made note of expensive long-term care options that are likely to destabilize financial comfort in the future. This is troublesome when contemplating the compounding effects of this already demanding position as a caregiver of a PWD, particularly if a caregiver initially presents with lower SES and lower socio-cultural privilege. Additionally, as one becomes more seasoned in their role as a primary caregiver, it is quite possible that the compounding effects of these pressures could seriously deplete caregivers physically, mentally, emotionally, and financially if they are not managed with adequate support to uphold these roles. As previously mentioned, the literature also acknowledges that this is generally an aging population (Bressan et al., 2020; Bussè et al., 2022; Harris and Titler, 2022; Hwang et al., 2021; Maffioletti et al., 2021; Pongan et al., 2021; Wong et al., 2021) therefore, caregivers themselves may also be managing their own age-related health concerns that impact the aforementioned domains, while providing primary care support for a PWD.

Additionally, an opportunity to present preliminary findings of this research to a group that was comprised of mostly caregivers via a Zoom presentation held by the *Centre for Aging and Community* at Saint Paul University on June 14th, 2022, offered additional insight into the informal caregiver of PWD experience throughout the pandemic. Some attendees spoke out about challenges experienced navigating the health care system and accessing adequate support outside of friends and family to foster a greater sense of community and consistency with the programs available, services provided, and other caregivers who are also accessing these supports. Certain attendees voiced being inspired about the research being done to investigate their experiences however, they also appeared to perceive research efforts in this domain as ongoing, with concrete actions being followed through very slowly. It was evident throughout these discussions that certain attendees yearned for more tangible action be taken at the level of government and community to effect changes that have been suggested by the emerging literature, along with an increased effort to build strong networks among those in this lived experience and the programs/services offered to this specific population.

One attendee of this presentation who is associated with the Interfaith Health Care Association of Manitoba (IHCAM) mentioned that the pandemic led to adopting creative means of addressing the challenges that this population is currently facing. She continued by sharing that this prompted the creation of a monthly online support group that she had been successfully running throughout the pandemic, and that she has been able to witness the positive reception and results of this specific intervention. Based on existing literature by Altieri et al. (2021), the use of online psychological and educational programs throughout the pandemic is encouraged to reduce depressive symptomology, anxiety, and burden levels in caregivers. Research by Tulloch and colleagues (2022) points to this suggestion as well; outlining the value in opportunities for natural social stimulation for both PWD and their caregivers throughout this time and highlighting that though there are many adverse outcomes of the pandemic, it has also created opportunities for ICs to connect more deeply with their care recipients and find profound meaning in the care they provide.

Limitations and Strengths

As mentioned earlier, this study does bring forth its own set of limitations. Firstly, the measure used to assess COVID-19 stress was developed to address COVID Stress Syndrome within the general population. The scope of this tool may have proven to be too general, as it was not specifically developed or informed with the informal dementia caregiver experience in mind. Though the factors of the CSS were inter-correlated, it is likely that a broad approach to assessing COVID-related stresses among a population that has very specific roles and demands may very well obscure aspects of their experience throughout this time. Furthermore, the concept of COVID Stress may actually require different constructs, depending on the context in which COVID Stress is being measured and the particular population of interest. However, given the nature of this new phenomenon, it is important to keep in mind that fully developed measures and tools for COVID Stress are limited and will only undergo necessary developments once research, such as ours, demonstrates a need for more attention surrounding population-specific COVID Stress measures.

Another limitation of the study was the self-reporting structure of both the quantitative and qualitative portions. Firstly, it is important to consider that globally, nationally, and locally, many have vacillated through various waves of the pandemic, and rather abruptly. We have navigated through strict public health measures, lockdowns, and the world seemingly being “shut down”. We have also experienced periods where restrictions loosened, lockdowns were lifted, and certain mandates were dropped. This experience and its acute nature can be both emotionally and mentally challenging to process for anybody. From an experiential perspective, it is important to contemplate how this could potentially impact one’s own perception of their current circumstances when reflecting on bleaker times throughout the pandemic. This may have led to cases of both recall and positive response bias. Additionally, temporal variance in the assessment portion of each of the measures used, as well as the qualitative questions, may have also created challenges with recalling experiences with accuracy. Participants also may have felt inclined to reply to certain parts of the survey with social desirability, to avoid being perceived as highly critical of others throughout a period where many people were also equally affected by a pandemic. For our study, the qualitative questions were captured in an online written format, as opposed to virtual, telephone, or in-person interviews. Establishing a collaborative format with participants and having an active dialogue could have resulted in more profound findings and willingness for participants to further elaborate on their experiences. However, given the scope of an MA-level thesis and conducting research on an aging population throughout a global pandemic, these approaches were necessary and contributed to the feasibility of undertaking this research. Should more resources and research support be made available to continue studies, a longitudinal approach that is more collaborative in nature could assist in effectively monitoring and capturing these complexities as they arise.

There were also notable limitations with participant diversity and sample size, which may have consequences on generalizability and power. The current sample size may possibly present a restriction in power and thus may not be representative of this population. Limitations with participant diversity, such as SES, and various socio-cultural factors, such as ethnicity, race, gender, education, and sexual orientation pose a challenge to understanding the experiences of caregivers of PWD throughout the pandemic through these lenses. Given that more than half of the respondents were recruited through the BRI, based in Ottawa, Canada, it is important to consider the Ottawan context when contemplating generalizability. As Canada's capital, Ottawa is known as a predominantly bilingual government city with many of its residents educated past the post-secondary level, which may indicate more privileged contexts than some other Canadian cities and towns. The sample may represent individuals who are experiencing the pandemic with certain levels of comfort due to demographic criteria, which increases the likelihood of their participation in the study, as the recruitment process was entirely voluntary in nature. This may not be representative of samples of ICs of PWD who live in more vulnerable conditions. Given the scope of the MA-level thesis with no initial funding and many research institutions charging fees for support services, and an abrupt stop to many projects being supported by these institutions due to the pandemic, we were quite fortunate to recruit these participants and receive the support we did from BRI in our recruitment efforts.

Though the study was offered as a Canada-wide study, participants only came from British Columbia, Manitoba, Ontario, and Québec. A large majority of the participants were actually from Ontario. Challenges in recruitment were present, considering that the research was conducted throughout a global pandemic. This may impact the generalizability of our results to the Canadian population. Additionally, the challenges that BRI (a large and credible research institution) experienced in recruiting for our study points to pandemic-related restrictions with all research being conducted in general.

A gift card incentive for our online study is another limitation, as it may cloud participant motives for engaging in this study. Initially, the study recorded 82 participants, though many were screened out in preliminary stages as a result of failing to comply with survey requirements. We hypothesize that the influx of random engagement was partly due to honorariums offered. Strict measures adhering to inclusion/exclusion criteria were taken in doing a preliminary data screening, to avoid the use of random data in our study. This incentive was seen as imperative, as recruitment throughout the pandemic was a real challenge and it was a necessary token of appreciation to those who took the time out of their busy caregiving schedules, amidst a pandemic, to support our research. A significant number of participants who were recruited for our study came directly from the BRI database, which increased accuracy in recruiting the desired population and ensuring responses were not at random.

A particular strength of this study is that it employed mixed methodology to explore the experiences of ICs of PWD throughout the pandemic. Both the quantitative and qualitative results offer much to be considered however, alone, they do not reveal the many nuances that emerged once they were considered in their interaction with one another. Additionally, in the case of our study, an all-quantitative or all-qualitative methodology could possibly have different implications which lead to an inaccurate representation of our sample and premature conclusions.

Another strength of this study, despite restrictions in resources due to the pandemic, is that the qualitative analysis employed a triangulated approach. The qualitative data was collaboratively interpreted through an iterative approach between a graduate-level research assistant, a clinical psychologist/researcher, and the primary investigator. This would generally increase inter-rater reliability in the coding process and in the extraction of relevant themes and sub-themes.

An additional strength of this study is that it is technically a Canadian study, with the majority of participants being from Ontario. The experiences of the COVID-19 pandemic also depend greatly on temporal considerations, such as geography (Bacsu et al., 2021). It is important to increase studies in this domain, particularly within the Canadian context, as they are limited. Given that the majority of our respondents were from Ontario, this also serves to document this phenomenon from an Ontarian perspective.

Impact and Implication

The most crucial implication of this study is that it will serve to scientifically document the impact of the COVID-19 pandemic on informal caregivers of persons with dementia. Given the fact that studies done on this very specific population continue to be a newer and less explored field of research with several existing gaps (Bacsu et al., 2021; Bressan et al., 2020; Daley et al., 2018; Greenberg et al., 2020; Harris and Titler, 2022; Pongan et al., 2021; Tsapanou et al., 2020), it is particularly useful to record findings based on the experiences of this population throughout such a novel time in recent history. Due to the very acute onset of this global crisis, there is a limited scope of studies available in a broader context, let alone within this specific demographic (Bacsu et al., 2021; Bressan et al., 2020; Daley et al., 2018; Greenberg et al., 2020; Harris and Titler, 2022; Pongan et al., 2021; Tsapanou et al., 2020).

Given the globally projected doubling of PWD, coupled with the projected reduction of available ICs within the next few decades (Manuel et al., 2016), it is imperative to take note of current experiences to address potential long-term repercussions of the pandemic on this often-overlooked population. Our current formal care systems are highly reliant on support that is provided by unpaid caregiving (Khayatzadeh-Mahani and Leslie, 2018) and actions taken to observe current caregiver consequences can also serve as a cost-effective measure in the long-term. Neglecting this research could result in dire consequences for both the local and global economic sustainability of elderly care, due to an inability to take note of declining QOL and WB of ICs throughout the pandemic.

The impact of documenting such findings may more tentatively allow for informed advocacy and policy formation, to eventually provide appropriate support to ICs of PWD, which could mitigate lower QOL and WB scores. The notion of support embodies a variety of branches, such as mental health, PSWs, community, and financial supports (to name a few). Prior to the pandemic, there was already a great need to improve caregiver navigation through a challenging and complex health care system, which is often experienced as fragmented in its approach to holistic care (Smith-Carrier et al., 2018). This research could facilitate the necessary groundwork required to eventually delve into consolidation strategies to create a more person-centered and cohesive care support system for both PWD and ICs, particularly throughout a global pandemic.

A critical exploration of the findings will also allow for an understanding of the phenomenon within a Canadian context. This research is among initial studies done on the local dementia caregiver demographic throughout the COVID-19 pandemic. This could greatly influence rethinking regional approaches to addressing caregiver needs throughout the pandemic era, with socio-cultural and intersectional sensitivity. This study’s ability to document current and local systemic fragments may encourage early interventions which could serve as preventative measures to circumvent more severe future consequences in the Canadian population. Additionally, these findings can better facilitate the implementation of future policies that may be put in place locally and nationally to support the transition into a post-pandemic society, while being informed of consequences that may potentially follow. It may also possibly offer strategies in the face of another global pandemic.

Through a clinical lens, this research provides an opportunity to raise awareness on the experiences of this population, to better inform mental health professionals in their clinical work with this population; whether in an individual, couple, family, or group setting. More specifically, an informed perspective is essential to accurate conceptualization and the understanding of current challenges and added stressors, which greatly informs clinical interventions. Additionally, with the term *self-care* becoming particularly ubiquitous throughout the pandemic, clinical interventions aimed at developing individual self-care strategies to promote QOL and WB need to be practical and informed of the dementia caregiver experience. A clinician suggesting particular strategies which are not considerate of the client's reality and current experiences may be harmful to a client's ability to believe that self-care is accessible to them, which may lead to more infrequent use of self-care methods. Lastly, clinicians would benefit from understanding the experiences of this population to determine which resource referrals are appropriate for the needs of these individuals and their care dyad.

Future Research Directions

Future research would benefit from a participatory and action-oriented approach that directly involves this population in the research, in order to reflect on current challenges and take concrete actions to address the gaps noted. This inclusive approach can also assist in gaining a more comprehensive outlook. Bacsu et al. (2021) also comment on the benefits of taking a collaborative, partnership-based approach to develop more in-depth knowledge on the impact of the pandemic on this population. Research by Masterson-Algar et al. (2021) highlights existing gaps in policy formation that would benefit from moving toward acknowledging and supporting pandemic outcomes related to caregiver QOL and WB. This approach can be made possible if this population is included in suggesting strategies that may address these gaps and viable ways to introduce changes. Additionally, a longitudinal approach to study this phenomenon could offer insight into variance associated with temporal factors throughout several stages of the evolving pandemic.

Future studies would also benefit from the addition of a resiliency measure, to further understand its interaction with pandemic-related stresses and both QOL and WB. This could also provide insight into possible protective or mediating factors that may reveal adaptive coping and meaning-making strategies that could mitigate adverse consequences related to pandemic stress, and increase both QOL and WB. This knowledge could also be integrated into the development of support programs and educational materials. Research by Altieri et al. (2021) recognizes that lower levels of resilience in caregivers make them more prone to an increase of psychological symptoms. Future research may also benefit from including psychological assessments related to depression and anxiety to measure baseline states and variance throughout the pandemic, and observe how these outcomes interact with other measures used in the study.

Research by Stubbs et al. (2021) urges the development of evidence informed resources and support that are informed of the dementia experience, which is considerate of caregivers from all SES backgrounds. Future research would benefit from a more inclusive demographic that could capture the many nuances and intersectionalities within this population and how these factors also impact their caregiving experience throughout the pandemic. Future research should focus on the development of concrete tools and support programs that are culturally and contextually appropriate, to address the diverse caregiver experience throughout the pandemic.

Conclusions

We anticipated that individuals who had higher COVID Stress scores would yield lower Quality of Life and Well-Being scores. These results could demonstrate that this population has experienced diminished QOL and WB due to burdening stressors related to the COVID-19 pandemic. This could also suggest a lack of appropriate pandemic-related supports in a domain that already experienced many challenges to QOL and WB prior to the pandemic, as noted in the aforementioned literature.

Though our quantitative analyses initially found no significant association between COVID Stress and both Quality of Life and Well-Being, this conclusion is not exhaustive. There are several considerations to make with this information that warrant further research and exploration, as noted in both the discussion and limitations. Additional quantitative analyses suggested that certain aspects of the caregiver demographic, their perception of being supported, and their perception of their role could possibly have either protective and/or mediating factors that could influence CSS scores. Several significant associations were found between QOL and WB scale and subscale measures.

Findings from our qualitative analyses confirm that there are pandemic-related stresses which have adversely impacted both the QOL and WB of caregivers. Our qualitative analyses noted an increase in caregiver burden, diminished quality of care for care recipients, and a lack of support and consideration by policy makers for caregivers throughout the pandemic. Notably, this area of analysis suggested that there are several challenges and gaps in program and policy making to support caregivers of PWD throughout the pandemic, which appears to have resulted in poorer outcomes related to caregiver QOL and WB.

The role of informal caregivers of persons with dementia is tremendous and contributes to the sustainability of formal care and support systems that are in place to manage the ever-growing dementia population. The time, care, and effort that they pour into their roles and caring relationships helps to support the health, quality of life, and well-being of our communities at large. Without proper attention and research that is concerned with their experiences and needs, particularly throughout a global pandemic, these individuals are very much at risk for more dire mental and emotional health outcomes. This research is an attempt to begin documenting the impact of the COVID-19 pandemic on the current experiences of informal caregivers of persons with dementia, so that it can build a foundation on which to carry out further action-oriented research concerned with effectively assessing and providing informed interventions to support this population.

References

Alspaugh, M. E., Stephens, M. A., Townsend, A. L., Zarit, S. H., & Greene, R. (1999). Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress as predictors. *Psychology and Aging*, *14*(1), 34–43. https://doi.org/10.1037/0882-7974.14.1.34

Altieri, M., & Santangelo, G. (2021). The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *The American Journal of Geriatric Psychiatry*, *29*(1), 27–34. https://doi.org/10.1016/j.jagp.2020.10.009

Alzheimer's research UK. Dementia Statistics Hub. (2022, February 2). Retrieved April 9, 2022, from https://www.dementiastatistics.org/

Bacsu, J., O'Connell, M. E., Cammer, A., Azizi, M., Grewal, K., Poole, L., Green, S., Sivananthan, S., & Spiteri, R. J. (2021). Using Twitter to understand the COVID-19 experiences of people with dementia: Infodemiology study. *Journal of Medical Internet Research*, *23*(2), e26254. https://doi.org/10.2196/26254

Ballesteros, J., Santos, B., González-Fraile, E., Muñoz-Hermoso, P., Domínguez-Panchón, A. I., & Martín-Carrasco, M. (2012). Unidimensional 12-Item Zarit caregiver burden interview for the assessment of dementia caregivers' burden obtained by item response theory. *Value in Health*, *15*(8), 1141–1147. https://doi.org/10.1016/j.jval.2012.07.005

Behavioural and psychological symptoms of dementia (BPSD). PsychDB. (2022, February 15). Retrieved March 5, 2022, from https://www.psychdb.com/geri/dementia/1-bpsd#primer

Bertrand, R. M., Fredman, L., & Saczynski, J. (2006). Are All Caregivers Created Equal? Stress in Caregivers to Adults With and Without Dementia. *Journal of Aging and Health*, *18*(4), 534–551. https://doi.org/10.1177/0898264306289620

Bloch-Jorgensen, Z.T. (2015). *MAP: Living a Centered Life*. Atlanta, GA: Freedomsway Press.

Bloch-Jorgensen, Z. T., Cilione, P. J., Yeung, W. W., & Gatt, J. M. (2018). Centeredness Theory: Understanding and measuring well-being across Core Life Domains. *Frontiers in Psychology*, *9*. https://doi.org/10.3389/fpsyg.2018.00610

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Breen, R., Savundranayagam, M. Y., Orange, J. B., & Kothari, A. (2021). Quality Home Care for persons living with dementia: Personal Support Workers' perspectives in Ontario, Canada. *Health & Social Care in the Community*. https://doi.org/10.1111/hsc.13692

Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, *28*(6), 1942–1960. https://doi.org/10.1111/hsc.13048

Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *SSRN Electronic Journal*. https://doi.org/10.2139/ssrn.3532534

Brown, A., Page, T. E., Daley, S., Farina, N., Basset, T., Livingston, G., Budgett, J., Gallaher, L., Feeney, Y., Murray, J., Bowling, A., Knapp, M., & Banerjee, S. (2019). Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*, *28*(8), 2299–2310. https://doi.org/10.1007/s11136-019-02186-w

Bussè, C., Barnini, T., Zucca, M., Rainero, I., Mozzetta, S., Zangrossi, A., & Cagnin, A. (2022). Depression, anxiety and sleep alterations in caregivers of persons with dementia after 1-year of COVID-19 pandemic. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.826371

Buuren, S. van. (2021). *Flexible imputation of missing data*. Chapman & Hall/CRC.

Cipolletta, S., Morandini, B., & Tomaino, S. C. (2021). Caring for a person with dementia during the COVID-19 pandemic: A qualitative study with family care-givers. *Ageing and Society*, 1–21. https://doi.org/10.1017/s0144686x21000696

Cohen, D. (2020). *Surviving lockdown: Human nature in social isolation*. Routledge.

Daley, S., Murray, J., Farina, N., Page, T. E., Brown, A., Basset, T., Livingston, G., Bowling, A., Knapp, M., & Banerjee, S. (2018). Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. International Journal of Geriatric Psychiatry, 34(1), 79–86. https://doi.org/10.1002/gps.4990

Farina, N., King, D., Burgon, C., Berwald, S., Bustard, E., Feeney, Y., Habibi, R., Comas-Herrera, A., Knapp, M., & Banerjee, S. (2020). Disease severity accounts for minimal variance of quality of life in people with dementia and their carers: Analyses of cross-sectional data from the MODEM study. *BMC Geriatrics*, *20*(1). https://doi.org/10.1186/s12877-020-01629-1

Givens, J. L., Mezzacappa, C., Heeren, T., Yaffe, K., & Fredman, L. (2014). Depressive symptoms among dementia caregivers: Role of mediating factors. *The American Journal of Geriatric Psychiatry, 22*(5), 481–488. https://doi.org/10.1016/j.jagp.2012.08.010

Gray, L. K. (2012). *First Nations 101: Tons of stuff you need to know about first nations people*. Adaawx Pub.

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

Grover, S., Nehra, R., Malhotra, R., & Kate, N. (2017). Positive Aspects of Caregiving Experience among Caregivers of Patients with Dementia. *East Asian Archives of Psychiatry, 27*(2), 71–78. https://doi.org/10.3316/informit.904051576236541

Harris, M. L., & Titler, M. G. (2022). Experiences of family caregivers of people with dementia during the COVID-19 pandemic. *Western Journal of Nursing Research*, *44*(3), 269–278. https://doi.org/10.1177/01939459211055773

Ho-yin Lai, F., Wai-hung Yan, E., Ka-ying Yu, K., Tsui, W. S., & Yee, B. K. (2021). The protective impact of telecare on persons with dementia and their caregivers during the

COVID-19 pandemic. *Alzheimer's & Dementia*, *17*(S7). https://doi.org/10.1002/alz.049297

Hollander, M., Liu, G., & Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, *12*(2), 42–49. https://doi.org/10.12927/hcq.2009.20660

Hwang, Y., Connell, L. S. M., Rajpara, A. R., & Hodgson, N. A. (2021). Impact of COVID-19 on dementia caregivers and factors associated with their anxiety symptoms. *American Journal of Alzheimer's Disease & Other Dementias*, *36*, 153331752110087. https://doi.org/10.1177/15333175211008768

Jenkins, E. K., McAuliffe, C., Hirani, S., Richardson, C., Thomson, K. C., McGuinness, L., Morris, J., Kousoulis, A., & Gadermann, A. (2021). A portrait of the early and differential mental health impacts of the COVID-19 pandemic in Canada: Findings from the first wave of a nationally representative cross-sectional survey. *Preventive Medicine*, *145*, 106333. https://doi.org/10.1016/j.ypmed.2020.106333

Khayatzadeh-Mahani, A., & Leslie, M. (2018). Policies supporting informal caregivers across Canada: A scoping review protocol. *BMJ Open*, *8*(6), e019220. https://doi.org/10.1136/bmjopen-2017-019220

Liu, H., Fang, B., Chan, J., & Chen, G. (2019). The relationship between comorbidities in dementia patients and burden on adult–child primary caregivers: Does having a secondary caregiver matter? *International Journal of Mental Health Nursing*, *28*(6), 1306–1317. https://doi.org/10.1111/inm.12640

Maffioletti, V. L., Baptista, M. A., Abranches, B., Koatz, G., Rodrigues, V. M., Deslandes, A., & Dourado, M. C. (2021). Virtual Day Center for people with dementia and their caregivers during the COVID-19 pandemic. *Dementia & Neuropsychologia*, *15*(4), 440–447. https://doi.org/10.1590/1980-57642021dn15-040003

Manuel, D. G., Garner, R., Finès, P., Bancej, C., Flanagan, W., Tu, K., Reimer, K., Chambers, L. W., & Bernier, J. (2016). Alzheimer's and other dementias in Canada, 2011 to 2031: A microsimulation population health modeling (POHEM) study of projected prevalence, health burden, health services, and caregiving use. *Population Health Metrics*, *14*(1). https://doi.org/10.1186/s12963-016-0107-z

Masterson-Algar, P., Allen, M. C., Hyde, M., Keating, N., & Windle, G. (2021). Exploring the impact of COVID-19 on the care and quality of life of people with dementia and their carers: A scoping review. *Dementia*, *21*(2), 648–676. https://doi.org/10.1177/14713012211053971

Miller, L. M., Kaye, J. A., Lyons, K. S., Lee, C. S., Whitlatch, C. J., & Caserta, M. S. (2019). Well-being in dementia: A cross-sectional dyadic study of the impact of multiple dimensions of strain on persons living with dementia and their family care partners. *International Psychogeriatrics*, *31*(5), 617–626. https://doi.org/10.1017/s104161021800203x

McShane, R. (2000). What are the syndromes of behavioral and psychological symptoms of dementia? *International Psychogeriatrics*, *12*(S1), 147–153. https://doi.org/10.1017/s1041610200006943

Mok, V. C., 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., 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 & Dementia, 16*(11), 1571–1581. https://doi.org/10.1002/alz.12143

Montour, L. (2000). The Medicine Wheel: Understanding "Problem" Patients in Primary Care. *Permanente Journal*. https://doi.org/10.7812/TPP/98-040

Murdoch-Flowers, J., Tremblay, M.-C., Hovey, R., Delormier, T., Gray-Donald, K., Delaronde, E., & Macaulay, A. C. (2019). Understanding how Indigenous culturally-based interventions can improve participants' health in Canada. *Health Promotion International*, *34*(1), 154–165. https://doi.org/10.1093/heapro/dax059

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Role captivity scale. *PsycTESTS Dataset*. https://doi.org/10.1037/t60647-000

Pongan, E., Dorey, J., Borg, C., Getenet, J. C., Bachelet, R., Lourioux, C., Laurent, B., Rey, R., & Rouch, I. (2021). COVID-19: Association between increase of behavioral and psychological symptoms of dementia during lockdown and caregivers' poor mental health. *Journal of Alzheimer's Disease*, 1–9. https://doi.org/10.3233/jad-201396

Prins, M., Willemse, B., van der Velden, C., Pot, A. M., & van der Roest, H. (2021). Involvement, worries and loneliness of family caregivers of people with dementia during the COVID-19 visitor ban in long-term care facilities. *Geriatric Nursing*, *42*(6), 1474–1480. https://doi.org/10.1016/j.gerinurse.2021.10.002

Quach, E. D., Franzosa, E., Moo, L. R., & Hartmann, C. W. (2021). Clinician experiences delivering dementia caregiver support services during COVID-19. *The American Journal of Geriatric Psychiatry*, *29*(5), 511–512. https://doi.org/10.1016/j.jagp.2021.01.002

Ringer, T. J., Wong-Pack, M., Miller, P., Patterson, C., Marr, S., Misiaszek, B., Woo, T., Sztramko, R., Vastis, P. G., & Papaioannou, A. (2020). Understanding the educational and support needs of informal care-givers of people with dementia attending an outpatient geriatric assessment clinic. *Ageing and Society*, *40*(1), 205–228. https://doi.org/10.1017/s0144686x18000971

Ruisoto, P., Contador, I., Fernández-Calvo, B., Palenzuela, D., & Ramos, F. (2019). Exploring the association between optimism and quality of life among informal caregivers of persons with dementia. *International Psychogeriatrics, 31*(3), 309–315. doi:10.1017/S104161021800090X

Sánchez-Teruel*, D., Robles-Bello*, M. A., Sarhani-Robles, M., & Sarhani-Robles, A. (2022). Exploring resilience and well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19. *Dementia*, *21*(2), 410–425. https://doi.org/10.1177/14713012211042187

Schumann, C., Alexopoulos, P., & Perneczky, R. (2019). Determinants of self- and carer-rated quality of life and caregiver burden in Alzheimer disease. *International Journal of Geriatric Psychiatry*, *34*(10), 1378–1385. https://doi.org/10.1002/gps.5126

Shooshtari, S., Duncan, K. A., Roger, K., Fast, J., & Han, J. (2017). Care-related out-of-pocket spending and caregiving consequences: Results from a Canadian population-based study. *Journal of Family and Economic Issues*, *38*(3), 405–420. https://doi.org/10.1007/s10834-016-9516-1

Smith-Carrier, T., Pham, T., Akhtar, S., Seddon, G., Nowaczynski, M., & Sinha, S. (2018). 'It's not just the word care, it's the meaning of the word…(they) actually care': Caregivers' perceptions of home-based primary care in Toronto, Ontario. Ageing and Society, 38(10), 2019–2040. doi:10.1017/S0144686X1700040X

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: Impact of demographic, mood, and care recipient variables. *The American Journal of Geriatric Psychiatry*, *22*(3), 294–300. https://doi.org/10.1016/j.jagp.2012.09.006

Stall, N. M., Kim, S. J., Hardacre, K. A., Shah, P. S., Straus, S. E., Bronskill, S. E., Lix, L. M., Bell, C. M., & Rochon, P. A. (2018). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *Journal of the American Geriatrics Society*, *67*(3), 609–617. https://doi.org/10.1111/jgs.15690

Stubbs, M., Govia, I., Robinson, J. N., Amour, R., & Freeman, E. (2021). The experiences of caregivers of persons living with dementia in Jamaica during COVID-19. *Gerontology* *and Geriatric Medicine*, *7*, 233372142110433. https://doi.org/10.1177/23337214211043384

Tam, M. T., Dosso, J. A., & Robillard, J. M. (2021). The impact of a global pandemic on people living with dementia and their care partners: Analysis of 417 lived experience reports. *Journal of Alzheimer's Disease*, *80*(2), 865–875. https://doi.org/10.3233/jad-201114

Taneska, M. (2021). COVID-19 pandemic: A curse and a blessing for informal dementia caregivers — a qualitative study. *Alzheimer's & Dementia*, *17*(S7). https://doi.org/10.1002/alz.052066

Taylor, S. (2020). *The psychology of pandemics: Preparing for the next global outbreak of infectious disease*. Cambridge Scholars Publishing.

Taylor, S., Landry, C. A., Paluszek, M. M., Fergus, T. A., McKay, D., & Asmundson, G. J. (2020). Development and initial validation of the COVID stress scales. *Journal of Anxiety Disorders*, *72*, 102232. https://doi.org/10.1016/j.janxdis.2020.102232

The Zarit Burden Interview. Dementia Pathways. (n.d.). Retrieved September 12, 2021, from https://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf

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. (2020). 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

Tulloch, K., McCaul, T., & Scott, T. L. (2021). Positive aspects of dementia caregiving during the COVID-19 pandemic. *Clinical Gerontologist*, *45*(1), 86–96. https://doi.org/10.1080/07317115.2021.1929630

Whitlatch, C. J., Zarit, S. H., & Von Eye, A. (1991). Efficacy of interventions with caregivers: A reanalysis. *The Gerontologist*, *31*(1), 9–14. https://doi.org/10.1093/geront/31.1.9

Wong, B. P., Kwok, T. C., Chui, K. C., Cheng, T. S., Ho, F. K., & Woo, J. (2021). The impact of dementia daycare service cessation due to COVID-19 pandemic. *International Journal of Geriatric Psychiatry*, *37*(1). https://doi.org/10.1002/gps.5621

World Health Organization. (n.d.). *Archived: Who timeline - COVID-19*. World Health Organization. Retrieved January 19, 2022, from https://www.who.int/news-room/detail/27 04-2020-who-timeline---COVID-19

World Health Organization. (2021, September 2). *Dementia*. World Health Organization. Retrieved December 16, 2021, from https://www.who.int/news-room/fact-sheets/detail/dementia

Worry, gratitude & boredom: As COVID-19 affects mental, financial health, who fares better; who is worse? Angus Reid Institute. (2022, March 31). Retrieved April 12, 2022, from https://angusreid.org/COVID19-mental-health/

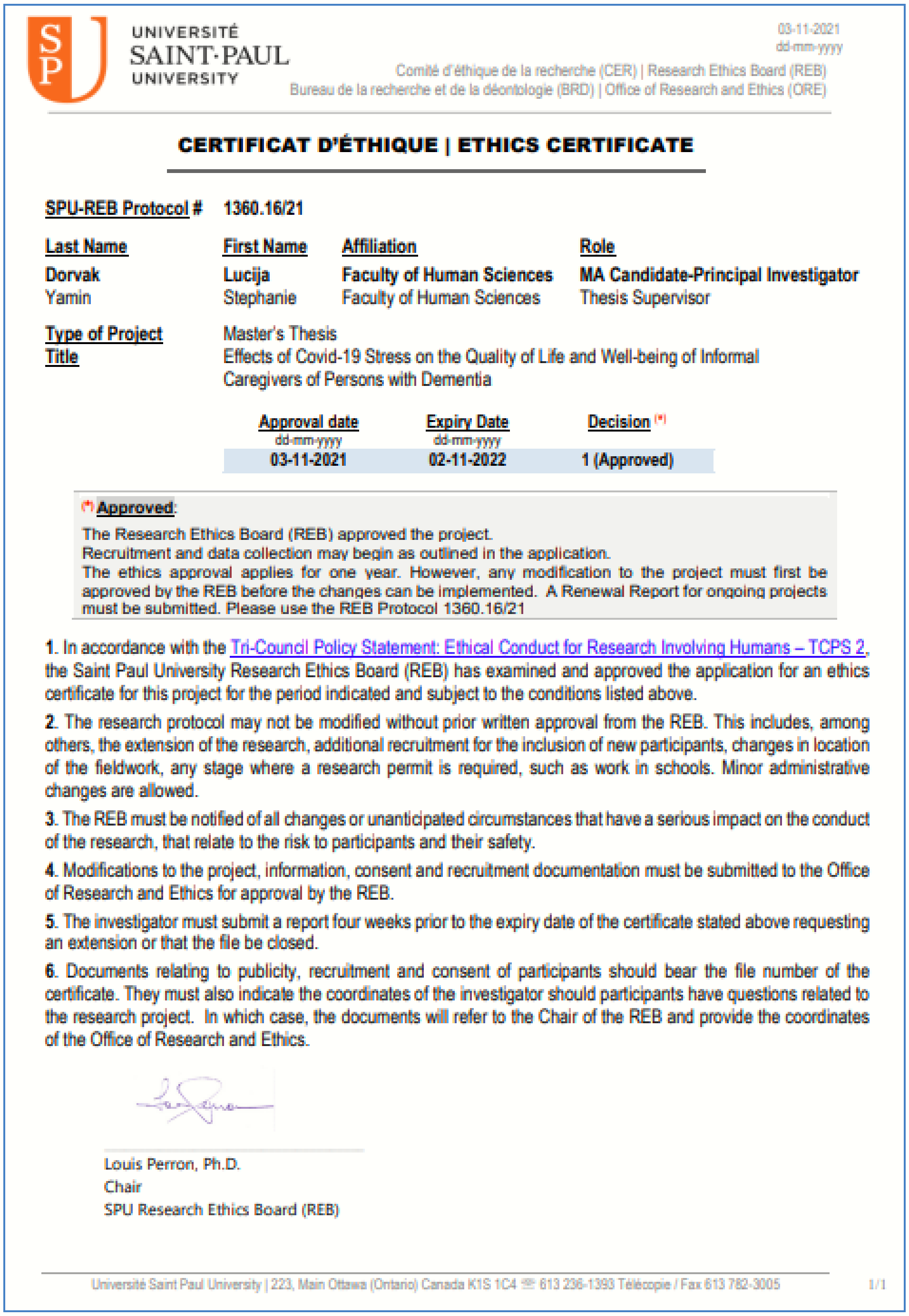
Yu, Y., Liu, Z., Li, T., Zhou, W., Xi, S., Xiao, S., & Tebes, J. K. (2020). A comparison of psychometric properties of two common measures of caregiving burden: The family burden interview schedule (FBIS-24) and the Zarit caregiver burden interview (ZBI-

22). *Health and Quality of Life Outcomes*, *18*(1). https://doi.org/10.1186/s12955-020-01335-x

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649

Appendix A

Saint Paul University Research Ethics Board Protocol Certificate



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03-11-2021
dd-mm-yyyy

Comité d'éthique de la recherche (CER) | Research Ethics Board (REB)
Bureau de la recherche et de la déontologie (BRD) | Office of Research and Ethics (ORE)

CERTIFICAT D'ÉTHIQUE | ETHICS CERTIFICATE

SPU-REB Protocol # **1360.16/21**

Last Name	First Name	Affiliation	Role
Dorvak	**Lucija**	**Faculty of Human Sciences**	**MA Candidate-Principal Investigator**
Yamin	Stephanie	Faculty of Human Sciences	Thesis Supervisor

Type of Project Master's Thesis
Title Effects of Covid-19 Stress on the Quality of Life and Well-being of Informal Caregivers of Persons with Dementia

Approval date dd-mm-yyyy	Expiry Date dd-mm-yyyy	Decision [*]
03-11-2021	**02-11-2022**	**1 (Approved)**

[*] **Approved**:
The Research Ethics Board (REB) approved the project.
Recruitment and data collection may begin as outlined in the application.
The ethics approval applies for one year. However, any modification to the project must first be approved by the REB before the changes can be implemented. A Renewal Report for ongoing projects must be submitted. Please use the REB Protocol 1360.16/21

1. In accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2, the Saint Paul University Research Ethics Board (REB) has examined and approved the application for an ethics certificate for this project for the period indicated and subject to the conditions listed above.

2. The research protocol may not be modified without prior written approval from the REB. This includes, among others, the extension of the research, additional recruitment for the inclusion of new participants, changes in location of the fieldwork, any stage where a research permit is required, such as work in schools. Minor administrative changes are allowed.

3. The REB must be notified of all changes or unanticipated circumstances that have a serious impact on the conduct of the research, that relate to the risk to participants and their safety.

4. Modifications to the project, information, consent and recruitment documentation must be submitted to the Office of Research and Ethics for approval by the REB.

5. The investigator must submit a report four weeks prior to the expiry date of the certificate stated above requesting an extension or that the file be closed.

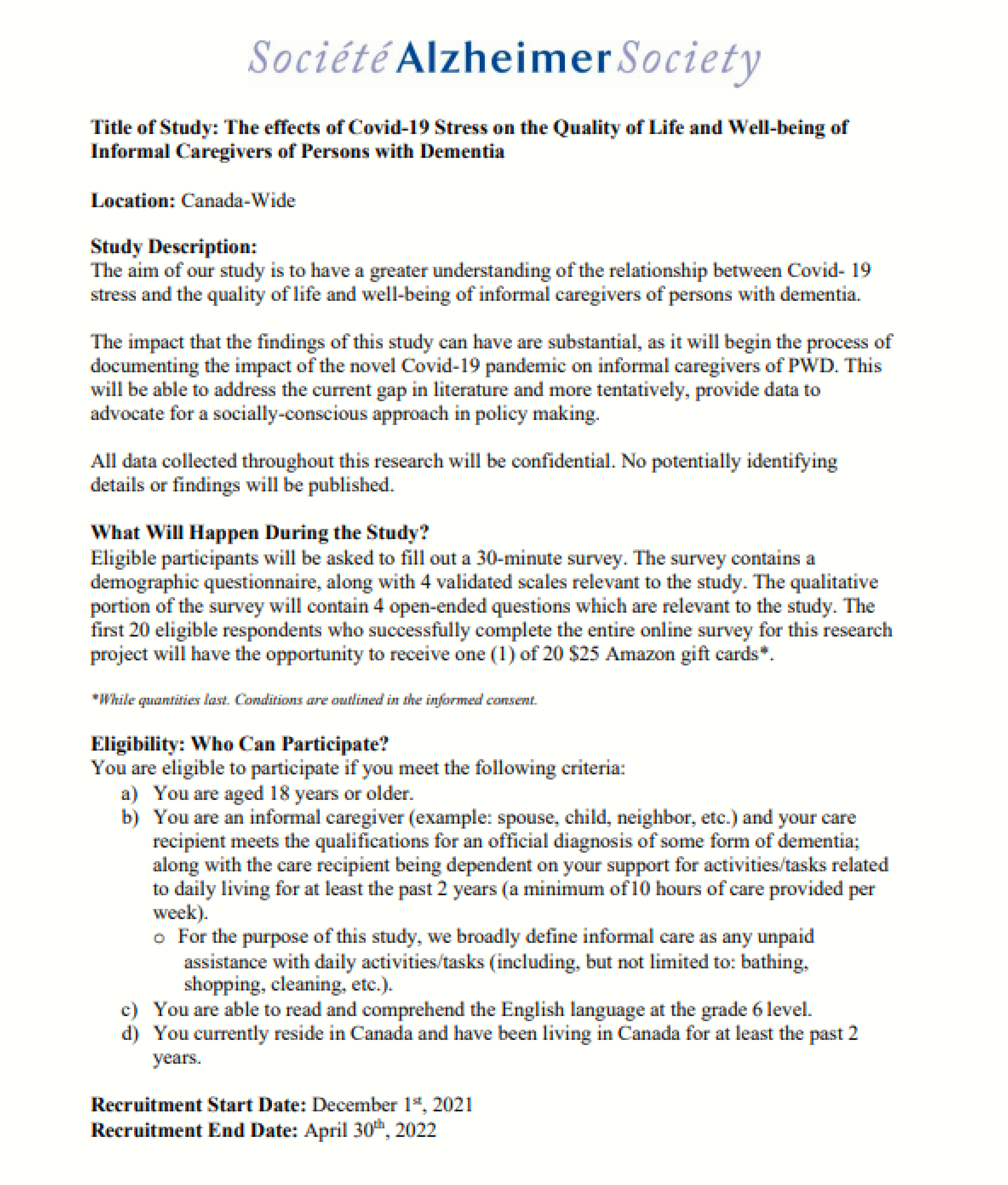
6. Documents relating to publicity, recruitment and consent of participants should bear the file number of the certificate. They must also indicate the coordinates of the investigator should participants have questions related to the research project. In which case, the documents will refer to the Chair of the REB and provide the coordinates of the Office of Research and Ethics.

Louis Perron, Ph.D.
Chair
SPU Research Ethics Board (REB)

Université Saint Paul University | 223, Main Ottawa (Ontario) Canada K1S 1C4 ☎ 613 236-1393 Télécopie / Fax 613 782-3005 1/1

Appendix B

Research Portal Posting for Alzheimer Society Website



Société Alzheimer Society

Title of Study: The effects of Covid-19 Stress on the Quality of Life and Well-being of Informal Caregivers of Persons with Dementia

Location: Canada-Wide

Study Description:
The aim of our study is to have a greater understanding of the relationship between Covid- 19 stress and the quality of life and well-being of informal caregivers of persons with dementia.

The impact that the findings of this study can have are substantial, as it will begin the process of documenting the impact of the novel Covid-19 pandemic on informal caregivers of PWD. This will be able to address the current gap in literature and more tentatively, provide data to advocate for a socially-conscious approach in policy making.

All data collected throughout this research will be confidential. No potentially identifying details or findings will be published.

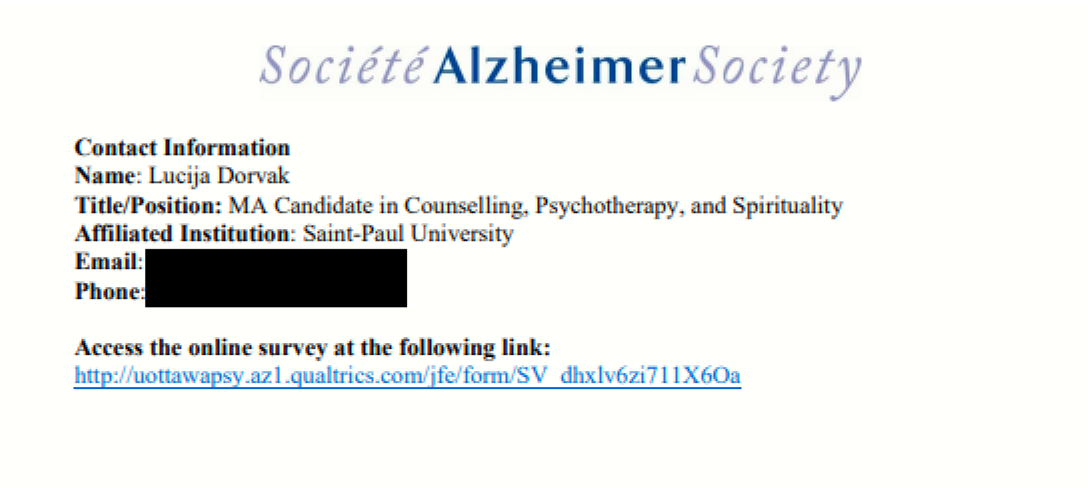
What Will Happen During the Study?
Eligible participants will be asked to fill out a 30-minute survey. The survey contains a demographic questionnaire, along with 4 validated scales relevant to the study. The qualitative portion of the survey will contain 4 open-ended questions which are relevant to the study. The first 20 eligible respondents who successfully complete the entire online survey for this research project will have the opportunity to receive one (1) of 20 $25 Amazon gift cards*.

**While quantities last. Conditions are outlined in the informed consent.*

Eligibility: Who Can Participate?
You are eligible to participate if you meet the following criteria:

a) You are aged 18 years or older.
b) You are an informal caregiver (example: spouse, child, neighbor, etc.) and your care recipient meets the qualifications for an official diagnosis of some form of dementia; along with the care recipient being dependent on your support for activities/tasks related to daily living for at least the past 2 years (a minimum of 10 hours of care provided per week).
  - For the purpose of this study, we broadly define informal care as any unpaid assistance with daily activities/tasks (including, but not limited to: bathing, shopping, cleaning, etc.).
c) You are able to read and comprehend the English language at the grade 6 level.
d) You currently reside in Canada and have been living in Canada for at least the past 2 years.

Recruitment Start Date: December 1st, 2021
Recruitment End Date: April 30th, 2022



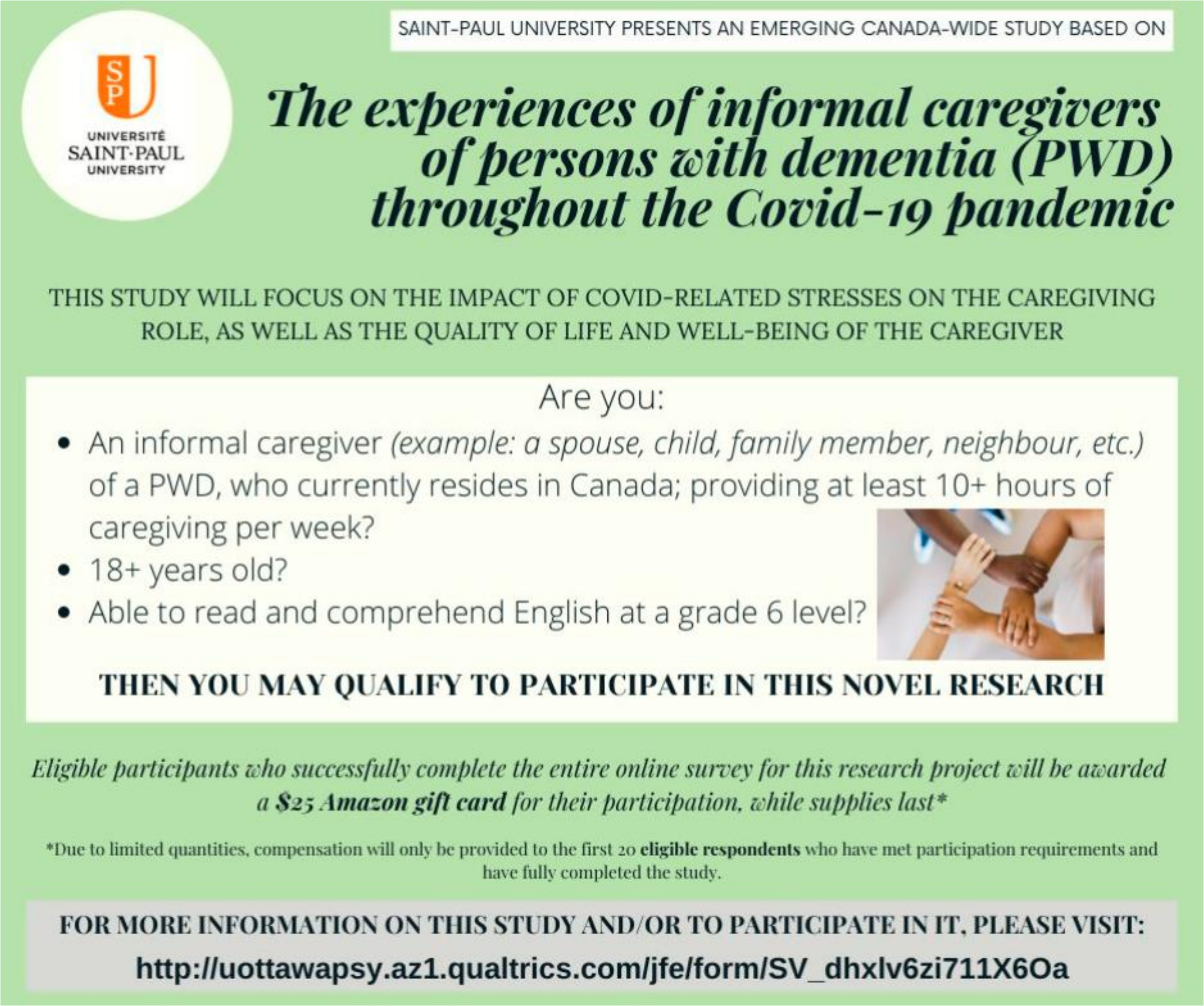
Société Alzheimer Society

Contact Information
Name: Lucija Dorvak
Title/Position: MA Candidate in Counselling, Psychotherapy, and Spirituality
Affiliated Institution: Saint-Paul University
Email: [redacted]
Phone:

Access the online survey at the following link:
http://uottawapsy.az1.qualtrics.com/jfe/form/SV_dhxlv6zi711X6Oa

Appendix C

Social Media Advertisement



SP
UNIVERSITÉ
SAINT-PAUL
UNIVERSITY

SAINT-PAUL UNIVERSITY PRESENTS AN EMERGING CANADA-WIDE STUDY BASED ON

The experiences of informal caregivers of persons with dementia (PWD) throughout the Covid-19 pandemic

THIS STUDY WILL FOCUS ON THE IMPACT OF COVID-RELATED STRESSES ON THE CAREGIVING ROLE, AS WELL AS THE QUALITY OF LIFE AND WELL-BEING OF THE CAREGIVER

Are you:

- An informal caregiver *(example: a spouse, child, family member, neighbour, etc.)* of a PWD, who currently resides in Canada; providing at least 10+ hours of caregiving per week?
- 18+ years old?
- Able to read and comprehend English at a grade 6 level?

THEN YOU MAY QUALIFY TO PARTICIPATE IN THIS NOVEL RESEARCH

*Eligible participants who successfully complete the entire online survey for this research project will be awarded a **$25 Amazon gift card** for their participation, while supplies last**

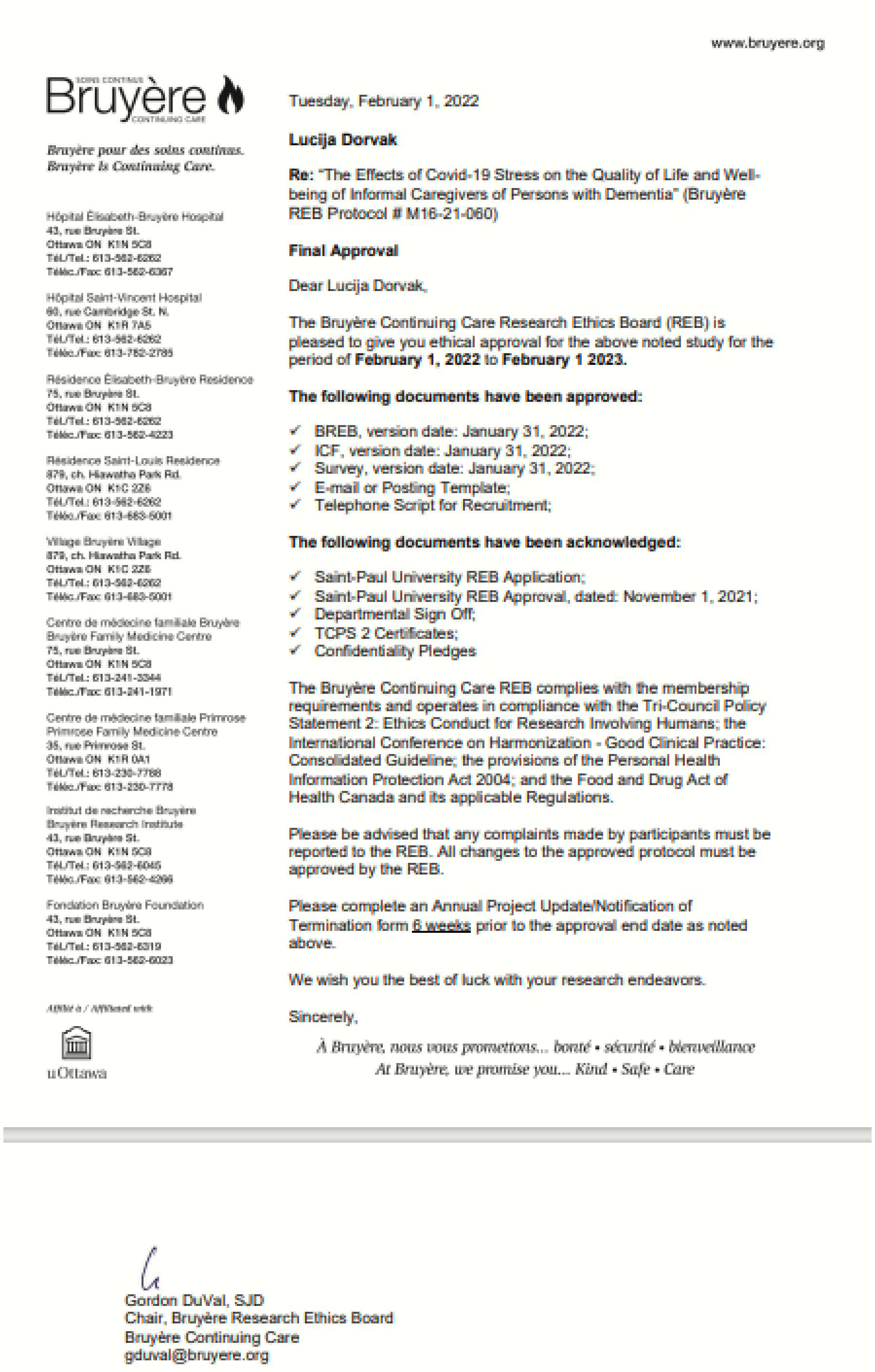
*Due to limited quantities, compensation will only be provided to the first 20 **eligible respondents** who have met participation requirements and have fully completed the study.

FOR MORE INFORMATION ON THIS STUDY AND/OR TO PARTICIPATE IN IT, PLEASE VISIT:

http://uottawapsy.az1.qualtrics.com/jfe/form/SV_dhxlv6zi711X6Oa

Appendix D

Bruyère Research Ethics Board Protocol Certificate



www.bruyere.org

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Hôpital Élisabeth-Bruyère Hospital
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-562-6367

Hôpital Saint-Vincent Hospital
60, rue Cambridge St. N.
Ottawa ON K1R 7A5
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-782-2785

Résidence Élisabeth-Bruyère Residence
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-562-4223

Résidence Saint-Louis Residence
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-683-5001

Village Bruyère Village
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Téléc./Fax: 613-683-5001

Centre de médecine familiale Bruyère
Bruyère Family Medicine Centre
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-241-3344
Téléc./Fax: 613-241-1971

Centre de médecine familiale Primrose
Primrose Family Medicine Centre
35, rue Primrose St.
Ottawa ON K1R 0A1
Tél./Tel.: 613-230-7788
Téléc./Fax: 613-230-7778

Institut de recherche Bruyère
Bruyère Research Institute
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6045
Téléc./Fax: 613-562-4266

Fondation Bruyère Foundation
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6319
Téléc./Fax: 613-562-6023

Affilié à / Affiliated with

uOttawa

Tuesday, February 1, 2022

Lucija Dorvak

Re: "The Effects of Covid-19 Stress on the Quality of Life and Well-being of Informal Caregivers of Persons with Dementia" (Bruyère REB Protocol # M16-21-060)

Final Approval

Dear Lucija Dorvak,

The Bruyère Continuing Care Research Ethics Board (REB) is pleased to give you ethical approval for the above noted study for the period of **February 1, 2022** to **February 1 2023.**

The following documents have been approved:

- ✓ BREB, version date: January 31, 2022;
- ✓ ICF, version date: January 31, 2022;
- ✓ Survey, version date: January 31, 2022;
- ✓ E-mail or Posting Template;
- ✓ Telephone Script for Recruitment;

The following documents have been acknowledged:

- ✓ Saint-Paul University REB Application;
- ✓ Saint-Paul University REB Approval, dated: November 1, 2021;
- ✓ Departmental Sign Off;
- ✓ TCPS 2 Certificates;
- ✓ Confidentiality Pledges

The Bruyère Continuing Care REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement 2: Ethics Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; the provisions of the Personal Health Information Protection Act 2004; and the Food and Drug Act of Health Canada and its applicable Regulations.

Please be advised that any complaints made by participants must be reported to the REB. All changes to the approved protocol must be approved by the REB.

Please complete an Annual Project Update/Notification of Termination form 6 weeks prior to the approval end date as noted above.

We wish you the best of luck with your research endeavors.

Sincerely,

À Bruyère, nous vous promettons... bonté • sécurité • bienveillance
At Bruyère, we promise you... Kind • Safe • Care

Gordon DuVal, SJD
Chair, Bruyère Research Ethics Board
Bruyère Continuing Care
gduval@bruyere.org

Appendix E

Informed Consent

Informal caregivers of persons with dementia (PWD) and the impact of the stresses related to the COVID-19 pandemic on their caregiving role, quality of life, and well-being.

Explanatory Statement

Principal Investigator: Lucija Dorvak, MA Candidate
Saint-Paul University– School of Counselling, Psychotherapy, and Spirituality

This research project is being conducted by the MA candidate to fulfill program requirements associated with the thesis stream of the program.

The following research is being conducted under the supervision of Dr. Stéphanie Yamin, Associate professor.

Emails:
xxxxxxxxxx@uottawa.ca (Principal Investigator)
xxxxxxxxxx@ustpaul.ca (Supervisor)

Please note that this research project has been approved by the Research Ethics Board (REB) at Saint-Paul University under protocol # 1360.16/21 and complies with all necessary requirements and considerations related to conducting ethical research.

This study has also been approved by The Bruyère Continuing Care Research Ethics Board (REB) under protocol # M16-21-060.

You are invited to take part in this research project. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any aspect of this research project, please contact the Principal Investigator via the email address listed above.

What does this research involve?

Saint-Paul University is conducting a research project to understand the experiences of informal caregivers of people with dementia (PWD) and the impact of the COVID-19 pandemic on their caregiving role, quality of life, and well-being.

You are eligible to participate in this research project if: a) you are aged 18 years or older; b) your care recipient meets the qualifications for an official diagnosis of some form of dementia; along with the care recipient being dependent on your support for activities/tasks related to daily living for at least the past 2 years (a minimum of 10 hours of care provided per week); c) you are able to read and comprehend the English language at the grade 6 level; d) you currently reside in Canada and have been living in Canada for at least the past 2 years. For the purpose of this study, we broadly define informal care as any unpaid assistance with daily activities/tasks (including, but not limited to: bathing, shopping, cleaning, etc.).

Participation in this research project involves completing a 30-minute online survey related to your demographic information (e.g., age, gender, etc.), your experiences providing informal care throughout the COVID-19 pandemic, your attitudes towards your own quality of life and well-being in light of your care recipient's dependency on you throughout the COVID-19 pandemic, and information related to possible stresses experienced in your role throughout the global pandemic.

Why were you chosen for this research project?

You have been invited to participate in this research project because you have clicked on a link advertising this research project.

Consenting to participate in the research project and withdrawing from this research project

If you would like to participate in this research project, you must read this Explanatory Statement and the Consent Form.

Clicking on the link to say that you 'Agree' to consent to participate in the online survey indicates you have provided consent to participate in this research project.

Your participation in this research project is voluntary. You can choose to withdraw from the online survey at any time without being penalized or disadvantaged in any way. You may withdraw from the research project at any time and for any reason by notifying the Principal Investigator. In the event of withdrawing from the research project, your data collected prior to this withdrawal will continue to be used and form part of the research project, unless you ask the Principal Investigator not to do so.

Possible risks and benefits to participants

There are several questions regarding pandemic stress and overall caregiver stress throughout the COVID-19 pandemic that may cause discomfort to some participants. If you find the survey questions distressing, you may withdraw from the online survey at any time. Some benefits involved with participating in this survey involve the opportunity to advocate for the needs of the general dementia caregiver community, along with a chance to self-reflect on your personal experience as a caregiver throughout the COVID-19 pandemic, to promote further awareness of your own quality of life and well-being.

Compensation

The first 20 eligible participants who meet participation criteria and successfully complete the entire online survey for this research project will be awarded a $25 Amazon gift card. At the end of this survey, there will be an option to "Click here" in order to be redirected to a new page to fill out contact information. Filling out the contact information does not mean that you are automatically entitled to a gift card. In the event that you qualify for gift card compensation, as outlined above, the electronic gift card prize will be e-mailed to the primary e-mail address that the participant provided in their electronic entry. Each participant that qualifies for gift card compensation is entitled to only one gift card, valued at $25.

Services on offer if adversely affected

If you experience any distress as a result of participating in this research project, we recommend you consult your General Practitioner or contact a support service, such as the Canadian Mental Health Association (CMHA) at 1-833-456-4566.

Confidentiality

All your data collected throughout this research will be confidential. Should you decide to provide them, your contact details will only be used to determine your willingness to be contacted about participating in follow-up research. No potentially identifying details or findings will be published. No names will be included into any research records, with all names replaced by codes.

Storage of data

All data collected will be stored in a secure location at Saint-Paul University for a minimum of five years. Only members of the Research Team will have access to this data.

Results

It is not possible to provide you with individual feedback about your online survey data, but group results will be available from the Research Team upon request, once the research project has been completed. Should you have any concerns about the conduct of this research project, you are welcome to contact the Saint-Paul University Research Ethics Board.

Executive Officer
Saint-Paul University Research Ethics Board
Research Office
Saint-Paul University
223 Main Street, Ottawa, Ontario, K1S 1C4
Tel: 613-236-1393 or 1-800-637-6859
Email: recherche-research@ustpaul.ca

Consent Form

I have been asked to take part in a Saint-Paul University research project specified above.

I have read and understood the information above and I hereby consent to participate in this research project which is being conducted by a MA candidate under the supervision of a qualified researcher. I am aware that this project has been approved by the Research Ethics Board at Saint-Paul University.

I understand that agreeing to take part means that I agree to complete an online survey related to my: demographic information (e.g., age, gender, etc.), experiences providing informal care throughout the COVID-19 pandemic, attitudes towards my own quality of life and well-being, my care recipient’s dependency on me throughout the COVID-19 pandemic, and information related to experiences in my caregiving role throughout the global pandemic.

I understand that any information I provide is confidential and that no information that could lead to the identification of any individual will be disclosed in any reports on the research project or to any other party. I also understand that my participation is voluntary and that I can choose not to participate in part or all of the online survey without being penalized or disadvantaged in any way. If I choose to withdraw, my data collected prior to this withdrawal will continue to be used and form part of the research project, unless I ask for it to be destroyed.

I have been informed that it is not possible to have access to individual feedback about my online survey data, but group results will be available from Saint-Paul University researchers upon request, once the research project has been completed.

I have also been informed that the information collected will be stored in a secure location at Saint-Paul University for a minimum of five years.

I consent to the above conditions and I am willing to participate in the research project.

Appendix F

Demographic Questionnaire

Description

The demographic questionnaire has been designed by the research team undertaking this project and aims at capturing participant data, relevant to the study at hand.

Please complete the following demographic questions:

1. **What is your age (years):** *[Blank field]*

2. **What is your sex?** *[Bullet points, with an option to select appropriate field]*

- Female
- Male
- Other (please specify) *[+ Blank field]*
- Prefer not to say

3. **What is your gender?** *[Bullet points, with an option to select appropriate field]*

- Woman
- Man
- Non-binary or Genderqueer
- Other (please specify) *[+ Blank field]*
- Prefer not to say

4. **Do you identify as BIPOC (black, indigenous, and/or a person of colour)?** *[Bullet points, with an option to select appropriate field]*

- Yes
- No
- Prefer not to say

5. **What is/are your ethnic origin(s)?** *[Bullet points, with an option to select several appropriate fields]*

- African (should you wish, you may specify) *[+ Optional blank field]*
- Asian (should you wish, you may specify) *[+ Optional blank field]*
- Caribbean (should you wish, you may specify) *[+ Optional blank field]*
- European (should you wish, you may specify) *[+ Optional blank field]*

- Latin, Central and South American (should you wish, you may specify) *[+ Optional blank field]*
- North American Indigenous (should you wish, you may specify) *[+ Optional blank field]*
- Other North American (should you wish, you may specify) *[+ Optional blank field]*
- Oceanic (should you wish, you may specify) *[+ Optional blank field]*
- Other (please specify) *[+ Blank field]*
- Prefer not to say

6. **Were you born in Canada?** *[Bullet points, with an option to select appropriate field]*

- Yes (should you wish, you may specify) *[+ Optional blank field]*
- No (should you wish, you may specify) *[+ Optional blank field]*
- Prefer not to say

7. **What is your marital status?** *[Bullet points, with an option to select appropriate field]*

- Single
- Married/ Common law
- Separated/ Divorced
- Widowed
- Other (please specify) *[+ Blank field]*

8. **In which province or territory do you currently reside?** *[Bullet points, with an option to select appropriate field]*
    - AB
    - BC
    - MB
    - NB
    - NL
    - NS
    - NT
    - NU
    - ON
    - PE
    - QC
    - SK
    - YT

9. **What is your highest level of completed education?** *[Bullet points, with an option to select appropriate field]*
   - Some high school, no diploma or GED
   - GED
   - High school graduate
   - Some CEGEP, no diploma
   - CEGEP graduate
   - Some college or trade school, no diploma
   - College or trade school graduate
   - Some undergraduate studies, no degree
   - Bachelor's degree (e.g. MA, MS, MBA)
   - Some doctoral or professional work, no degree
   - Doctoral or professional degree (e.g. PhD, MD, JD)
   - Prefer not to say

10. **Are you currently employed?** *[Bullet points, with an option to select appropriate field]*
   - Yes
   - No
   - Other (please specify) *[+ Blank field]*
   - Prefer not to say

11. **What is your current yearly household income, before taxes?** *[Bullet points, with an option to select appropriate field]*
   - Less than (<) $25,000
   - $25,001 - $50,000
   - $50,001 - $75,000
   - $75,001 - $100,000
   - $100,001 - $125,000
   - $125,001 - $150,000
   - $150,001 - $175,000
   - $175,001 - $200,000
   - $200,001 - $250,000
   - More than (>) $250,001

12. How many individuals currently live in your household? *[Blank field]*

13. What is the relationship between you and your care recipient? Are they your… *[Bullet points, with an option to select appropriate field]*

- Husband/Wife
- Common-law partner
- Parent
- Child
- Sibling
- Grandparent
- Mother-in-law/father-in law
- Daughter-in-law/son-in-law
- Sister-in-law/brother-in-law
- Other relative (please specify) *[+ Blank field]*
- Friend/neighbour
- Other (please specify) *[+ Blank field]*
- Don’t know/No answer
- Prefer not to say

14. What is the sex of your care recipient? *[Bullet points, with an option to select appropriate field]*

- Female
- Male
- Other (please specify) *[+ Blank field]*
- Prefer not to say

15. What is the gender of your care recipient? *[Bullet points, with an option to select appropriate field]*

- Woman
- Man
- Non-binary or Genderqueer
- Other (please specify) *[+ Blank field]*
- Prefer not to say

16. Does your care recipient identify as BIPOC (black, indigenous, and/or a person of colour)? *[Bullet points, with an option to select appropriate field]*

- Yes
- No
- Prefer not to say

17. What is/are the ethnic origin(s) of your care recipient? *[Bullet points, with an option to select several appropriate fields]*

- African (should you wish, you may specify) *[+ Optional blank field]*
- Asian (should you wish, you may specify) *[+ Optional blank field]*
- Caribbean (should you wish, you may specify) *[+ Optional blank field]*
- European (should you wish, you may specify) *[+ Optional blank field]*
- Latin, Central and South American (should you wish, you may specify) *[+ Optional blank field]*
- North American Indigenous (should you wish, you may specify) *[+ Optional blank field]*
- Other North American (should you wish, you may specify) *[+ Optional blank field]*
- Oceanic (should you wish, you may specify) *[+ Optional blank field]*
- Other (please specify) *[+ Blank field]*
- Prefer not to say

18. Do you currently cohabitate (live with) your care recipient? *[Bullet points, with an option to select appropriate field]*

- Yes
- No
- Prefer not to say

19. How many hours per week, on average, do you spend caring for this individual? *[Blank field to enter #]*

20. How many years have you been a primary caregiver for this individual, specific to their dementia-related needs for tasks/activities associated with daily living? *[Blank field to enter #]*

21. Do you consider yourself a spiritual and/or religious individual? *[Bullet points, with an option to select appropriate field]*

- Yes
- No
- Prefer not to say

Appendix G

COVID Stress Scales

Description

The COVID Stress Scales (CSS) were developed based on a study by Taylor et al. (2020), which were designed to measure participant stress in relation to the COVID-19 virus.

[A Likert scale with 5 fields of measurement was available for each question, with a bullet point set-up for the participant to select one]

The following asks about various kinds of worries that you might have experienced **over the past seven days.** In the following statements, we refer to COVID-19 as "the virus".

Responses:

(0)Not at all; (1) Slightly; (2) Moderately; (3) Very; (4) Extremely

1. I am worried about catching the virus

2. I am worried that I can’t keep my family safe from the virus

3. I am worried that our healthcare system won’t be able to protect my loved ones

4. I am worried our healthcare system is unable to keep me safe from the virus

5. I am worried that basic hygiene (e.g., handwashing) is not enough to keep me safe from the virus

6. I am worried that social distancing is not enough to keep me safe from the virus

7. I am worried about grocery stores running out of food

8. I am worried that grocery stores will close down

9. I am worried about grocery stores running out of cleaning or disinfectant supplies

10. I am worried about grocery stores running out of cold or flu remedies

11. I am worried about grocery stores running out of water

12. I am worried about pharmacies running out of prescription medicines

13. I am worried that foreigners are spreading the virus in my country

14. If I went to a restaurant that specialized in foreign foods, I'd be worried about catching the virus

15. I am worried about coming into contact with foreigners because they might have the virus

16. If I met a person from a foreign country, I'd be worried that they might have the virus

17. If I was in an elevator with a group of foreigners, I'd be worried that they're infected with the virus

18. I am worried that foreigners are spreading the virus because they're not as clean as we are

19. I am worried that if I touched something in a public space (e.g., handrail, door handle), I would catch the virus

20. I am worried that if someone coughed or sneezed near me, I would catch the virus

21. I am worried that people around me will infect me with the virus

22. I am worried about taking change in cash transactions

23. I am worried that I might catch the virus from handling money or using a debit machine

24. I am worried that my mail has been contaminated by mail handlers

Please read each statement and indicate how frequently you have experienced each problem **<u>during the past seven days</u>.**

25. I had trouble concentrating because I kept thinking about the virus

26. Disturbing mental images about the virus popped into my mind against my will

27. I had trouble sleeping because I worried about the virus

28. I thought about the virus when I didn't mean to

29. Reminders of the virus caused me to have physical reactions, such as sweating or a pounding heart

30. I had bad dreams about the virus

The following items ask about checking behaviours. **<u>During the past seven days</u>**, how much have you done the following because of concerns about COVID-19?

31. Searched the Internet for treatments for COVID-19

32. Asked health professionals (e.g., doctors or pharmacists) for advice about COVID-19

33. Checked YouTube videos about COVID-19

34. Checked your own body for signs of infection (e.g., taking your temperature)

35. Sought reassurance from friends or family about COVID-19

36. Checked social media posts concerning COVID-19

Appendix H

The Zarit Burden Interview (ZBI-22)

Description

The ZBI-22 Scale is based on studies done by Zarit et al. (1980). It is a validated scale which aims at capturing caregiver burden in participants.

Responses

0 : NEVER
1 : RARELY
2 : SOMETIMES
3 : QUITE FREQUENTLY
4 : NEARLY ALWAYS

Please select the response that best describes how you feel.

[A Likert scale with 5 fields of measurement was available for each question, with a bullet point set-up for the participant to select one]

1. Do you feel that your care recipient asks for more help than he/she needs?

2. Do you feel that because of the time you spend with your care recipient that you don’t have enough time for yourself?

3. Do you feel stressed between caring for your care recipient and trying to meet other responsibilities for your family or work?

4. Do you feel embarrassed over your care recipient’s behaviour?

5. Do you feel angry when you are around your care recipient?

6. Do you feel that your care recipient currently affects your relationships with other family members or friends in a negative way?

7. Are you afraid what the future holds for your care recipient?

8. Do you feel your care recipient is dependent on you?

9. Do you feel strained when you are around your care recipient?

10. Do you feel your health has suffered because of your involvement with your care recipient?

11. Do you feel that you don’t have as much privacy as you would like because of your care recipient?

12. Do you feel that your social life has suffered because you are caring for your care recipient?

13. Do you feel uncomfortable about having friends over because of your care recipient? (please answer as if we were not in a pandemic)

14. Do you feel that your care recipient seems to expect you to take care of him/her as if you were the only one he/she could depend on?

15. Do you feel that you don’t have enough money to take care of your care recipient in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your care recipient much longer?

17. Do you feel you have lost control of your life since your care recipient’s illness?

18. Do you wish you could leave the care of your care recipient to someone else?

19. Do you feel uncertain about what to do about your care recipient?

20. Do you feel you should be doing more for your care recipient?

21. Do you feel you could do a better job in caring for your care recipient?

22. Overall, how burdened do you feel in caring for your care recipient?

Appendix I

C-DEMQOL [A Measure of Carer QOL]

Description

The C-DEMQOL is based on a study by Brown et al. (2019) which developed a measure to determine Quality of Life for caregivers of PWD.

PURPOSE

This questionnaire is designed to find out about your life and experiences of being a carer of a person with dementia.

INSTRUCTIONS

Please think of how things have been and how you have felt in your caring role in the past 4 weeks. Of course, there might have been good and bad days, but we want to capture a snapshot of how you have felt on a typical day during the past month. For each question, choose one option that best describes how you feel and mark it by putting a cross in the box, as shown x

Please remember:

• There are no right or wrong answers, so please be as open as you can, and try to answer all the questions to the best of your judgement.

• If you feel that a question does not apply to you or to the person you care for, write “N/A” (stands for Not Applicable) next to the question.

[A Likert scale with 5 fields of measurement was available for each question, with a bullet point set-up for the participant to select one]

Subsection: Carer Responsibilities and Personal Needs

First, we would like to know how you feel about your **caring responsibilities**, which may include managing medications, providing help with washing and dressing, medical visits or social outings, and also anything you need to do if the person with dementia is in a care home. We would also like to know how your caring responsibilities affect your **ability to have time for yourself**, and doing the things that you enjoy or want to do, in particular activities that are **important to your quality of life**.

1. Carrying out my caring tasks and responsibilities takes up…
    - very little of my energy
    - some of my energy
    - a considerable amount of my energy

- most of my energy
- all of my energy

2. Being a carer for the person with dementia takes up…
    - very little of my time
    - some of my time
    - a considerable amount of my time
    - most of my time
    - all of my time

3. Meeting my **own needs** (for doing things I enjoy) whilst also caring has been…
    - not a problem for me
    - quite easy
    - a problem at times
    - quite difficult
    - very difficult

4. Thinking of my ability to do things I enjoy, I have felt…
    - free to do them when I want
    - restricted in a little way by my caring duties
    - restricted to some extent by my caring duties
    - restricted a lot by my caring duties
    - unable to do them due to my caring duties

5. In terms of freedom to do things I enjoy, my caring responsibilities have had…
    - no impact on my freedom
    - little impact on my freedom
    - some impact on my freedom
    - a significant impact on my freedom
    - restricted my freedom completely

6. Thinking of my ability to do activities I enjoy whilst also caring, I feel that…
    - all of my needs are met
    - most of my needs are met
    - some of my needs are met
    - only a few of my needs are met
    - none of my needs are met

Subsection: Carer Wellbeing

Next, we would like to find out about **your wellbeing** and how this has been affected by your caring role. Think of how you have felt in the **past 4 weeks**.

7. I consider the emotional demands that caring places on me…
    - very light
    - quite light
    - moderate
    - quite heavy
    - very heavy
8. In terms of my wellbeing, meeting the demands of caring has been…
    - not at all stressful
    - a little stressful
    - quite stressful
    - stressful
    - very stressful

9. I have been having emotional problems (such as feeling sad, stressed or anxious) …
    - none of the time
    - a little of the time
    - some of the time
    - most of the time
    - all of the time

10. Whenever I need to get away from the person I care for, I feel…
    - not at all guilty
    - a little guilty
    - quite guilty
    - guilty
    - very guilty

11. Thinking of changes in the person I care for due to dementia (such as changes in ability, memory, or behaviour), I find them…
    - not at all upsetting
    - a little upsetting
    - quite upsetting
    - upsetting
    - very upsetting

12. Thinking of the physical and emotional demands of caring, I feel that they have…

- no impact on my health
- little impact on my health
- some impact on my health
- a significant impact on my health
- a very significant impact on my health

Subsection: Carer Role

Now we would like to know how you feel about **being a carer** for a person living with dementia. This includes how you feel about your **relationship with the person you care for**, and your feelings about them.

13. Considering all the demands that caring places on me, I feel that overall I have…
    - coped very well
    - coped quite well
    - coped OK
    - coped quite poorly
    - coped very poorly

14. When thinking of my present role as a carer for a person with dementia, I feel...
    - not at all resentful
    - a little resentful
    - quite resentful
    - resentful
    - very resentful

15. Since the person I care for developed dementia, our relationship has…
    - improved a lot
    - improved a little
    - not changed
    - deteriorated a little
    - deteriorated a lot

16. My relationship with the person I care for in the past 4 weeks has been...
    - very good
    - quite good
    - fair
    - quite poor
    - very poor

17. I feel appreciated by the person I care for…
    - always or almost always
    - often
    - sometimes
    - once in a while
    - never

18. I feel frustration toward the person I care for…
    - none of the time
    - a little of the time
    - some of the time
    - most of the time
    - all of the time

Subsection: Feelings about future

Now we would like to know how you feel about your **own future as a carer**, and the future for **the person you care for**. Again, think of how you have felt in the **past 4 weeks**.

19. When thinking about meeting the future care needs of the person with dementia, I…
    - feel relaxed
    - have only a few worries
    - have some worries
    - have significant worries
    - worry a lot

20. I worry about how I will be able to cope emotionally as the dementia gets worse in the future…
    - none of the time
    - a little of the time
    - some of the time
    - most of the time
    - all of the time

21. I worry about what may happen to the person I care for in the future…
    - none of the time
    - a little of the time
    - some of the time
    - most of the time
    - all of the time

22. I anticipate that trying to meet the needs of the person with dementia in the future will be…
    - not at all difficult
    - a little difficult
    - quite difficult
    - difficult
    - extremely difficult

23. When thinking of making important caring decisions in the future, I …
    - feel relaxed
    - have only a few worries
    - have some worries
    - have significant worries
    - worry a lot

24. When thinking about the future impact of caring on my finances, I …
    - feel relaxed
    - have only a few worries
    - have some worries
    - have significant worries
    - worry a lot

Subsection: Carer Support

Lastly, we would like to know how you feel about the **help and support** that you may need as a carer. This includes the help and support given by **family and friends**, as well as any **professional support** provided by health and social services, or other groups or organizations. Of course, some members of your family may help a lot and some not at all. The same may be true for your friendship group or other groups. However, we want to capture how you feel about the help provided by these groups **on balance**, perhaps considering only the help from members who you **expect to help**.

25. Overall, my needs for support have been met…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

26. The level of professional support offered or provided to me has met my expectations…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

27. I feel supported by professionals (for example, doctors, social workers, care workers)…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

28. I feel supported by family members…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

29. I feel supported by my friends…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

30. I feel supported by community groups (for example, charities, faith groups)…
    - completely
    - considerably
    - to some extent
    - a little
    - not at all

Appendix J

Role Captivity

Description: The Role Captivity Scale is based on studies done by Pearlin et al. (1990). It is a validated scale which aims at capturing caregiving role captivity in participants.

[A Likert-type scale with 4 fields of measurement was available for each question, with a bullet point set-up for the participant to select one]

Responses:

(4) Very much; (3) Somewhat; (2) Just a little; (1) Not at all

How much do you:

1. **Wish you were free to lead a life of your own?**
2. **Feel trapped by your care recipient's illness?**
3. **Wish you could just run away?**

Appendix K

Qualitative Survey

1. What changes in caregiver-related supports did you experience throughout the COVID-19 pandemic? (For example: If you had a PSW, other paid/publicly funded supports, a community, etc. that you relied on prior to the pandemic to facilitate your caregiving, and their support became affected by the onset of the pandemic)

2. Describe how personally seen and understood you have felt by local and nation-wide policy makers regarding relief provided to caregivers throughout the COVID-19 pandemic? (For example: Are they personally and culturally informed of your caregiving needs at this time? Are they considerate of your own physical and emotional well-being as a caregiver throughout this time? Do they consider financial challenges you are currently experiencing, in relation to your caregiving role, throughout the pandemic?)

3. How hopeful do you feel about the well-being of your future as a caregiver in light of the COVID-19 pandemic, and what are some of the greatest challenges you face at the moment, in regards to caregiving throughout the pandemic? (For example: What type of impact do you think these challenges will have on the quality of care provided to your care recipient? Are there any other lingering worries, in relation to your caregiving role throughout the pandemic? What is your experience with feeling supported by a greater community throughout this time?)

4. What types of changes would you personally like to see implemented to better support you in your caregiving role throughout the pandemic? (For example: Which areas of support do you consider most important to address immediately?)

Appendix L

Table L1

COVID Stress Scales Score Interpretation

Measure	Not at all	Slightly	Moderately	Very	Extremely
CSS *General measure* (36 questions)	0	36	72	108	144
CSS Subscale 1 *Danger and contamination* (12 questions)	0	12	24	36	48
CSS Subscale 2 *Economic consequences* (6 questions)	0	6	12	18	24
CSS Subscale 3 *Xenophobia* (6 questions)	0	6	12	18	24
CSS Subscale 4 *Compulsive checking and reassurance seeking* (6 questions)	0	6	12	18	24
CSS Subscale 5 *Traumatic stress* (6 questions)	0	6	12	18	24

Note. Scale scores are estimated as the average of the present responses multiplied by the number of items in the scale, as indicated by Taylor et al. (2020).

Table L2

C-*DEMQOL Scale Score Interpretation*

Measure	Very Good	Mostly Good	Satisfactory	Quite Poor	Very Poor
C-DEMQOL *General measure* (30 questions)	30	60	90	120	150

Measure	Very Good	Mostly Good	Satisfactory	Quite Poor	Very Poor
C-DEMQOL Subscale 1 *Carer responsibilities and personal needs* (6 questions)	6	12	18	24	30
C-DEMQOL Subscale 2 *Carer wellbeing* (6 questions)	6	12	18	24	30
C-DEMQOL Subscale 1 *Carer role* (6 questions)	6	12	18	24	30
C-DEMQOL Subscale 1 *Feelings about the future* (6 questions)	6	12	18	24	30
C-DEMQOL Subscale 1 *Carer support* (6 questions)	6	12	18	24	30

Note. Scale scores are estimated as the average of the present responses multiplied by the number of items in the scale, as indicated by Taylor et al. (2020).

Table L3

ZBI-22 Scale Score Interpretation

ZBI-22 total scores	Interpretation
0-21	Little or no burden
21-40	Mild to moderate burden
41-60	Moderate to severe burden
61-88	Severe burden

Note. Scale scores as indicated by dementiapathways.ie, based on Zarit et al. (1980).

Table L4

ZBI-22 Subscale Score Interpretation

ZBI-22 Subscales	**Never**	**Rarely**	**Sometimes**	**Quite frequently**	**Nearly always**
Personal Strain (12 questions)	0	12	24	36	48
Role Strain (6 questions)	0	6	12	18	24

Note. Scale scores as indicated by dementiapathways.ie, based on Zarit et al. (1980).

Table L5

Role Captivity Scale Score Interpretation

Measure	**Very much**	**Somewhat**	**A little**	**Not at all**
Role Captivity (3 questions)	3	6	9	12

Note. Scale scores are estimated as the average of the present responses multiplied by the number of items in the scale, as indicated by Pearlin et al. (1990).