

How to Best Support Caregivers of Those with Neurocognitive Disorder:
Preferred Modalities of Psychotherapy

by

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Abstract

Caregivers of those with neurocognitive disorder (NCD) are currently not receiving clinical therapeutic counselling, to support their mental health needs. The current research shows that Canada's public health care system is ill equipped to address the health care needs of our aging population which does not touch on the needs of caregivers including clinical therapeutic counselling which would support their mental and physical health. This problem will only increase as our aging population grows significantly as it is predicted to do. A review of existing literature that demonstrates what the risks are for caregivers of those with NCD and what supports them during a life space wrought with physical and emotional stress is documented in this paper. The critical review of existing literature determined that neurocognitive disorder significantly affects caregivers and family members with overwhelming feelings of frustration, loneliness, sadness and anxiety which is exasperated by a lack of psychological care, guidance and support (Guedes do Nascimento & Basos Figueiredo, 2019). Caregivers are at heightened risk to their physical and emotional health during a disease progression that last decades. This paper concludes with a proposed program that will provide clinical therapeutic counselling for caregivers and families of those with NCD. Lastly, the need for advocacy for such services to be legislated as a minimal service of care and funded through public funds is discussed.

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Chapter 1

How to Best Support Caregivers of Those With Neurocognitive Disorder: Preferred Modalities of Psychotherapy

Senior people with neurocognitive disorder (NCD) and the families who care for them are currently not receiving adequate health care, including therapeutic counselling, to support their needs (Finkelstein et al., 2012). Personal support including therapeutic counselling are not required either federally by The Canada Health Act nor provincially by the Community Care and Assisted Living Act (Canada, 2021), (Printer, 2020). This problem will only increase as our aging population grows significantly as it is predicted to do (Statistics Canada, 2021). The current research shows that Canada's public health care system is ill equipped to address the health care needs of our aging population and most notably burdensome for racialized, Indigenous, LGBTQ (lesbian, gay, bi-sexual, queer, trans-gender) and low-income seniors (Canadian Health Coalition, 2018). While some of this population are cared for at home by family caregivers and home health care provided by the province, much of this care is provided in institutionalized long term care facilities both privately and publicly funded. The BC Care Providers Association has called the current state of long term care being provided as challenging due to out of date infrastructure, staffing shortages and growing demand (Kay, 2019). However, their claim of the current status, which appears dismal, is only a small part of the problem as it is predicted that long term care will be in a state of "bedlam" as our population ages (Kay, 2019). The health care needs for this demographic, which do not address therapeutic counselling, are predicted to increase by 71% in 2026 from 2011 (The Conference Board of Canada, 2015). With the current situation being in such crisis and the anticipated future so dark, it is worrisome that therapeutic counselling will continue to be missed in the baseline requirements for seniors with NCD and their families.

The Crisis is Real

The crisis is looming as it is predicted that an estimated 458,000 Canadian seniors could experience unmet or under-met needs by 2046 (The Conference Board of Canada, 2015). These estimates do not address the needs of family caregivers or family members who are struggling with the emotional implications that come with this end stage of life, which often includes chronic sorrow and non-finite grief. Of paramount importance, is that these needs and care do not remotely refer to quality, but rather refer to just minimal standards for health and safety as that is all that is legislated (Ministry of Health, 2016). The Canadian government is required to ensure that minimal standards in licensed care be met based upon risk to health and safety but has not committed to addressing the psychosocial or emotional needs of those requiring care or their families. There is no legislation currently in place provincially or federally that would ensure that therapeutic counselling to address the needs of these seniors or their families is met. As one can hear in the discourse of the participants in one study, neurocognitive disorder significantly affects family members with overwhelming feelings of frustration, loneliness, sadness and anxiety, which is exasperated by a lack of psychological care, guidance and support (Guedes do Nascimento & Basos Figueiredo, 2019).

What is the Problem?

It is of concern that the discussion that is occurring throughout all levels of government and across multiple stakeholders does not show consideration of the social and emotional impact on the families of institutionalized long term care residents. In researching how psychotherapeutic counselling could be effective, one can open the door to better understanding how this growing population and their families can be best supported. As Cheek and Ballantyne (2001) found in their Australian study, family caregivers felt that they were at the mercy of the health care system when transitioning to assisted living homes and

were wrought with feelings of discontentment, being out of control and unsure of what was happening. This highlights the need for strong consideration of how family members and policy makers want to address this issue and move forward. The purpose of this study is to explore what social and emotional supports are most beneficial for families whose loved ones are transitioning into and living within long term care in Canada. The study will address the problem that therapeutic counselling is not mandated or provided for long term care residents or their families and will explore the impact on both psychological and physiological health.

When families begin to seek long term care for their loved one with NCD, it is often preceded by a long road of caregiving by family members which could have lasted for many years or even decades (Schulz & Martire, 2004). It is evidenced that this caregiving takes a toll on the family members closest to the person needing care and often leads to compromised psychological and physiological health (Lykens et al., 2014). This highlights the need for interventions to address the needs of both patients and caregiving family members. Hence, this study will focus on those who are at the centre of this issue: the seniors with NCD and their families.

Who Can Best Speak to The Problem?

The voices that are left unheard in these situations are those of the siblings, children and grandchildren, and most disturbingly, the life partners who are frequently caregivers until the transition into institutional long term care becomes the only option. The guilt that often goes with this transition and the helpless feeling of letting a loved one down, can settle deeply within one's conscious and unconscious mind. The work of Ball et al., (2009) gives an emotional lens into these feelings when one family member spoke of his helpless feelings, "I feel really guilty. I promised her I would never put her in a home, that I would let her stay home. I tried, and it just didn't work" (pg. 99). The feelings of chronic sorrow and the ambiguity of loss that many of these people live with come from the depths of love and grief,

yet policy makers don't recognize the value or provide therapeutic counselling as part of our long-term care services. Policy makers must seek to understand how this lack of support impacts one's psychological and physiological health if the Canadian government will truly meet the needs of the aging population and their families and "make sure all Canadians get the high-quality care they deserve" (Trudeau, 2019).

The voices that must be heard are wide ranging, coming from the diverse landscape of Canadians including all ages, genders, languages, education levels, socioeconomic status levels, religions, sexual orientations, ethnicities and cultures. Ensuring that our ethical obligation for cultural accountability is met, requires that these voices are heard and included in doing this work (Sheppard et al., 2007). In order to do so, health professionals are called upon to bear witness to the nuances spoken (or unspoken) that allow for a path to trust, safety and belonging to develop between those who need care and support and those who provide care and support. Space must be made that will allow for an intimate connection with family members and family caregivers given the vulnerability that is experienced when caring for or placing a loved one in long term care. Connecting with these individuals and hearing their voices would also address the intention of the Public Health Act which calls on the health authorities to promote and protect the health and wellbeing of all British Columbians (Province of British Columbia, n.d.).

This place of despair is strikingly difficult to make sense of and navigate without proper tools and methods of support (Neimeyer et al., 2011). In a study by Nolan & Delassega (2000), one partner shared her mixed feelings and how overwhelming her sadness was because "it's the end of life as we know it. Relief, because of the tremendous responsibility. Worry, that the home is the right one and they'll look after him properly". It is these voices that must be heard and the need for social and emotional support that must be addressed as Canada faces the looming health care crisis in caring for seniors. These stories

come hauntingly close to home and my empathy for these people and their loved ones is felt deeply which gives me the fortitude to explore this issue.

My Positionality in This Study

Both professionally and personally I am nestled within BC's health care system with a lens from both the inside as an investigator for the Fraser Health Authority and the outside as a family member of one living in long term care with neurocognitive disorder - Alzheimer's. My positionality on both fronts has provoked me to explore and query the processes and regulations that are in place for our health, safety and dignity and to speak up to situations that I find to be deficient or unjust. While my job with the health authority requires me to do so, it is the love for my family that draws the most emotion and commitment.

I strongly believe that our society needs to care for those who are struggling in life or suffering with mental health diagnoses; something I do not believe Canada does well enough. If we don't do this, what kind of human beings are Canadians? My personal position is that I feel extreme empathy for those that I see suffering in our community and I have an innate drive to reach out and help in whatever way I can. I also admit to feeling impatience and a sense of distaste when I hear others show a lack of empathy or understanding for those who are suffering, which is something I actively have to keep in check and try to maintain an openness to - the perspectives of others. The passion I feel for this topic and the inner belief that I want to live my life with purpose spurs me on to do what I can to contribute to improving this situation.

As the daughter-in-law of a woman who was once steadfast and tough and who lived her life with vigour, passion and occasional conflict due to her outspoken nature, but now relies on health care aids for her most basic daily needs, I am not without bias in this study. The 35-year relationship I have had with her has been rooted in family life; caring for and raising my children while tussled with conflicts and tensions that come when two women

share strong emotions but not necessarily the same opinion. Throughout the years, all while being on the low rung on the hierarchical ladder under the outspoken matriarch, our family grew, children moved on and tensions settled. Sadly, the reality is that much of what she will share with her family is behind her now as we – her children, grandchildren and siblings - all move on to figure out our new roles and responsibilities as we care and advocate for the once force to be reckoned with. Damn, that went quick. I am now situated in a place where I am advocating for her and feeling the protective sense of a mother bear all while awakening to the realization of my own aging and mortality. As I feel the aches and pains of middle age and the brain fog of menopause, I'm quite aware - although maybe not accepting – that I may need this kind of care myself one day.

Navigating through the structure of BC's community care and assisted living services, has been eye opening for me and my family and not without frustration. Making endless phone calls to try to obtain basic health care for her has been threaded with feelings of hopelessness and irritation that has created family tensions rather than being helpful or supportive. It is also notable that our family is one of privilege; middle class cisgender Canadians who have never had to think about being treated with fairness or respect because of our color, sexual orientation, faith, or ability. While this journey has been difficult for us, families from other social locations experience additional hurdles for obtaining basic health care for their loved ones within an atmosphere of disrespect, which Canadians should find unacceptable (Bellrichard, 2020). Canada is far from meeting any need for therapeutic counselling for long term care residents or their families when just finding a bed can't be reached in a timely, satisfying and respectful manner.

“How are you doing? Can we help you at all? Can we offer you some support” These are words that our family has not heard over the past three years in moving through the health care system as she drifts away. If I am honest, to say I am biased may be an understatement.

I feel myself being fearful of ever needing any real kind of health care or being vulnerable to needing health care services. My personal experience coupled with my professional responsibilities of leading investigations into high-risk incidents and allegations of neglect and abuse in long term care facilities, does not allow for the passion I feel to settle, but rather provokes it.

As an investigator for the Fraser Health Authority, I have in depth daily dealings with long term care including staff who neglect residents, alleged abusers and victims of abuse and their families. The work is often disturbing and frankly sometimes repulsive; in particular when extremely frail and vulnerable people have been harmed. In this work, I have been struck with the lack of social and emotional support the families of those living in long term care are provided in particular when their loved one has neurocognitive disorder, during palliative care or even after death. I see a gaping hole where families could be provided with more psychoeducation, group and individual counselling and opportunities for social and emotional connection. Given that these situations are not acute as often these individuals live for many years in these facilities, it gives further argument that this kind of research is needed. As Nolan & Dellasega (2000) and Garity (2006) postulate, positive outcomes have been correlated with family involvement in long term care support groups. This finding gives a glimpse into how this research project may uncover what is thought to be beneficial for families.

Chapter 2 Literature Review

This review provides a critical summary of five main topics of the current literature available, including: what issues caregivers are facing, what supports caregivers, issues faced when transitioning a loved one into long term care, inclusion and fairness in health care for the vulnerable population, and alternative ways to think about how care can be provided for those with NCD. The scope of the literature review goes beyond what is found in North

America in an endeavour to gain a wider lens into how this life space is lived globally. With this broader world view, the literature review will contribute to further understanding of why this problem is significant, a deeper understanding of the issues it encompasses and what ways this problem is being addressed without geographic or cultural limitations. This review will include a multicultural lens given the variety of cultures that make up the Canadian landscape. Popular culture references will also be explored including podcasts and movies such as *The Notebook* and *Still Alice* which so eloquently demonstrate the devastation of this disease for loved ones.

Method

A rationale on why the literature included has been chosen is provided that will explain why the material has relevance and meaning for the final capstone project. The literature reviewed will be grouped together by theme to make for an easy readable flow. For example, research papers on grief and culture are placed together while papers that speak to the effective modalities of psychotherapy are placed in another group. By completion, the reader will have a good understanding of why this research is necessary and what the literature tells us.

At first glance into one of these categories of literature are the research papers that focus predominantly on social connection for this demographic. This category of the literature review explored what research has already taken place in this area of social connection, giving us deeper insight into what the problems are and what solutions might be viable that policy makers are not currently aware of. Through reviewing the literature available on how social and emotional support is best served to families of those in long term care, I predict that what modalities of psychotherapy will be most effective will become apparent. The literature review will explore what health benefits are evident when comprehensive emotional and social support is provided and how it is implemented. The

review will also explore what therapeutic approaches for living loss could fit within the long-term care system to support families.

In considering neurocognitive disorder specifically, the literature review seeks to gain an understanding of what therapeutic modalities are found to be the most and least effective and what aspects of any support received are beneficial or not. The study will endeavour to look through the lens of the family and not the lens of the health care system in determining the beneficial components for those it will serve. Exploring any available narratives of lived experiences with an eye on building an understanding on what is needed from familial perspectives will contribute to the outline for the final project portion of the capstone. My goal is that the finished project will satisfy the voices that often go unheard, as this is the discourse that the decision makers should attest to.

The literature that was reviewed fell into the following 5 main categories: The Issues Faced by Caregivers of those with Neurocognitive Disorder, including Grief and Caregivers, Grief and Culture, Mental Health Effects of Caring for those with Neurocognitive Disorder, Health of Caregivers (make this physical health); What Helps Caregivers of those with Neurocognitive Disorder? including Social Support, Social Media, Mindfulness, Grief Therapy & Cognitive Behavioural Therapy, Group Therapy, Open Dialogue – A promising Alternative; Transitioning into Long Term Care; Inclusion and Fairness – The Ugly Truth; Alternative ways to think about Caring for Those with Neurocognitive Disorder, including Aging at Home with Neurocognitive Disorder, Aging at Home Infrastructure, Global Approaches to Caring for Those with Neurocognitive Disorder. This review will begin, however, with a look at popular movies and the roles that give the viewer an emotional lens into the disease of Alzheimer's.

Movies

Films in particular allow for us to gain a strong sense of the loss and sadness that is felt those with NCD and their families as the viewers are moved by these life-like stories. The reality of NCD, the grief that is felt and the burden on families is passionately portrayed in two movies in particular; *Still Alice* and *The Notebook*. Once lovers and friends who shared affection, dreams and life's successes, the couples in these movies sadly turn to roles of caregiver and patient. In *Still Alice*, Dr. Alice Howland is a woman who is diagnosed with early onset Alzheimer's disease, played by Julianne Moore (Glatzer & Westmoreland, 2015). Living a full, successful and rich life, the viewer sees Dr. Alice Howland and her husband Dr. John Howland, played by Alec Baldwin, as their life spirals downward while she becomes more dependent on him and he takes on more of a caregiver role. Alice speaks eloquently of her experience.

I used to be someone who knew a lot. No one asks for my opinion or advice anymore.

I miss that. I used to be curious and independent and confident. I miss being sure of things. There's no peace in being unsure of everything all the time. I miss doing everything easily. I miss being a part of what's happening. I miss feeling wanted. I miss my life and my life.

The loss and sadness that she feels is shared by her husband, however he has an additional role of protecting her and providing care as is seen when she forgets where the bathroom is and urinates in her clothes. He soothes her and helps her, "It's okay, baby... we'll...we'll get you cleaned up...". The scene depicts the spouses' sorrow and loss.

Similarly, *The Notebook* is a love story that unfolds as a family comes to understand and accept the reality that their matriarch is slowly drifting away to NCD (Cassavetes, 2004). James Garner plays the role of Duke who reads a story of young lovers every day to Allie, played by Gena Rowlands. She cannot remember the story from day to day, nor does she

recognize Duke or her own children. One day while Duke is reading to her, she says, “They fall in love, didn’t they?”

“Yes, they did”, he replies as the viewer begins to realize that the story is their story – the story of them falling in love – a story of life. He never stops loving her or caring for her even as her disease progresses with aggressive outbursts and detachment from all that she once knew, “That’s my sweetheart in there. Wherever she is, that’s where my home is.”

Although this is a fictional story, it is representative of so many who suffer, of their families and of those who care for them. While these stories are incredibly heart wrenching, this place of discomfort holds meaningful space as one considers how to support caregivers. One has to be emotionally connected to the issue if this topic is to be considered in a meaningful way.

This Issues Faced by Caregivers of Those with Neurocognitive Disorder

Grief and Caregivers

An emerging theme from this review is how destructive caregiving is on a family caregiver’s ability to grieve their loved one during and after the long illness of dementia. Generally, grief is understood as a psychological response to a significant disruption of attachment through death or loss (Blandin & Pepin, 2017). Known as the disease of a thousand goodbyes, dementia lasts for many years with a slow progression of decline until the person reaches the final stage of actively dying. While grief is a normal reaction to loss, in the context of dementia, the family caregiver suffers a gradual loss over many years which increases the potential for psychological morbidity, depression, and suicidality which persists long after the care recipient has died (Paun, et al., 2015, Supiano, et al., 2017). Blandin & Pepin (2017) posit that the gradual loss associated with pre-death grief increases as dementia advances, as caregiver health deteriorates and a sense of burden increases. The greater the pre-death grief, the more likely it is that complicated post-death grief in dementia caregivers will occur and it is been shown that pre-death interventions mitigate post death depression

and complicated grief (Blandin & Pepin, 2017). The complicated grief experienced in bereaved caregivers is well understood and has been addressed in previous research projects that sought to understand the issue in general and how best to support family caregivers (Paun, et al., 2015).

Paun et al's (2015) Chronic Grief Management Intervention (CGMI) program placed loss and chronic grief at its centre and focused on improving knowledge and skills in communication, conflict resolution and grief processing and assisted caregivers with the transition into long term care by managing the loss associated with this process (Paun, et al., 2015). The program, which included 83 participants from 16 randomly selected care homes, ran over 12 consecutive weeks in a group format. Significant improvements were found in the areas of heartfelt sadness and longing, loss of relationship, guilt and knowledge immediately following the program and a 6 month post-review found a significant drop in guilt and improvements in heartfelt isolation & longing and grief over loss of relationship. It is notable that baseline depression scores were not significantly different following the intervention or when reviewed 6 months after the start of the intervention.

The findings of Paun et al. (2015) are echoed in the work of Supano et al. in another group therapy project that ran for 16 weeks for caregivers suffering with complicated grief following the death of a loved one (Supiano et al., 2017). Their project focused on three key treatment areas directly associated with reconstructing the meaning of grief including retelling the narrative of death, having an imaginal conversation with the deceased and memory integration. The project found that there were three major themes in how caregivers understood the meaning of loss; affirmation for the deceased, personal preparation for their loved one's death and family bonds which could be both positive or negative. With the skilful guidance of group facilitators, the participants were able to construct and reconstruct each other's catastrophic grief experience which fit with their goal to not cure or resolve grief, but

to facilitate a normal grief process that would lead to integrated grief. Uncoupling the deceased memory from the circumstances of their death allows for the deceased to not be uniformly associated just with dementia. The outcomes of this treatment program found that there was a significant reduction in complicated grief for participants and supported the argument that meaning making is congruent with progressive and effective coping of loss (Supiano et al., 2017).

The work of Blandin & Pepin (2017) offers a unique theoretical model to better understand the unique grief process of dementia they call the Dementia Grief Model. Dementia grief cycles through three specific psychological states that have dynamic mechanisms which propel movement through the grief process. The first state, that of *separation* is characterized by compounded serial losses such as losing the ability to manage finances, to drive a car or be left alone in a relatively short period of time. By acknowledging these losses as they occur, the caregiver is better able to move onto the second state of *liminality*. The dynamic mechanism of this state is the ability to tolerate difficult feelings which are riddled with ambiguity as the known self is slowly receding, yet final physical death is looming in an unknown future. Confronting and tolerating the deeply difficult emotions in the liminal state unfurls into a state of clarity when the loss is acknowledged, accepted and understood. Through the dynamic mechanism of adaptation, one reaches the third state of *re-emergence*. The Dementia Grief Model captures the experiences of dementia caregivers that is unique to this devastating disease (Blandin & Pepin, 2017).

Grief and Culture

As previously discussed, pre-death grief is a well understood concern faced by caregivers of persons with dementia cross culturally. Regardless, Liew et al. (2018) posit that while caregiver grief inventory scales are readily available for the English-speaking population, there has not been a Mandarin-Chinese version available for this population who

make up one-sixth of the world's population (Liew, et al., 2018). This is of particular concern, given that the Chinese speaking population have among the largest number of persons living with dementia and are a significant segment of the Canadian immigrant population. The work of Liew et al. (2018) that saw the creation of a Mandarin-Chinese version of an existing empirically-developed English-speaking caregiver grief inventory scale, concluded similar performance in terms of reliability and validity. While studies have been conducted to determine benefits of pre death grief interventions, they have been mainly conducted with Caucasian populations, likely due to the lack of available Chinese language assessments (Liew, et al., 2018). The research of Liew et al. (2018) coupled with the vast number of Chinese-speaking caregivers who experience pre-death grief signifies the need for further research that is culturally relevant and sensitive to the Chinese community. The importance of ensuring culturally relevant practices in a dementia specific context is not unique to the Chinese community in Canada where a plethora of cultures exists.

Finkelstein, Forbes & Richmond (2012) discuss how care is provided for persons with dementia in First Nations communities in southwestern Ontario by examining two interrelated frameworks; a care delivery framework and a knowledge framework. With dementia as a relatively new phenomena in First Nations communities, the study sought to fill a gap in knowledge as to how First Nations communities experience dementia care within a culturally sensitive context. There were few dementia care programs and resources available that incorporated First Nations knowledge and First Nations-specific dementia care literature did not exist, although one traditional healer spoke from experience of how self-esteem goes down and fear sets in after a diagnosis and this can feed the illness. Clients are supported to recognise these negative reactions, accept them and then find a solution. While knowledge was plentiful between the health care providers who had formal dementia training, clients and family care givers who understood client's health and symptoms and

community members who held traditional beliefs and values, collaboratively sharing this knowledge was difficult. Some elders spoke frankly about group-based education and how there was mistrust that what was shared would actually stay within the group. However, it was determined that the knowledge framework was not the underlying issue of barrier to care, but rather, lack of resources, failure to collaborate, encountering mistrust, unwillingness to access care and caregiver burnout were found to be significant (Finkelstein et al., 2012).

Finkelstein et al. (2012) posit that health care professionals had effective strategies for providing care which encompassed ways to share knowledge and overcome barriers. These strategies included providing culturally appropriate care by blending both Western and traditional medicines, ensuring that care was suited to client's needs, was supported by a personal support worker and invited involvement of community elders. The findings showed that it was of benefit when health care providers were genuine when actively seeking to collaborate with family and community and in developing relationships and building trust. The nature of NCD is one that is peculiarly progressive, difficult to understand and accept, emotionally challenging and onerous to navigate for families. With a relationship and trust laid as a foundation between health care providers, family and the Indigenous community, sharing the reality of the disease process, applying health promotion strategies, and making care planning decisions can be more easily and less stressfully accomplished.

Health Effects of Caring for Those with Neurocognitive Disorder

Before the health effects of those who care for individuals with NCD is considered, one must first understand what it is they do, what they are faced with on a daily basis and what this experience is like for them. Persons with NCD experience a declining psychological sense of self, a progressive loss of identity and cognitive decline which often coincides with a decline in inhibitory control and social cognition (Guedes do Nascimento & Basos Figueiredo, 2019). Caregivers are often faced with aggressive behaviours such as agitation,

spitting, cursing, clawing, urinary and fecal incontinence, throwing things or verbal violence, which reaches escalated levels, impacting how these actions are interpreted and limiting the caregiver to take time away (Guedes do Nascimento & Basos Figueiredo, 2019). Often, met with abandonment of family members, caregivers are left with a loss of freedom, isolation and family conflict (Guedes do Nascimento & Basos Figueiredo, 2019). Feelings of frustration, loneliness, sadness and anxiety are understandably felt and speak to the need for multidisciplinary care for persons with NCD and their caregivers (Guedes do Nascimento & Basos Figueiredo, 2019)

Paun et al. (2015) posit that caregivers of those with NCD suffer long term mental health effects including most frequently depression, and physical ill health which increases their risk for premature death. The high level of stress associated with caregiving is related to burden and depression, which is over represented in individuals of lower socioeconomic status, higher level of urbanicity, and advanced age (DeFazio, et al., 2015). This is particularly worrisome for caregivers who live with patients, as impairment to caregivers' mental and physical well-being is elevated even when the patient has only mild levels of dementia (DeFazio, et al., 2015). DeFazio et al (2015) posit that at least 50% of caregivers show at least mildly severe depressive symptoms, which speaks to the need of providing psychotherapeutic support far before transition into long term care.

This contributes to conflict with facilities and tensions with the staff who are now tasked with providing care for their loved ones. Placing a loved one in long term care is a stressful turning point for those living with NCD, their caregivers and families, yet grief focused support for transition is generally not provided. The chronic grief that these caregivers experience increases psychological morbidity and suicide risk that persists long after their loved one has died (Paun, et al., 2015).

As discussed, informal caregivers often care for their loved ones for several years before placement in a long-term care facility. Often the informal caregivers of those with NCD are considered the ‘invisible second patients’ due to the numerous and stressful demands that come with caring for their loved one that leads to negative mental health outcomes (Mandy Ma et al., 2018). In particular, for those caring with patients of Alzheimer’s type dementia, there is a greater emotional burden on caregivers, likely due to functional impairment and challenging behaviours associated with this particular type of NCD (Mandy Ma et al., 2018). In particular, anxiety levels are found to be significantly higher in caregivers of Alzheimer’s patients when compared to non-caregivers, which speaks to unmet mental health supports of these family caregivers (Mandy Ma et al., 2018).

What Helps Caregivers of Those with Neurocognitive Disorder?

Caregivers of those with NCD who access counselling services tends to be low, even though the need is evidently high due to the potential for long-term ill mental and physical health of caregivers (Mandy Ma et al., 2018; Paun, et al., 2015). To encourage caregivers to utilize resources that are available, barriers must be removed that may include providing education on what supports are available and the value of these (Mandy Ma et al., 2018). It is imperative that the ability to find what information and services are available is easy as this is considered a significant barrier for caregivers (Macleod et al., 2017).

Clark et al., (2016) posit that wellness counselling in particular provides a cooperative strength-based framework from which treatment plans and interventions can be best constructed with caregivers. This holistic counselling approach addresses the interrelatedness of caregiver stress and well-being, mobilizes internal and environmental resources, incorporates dyadic and family sessions and nurtures positive mental health for caregivers (Clarke et al., 2016). Because the wellness counselling approach comprehensively addresses multiple key factors in caregiver well-being, positive intervention outcomes can come from

multiple domains. Due to the breadth of this approach, assessment and planning is done to ensure that the greatest areas of burden are addressed and considered in how they affect different areas of well-being (Clarke et al., 2016).

Grief Therapy & Cognitive Behavioural Therapy

Noyes et al (2010) created a grief-stress model of caregiving that integrates ideas of ambiguous, anticipatory and disenfranchised grief as described below into a model that recognizes that the grief inherent in dementia caregiving is often misunderstood as a more normative type of stress. This is a risky oversight as ambiguous loss is associated with a loss of companionship, communication, support and hope for improvement and the future which is associated with physical and mental health problems of caregivers of those with NCD (Noyes, et al., 2010). Caregivers of those with NCD experience grief similar to grief that occurs after bereavement, however caregiver grief is prolonged lasting over 8 to 10 years with no clear starting or ending point (Meichsner et al., 2016). As the disease progresses and while the person is physically present, yet psychologically becomes more lost over time, a phenomenon of ambiguous grief sets in for the loved ones and caregivers. As well, as the loved ones and caregivers slowly lose the person, anticipatory grief sets in that challenges one to mourn while their loved one is still alive, which is not always a socially recognized or accepted by religious, family or cultural values. Feelings of helplessness and isolation from the broader community have been described as disenfranchised grief that adds to a person's feelings of helplessness and isolation (Meichsner et al., 2016).

Meichsner et al (2016) posit that different interventions are required for different factors of caregiver grief. The factor of *personal sacrifice and burden* measures the extent to which the caregiver experiences their own personal losses of time, freedom, sleep, health, etc. due to their caregiving duties. The factor of *heartfelt sadness and longing*, represents the emotional reaction to the loss of relationship with their loved one with NCD which rings

feelings of powerlessness, sadness and wishing for the way things used to be. It is noted that this factor has the least overlap with measures of depression when caregivers had been prepared for their loved one's death. The final factor of *worry and felt isolation* represents how a caregiver perceives the loss of personal connection with others due to the heavy demands of caregiving and worries about their own current and future situation (Noyes, et al., 2010). These differences in caregiver experiences speak to how different interventions would be suitable to different individuals based upon their own unique needs. Meichsner et al. (2016) posit that the most important intervention that therapists can provide is to normalize their feelings and to underscore the fact that caregiver grief interventions do not need to ameliorate a pathological condition. Grieving is a normal part of caring for a loved one with NCD.

Meichsner et al (2016) conducted a Cognitive Behavioural Therapy (CBT) based trial that included techniques such as psychoeducation, restructuring of dysfunctional thoughts regarding grief and incorporating engagement in positive activities to outbalance negative emotions, redefining the relationship and roles, normalizing grief, and addressing future loss during disease progression. It became evident that while caregivers recognized feelings of loss, they did not see these feeling and emotions as being associated with NCD and found it difficult to understand their own emotions and only do so when explicitly told that this is what is happening to them (Meichsner et al., 2016). The work of Meichsner et al (2016) brings attention to how difficult it is for caregivers of those with NCD to recognize and talk about their grief, which they posit, calls on therapists to keep this difficulty in mind, and to also make appropriate interventions on a case-by-case basis. While their findings showed that grief interventions supported caregivers to accept loss and facilitate emotional processing, there were limitations. First, it was indeterminable if other grief techniques that were unaccounted for may have been indirectly connected to outcomes; second, due to the nature

of difficulty in recognizing and addressing feelings and emotions of grief, some may have gone unaddressed; and finally, because their work was done via telephone, some grief may not have been recognized and therefore not addressed (Meichsner et al., 2016).

The evidence review of Verrier et al. (2017) evaluated effectiveness of CBT for caregivers of those with NCD and found strong support for interventions that focused on cognitive reframing and skills training reducing caregiver depression, anxiety, and stress. Greater satisfaction was found when interventions included facilitator interaction compared to self-directed programs without a facilitator and the mode of delivery via telephone or in person did not make any difference to caregiver outcomes (Verrier Piersol, et al., 2017).

Social Support

There is mounting research that shows that caregiving for those with NCD leads to social isolation and loneliness which indicates that social support is not always available to these individuals (Dam, Boots, van Boxtel, Verhey, & de Vugt, 2018). Tanskanen et al. (2016) posit that there is strong evidence showing a negative correlation between extremely social individuals and mortality, which shows the importance of planning for a variety of social networks for caregivers. When social engagement exists alongside the caregiving role, the caregiver has enhanced feelings of wellness and often nursing home placement is delayed. While people in the caregiver's social environment are often willing to help, one barrier is that there is often no insight into what type of support is needed and when. This barrier can be addressed and network involvement enhanced by adopting a positive and open view toward caregiving as being a normal process that focuses on opportunities rather than limitations (Dam et al., 2018). Other ways to enhance social support were found to be communicating thoughts and feelings between caregivers and social supporters, seeking social support early in the disease course and healthcare professionals creating an awareness that social support is not only beneficial but essential (Dam et al., 2018).

Dichter, et al. (2020) recognize that globally, informal caregivers are the cornerstone for care recipients living at home and half of these people live with NCD, which requires considerable time, significant personal engagement and extensive day to day management. Due to these weighty responsibilities, informal caregivers of those with NCD show higher stress levels than those who care for physically frail elderly people and they have an increased risk of becoming physically and mentally ill. Their study looked at the effects of an efficient easy access telephone-based intervention which endeavoured to strengthen the psychological health related quality of life and social support of family caregivers living with NCD patients living at home (Dichter, et al., 2020). While their findings showed nonsignificant promising results in regard to self-reported psychological health related quality of life, the intervention would have to be evaluated in a full trial for efficacy to be determined (Dichter, et al., 2020).

Through questionnaires, Khusaifan & El Keshky (2017) assessed how informal social supports were perceived by caregivers, what depressive symptoms were seen, and how general life satisfaction was for caregivers of those with NCD in Saudi Arabia, a Muslim majority country. Khusaifan & El Keshky (2017) posit that social support mediates the relationship between depression and life satisfaction for caregivers of those with NCD. Their findings from this show that this is the case when social support comes from family and friends, but not from significant others, which they posit, speaks to the role of cultural differences in the value of informal social supports (Khusaifan & El Keshky, 2017). Earlier research based upon western cultures shows that friends were more likely to be the providers of emotional support compared to family members. This is in contrast to eastern cultures that look for social support from kin relationships rather than non-kin relationships (Khusaifan & El Keshky, 2017). It is relevant given the multitude of cultures living amongst one another in

Canada, that consideration is given to what role culture plays in planning for and implementing social supports for caregivers.

Social Media

It is evident that social media is becoming a main stream resource for people sharing information including family situations on platforms such as Facebook where private discussion groups for caregivers are active amongst the caregiver community (Bachmann, 2020). Bachmann (2020) posits that topics frequently discussed are related to exhaustion and feelings of “giving up” by caregivers, interpersonal communication and help from other family members. Most support was found to be on topics of aging, death, dying, family events and communications (Bachmann, 2020). The discussion group was found to be mostly supportive in coping with fundamental life changes and how to communicate and interact with the person with NCD. Questions posed to others in the group queried such notions as what to tell a mother when she asks why she can’t remember where the dishes go, what to say to a father when he asks his 48 year son if he thinks he might grow an inch or two taller, how to deal with violent outbursts, or sorrow in missing a wife’s voice and conversations who is now non-verbal (Bachmann, 2020). Caregiving can be isolating which speaks to the value of considering other technologies as well, such as Facetime©, Zoom© or Instagram© in connecting with others.

The work of Wilkerson et al., (2017) demonstrates that friend sourcing on social media as a way to seek out others caring for those with NCD is a promising strategy for improving psychological well-being of caregivers. Their social media intervention was conducted through a closed online Facebook support group where participants could post and respond to each other’s comments about many topics including self-care, caregiver roles, obtaining caregiver information and techniques, creating more family dialogue and requesting support (Wilkerson et al., 2018). 70% of those who participated reported

experiencing a critical point of realization that their values, beliefs, opinions or expectations of caregiving had changed by the end of the 6-week intervention (Wilkerson et al., 2018).

Although this research was limited as it only included participants who had a small number of friends on Facebook, minimal Facebook activity and the participants were mostly Caucasian which limits cultural diversity, the findings warrant further investigation.

Mind Body Programs

In considering the harmful effects of caregiving on our physical and mental health, one would be remiss to not explore the holistic approach of mind body programs (MBP) that are founded upon formal mindful meditation training (Crane, et al. 2017). MBPs include those that engage one in developing skills in recognizing direct experiences of thoughts, emotions and sensations, patterns relating to experience and the wider implications of understandings that emerge. These programs have allowed for mindfulness interventions to develop, providing learning experiences that improve psychological well-being (Berk et al., 2018). Mindfulness Interventions (MI) are body-mind interventions that calls on one to focus on the present moment which effects how stressful life events are interpreted. With developed awareness, mental flexibility and the ability to see distressing thoughts and emotions as temporary, the impact of stressful events on our physical and mental health is mitigated (Berk et al., 2018). Berk et al., (2018) posit that two types of mindfulness interventions including mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT) are proven to show improved outcomes in anxiety, social support, and burden, while MBSR specifically showed improvement in overall mental health, stress and depression for caregivers. One investigation found that when caregivers were trained in MBSR specifically modified for the goal of promoting and preserving the psychological health of non-professional caregivers of those with NCD, significant improvements were seen in self-reported depression, stress, burden and enduring traumatic grief (Ho, et al., 2016).

Open Dialogue Therapy

The Open Dialogue approach is a model of mental health service that ensures all psychotherapeutic treatment is done in the presence of a patient's support system often beginning when the client is in crisis. The goal of this approach is to develop communication between the client, their support system, and the clinical team, to remain flexible with care approaches that include input from family and support members, and to ensure the clinical team maintains consistent contact and that the family is heard (Razzaque & Wood, 2015). The dialogic practice of Open Dialogue contends that *being with* clients and their support persons is preferred rather than *doing to*. The client and their supporters are placed at the centre of practice and their words and stories are felt to be precious and mindfully attended to by therapists along with their silences, gestures, emotions and bodily based utterances (Olson et al., 2014).

Promoting an Open Dialogue approach throughout the client's care contributes to positive change as seen in the Tornio project in Finland, where diagnosis of schizophrenia has been significantly reduced, hospitalizations and neuroleptic medication use have been lowered, and clients are mostly employed or studying (Jackson & Perry, 2015). While Open Dialogue has been mostly studied as an approach for schizophrenia with startling positive outcomes, it has the potential for a more compassionate and emancipatory approach to other forms of mental distress (Jackson & Perry, 2015). In considering the distress placed on family and informal caregivers of those with NCD, it is presumable that the Open Dialogue approach may be equally beneficial.

Group Therapy

Group therapy interventions allow for caregivers to share personal experiences, to learn from one another and feel like they are not alone (Saxena, et al. 2020). Becoming part of a group allows for caregivers to meet others in a similar situation, giving way to more

positive feelings and a sense of feeling supported in an extremely burdensome time. Group members encourage one another to reach out within the group for guidance, support and connection rather than relying on a clinician, which instils a sense of confidence in their role of caregiver as they support and guide each other (Saxena et al., 2020). Evidence reviews indicated that in-person caregiver support groups led by professionals had improved outcomes for caregiver well-being, reduced depression, burden, and stress and caregivers felt more prepared and confident in managing memory loss of their loved ones (Verrier Piersol et al., 2017; Canton et al., 2017). This finding is further supported by Saxena et al., (2020) who posit that group therapy for caregivers which includes psychoeducation about NCD, behavioural management strategies and tips on self-care has a positive impact on both caregivers and those with the NCD diagnosis. Interventions involving psychoeducation that provides awareness of disease progress, available treatments and how to manage the illness helped caregivers to moderate their expectations of their loved ones and their approach, resulted in reduced caregiver burden and an improved quality of life (Saxena et al., 2020).

It is of interest that similar group interventions as discussed above, when conducted with family members did not reduce caregiver burden or improve quality of life (Verrier Piersol, et al., 2017). It may be that this is due to the fact that within a family, usually one single member such as a spouse is deeply burdened with the stress of providing care while other members are not associated with the care process as closely as found by Saxena et al., (2020).

Transition to Long Term Care

Caregivers of those with NCD are considered to be an at-risk group following institutionalization of a family member as caregiver's mental health may actually worsen after placement (Cottrell, et al., 2018). Feelings of blame, self-doubt, loneliness, isolation and powerlessness are wrought in caregivers when friends and support networks are lost in the

post-placement period. Furthermore, caregivers feel abandoned by the medical system and argue that they don't feel listened to by staff and didn't understand the processes to be followed (Cottrell, et al., 2018). Families report feelings of despair that fuel distrust and anger with health care workers including doctors in a system that they saw as blunt and forceful (McCormack et al., 2017). Family members often find themselves in an adversarial position with the hierarchical and powerful health care system that places them in a role of advocate where trust and inclusion was initially expected (McCormack et al., 2017). Caregivers and families are frequently plagued with grief, guilt and a sense of failure at relinquishing care to the health care system that they consider to be further traumatizing (McCormack et al., 2017). Interestingly, Moon et al (2016) found in their literary review that small scale facilities such as group homes or specialized care settings that focused more on person centred care rather than a medical based model showed better quality of life outcomes for caregivers. Caregivers had continued involvement in care and demonstrated less caregiver burden (Moon et al., 2017).

Kazimiera Andersson et al (2018) posit that relatives of those admitted to long term care found it important to be the voice of their loved one and that they needed sufficient time to tell their life story. Sharing the life story can be a way to grieve their loss and changing life situation and helped to accept the separation from their loved one (Kazimiera et al., 2018). However, achieving this is difficult as the active transition period is often reported as a time filled with pressure, limited choice and control and feelings of being rushed by the system (Merla, et al., 2018). Some even liken this transition process to an obstacle course that calls on family members to jump through hoops (Merla, et al., 2018).

While interactions with a placed loved one, support from nursing staff, and interactions with other residents were found to be supportive for family caregivers, it is most important that peer groups were found to be most significant in supporting family caregivers

(Garity, 2006). Garity posits that participation in support groups facilitated by long term care facilities on a continual bases, provides a significant form of interaction between families and increases the family caregivers' ability to cope through sharing perspectives and comparing narratives post-placement (Garity, 2006). These efforts support the caregiver's ability to cope during placement, which is often wrought with guilt, the uncertainty of role disruption and uneasiness about the future. Conversely, caregivers found that conversing with friends and family without long term care experience increased their stress as they were often met with non-supportive comments regarding long term care facilities in general. Judgements from family and friends such as how one could "warehouse" their loved one exacerbates feelings of guilt during a period of intense loneliness as the caregiver is suddenly living alone and feeling immensely isolated (Cottrell, et al., 2018). Many family caregivers report having conflict with family members in placing a loved one in long term care and this is more prevalent with caregivers are adult children compared to spouses (Fukui et al., 2018). Support groups provided a major means for obtaining knowledge and information about Alzheimer's Disease and allowed some participants to put things into perspective (Garity, 2006). Given the complexity of family relationships, navigating the health care system and weighty emotional turmoil, the value of the provision of therapeutic counselling to caregivers is evident.

Inclusion and Fairness – The Ugly Truth

In considering how to care for those with NCD and their caregivers, it is of significance that Canadians report being from over 250 ethnic origins or ancestries (Government, 2017). When the intersectionality of socio-economic status, gender, sexuality, ability, class, religion and age, are considered, one is sighted with a complex conundrum of how best to provide fair, inclusive, effective psychotherapy. While one size can not fit all, all must be treated with respect for their unique worth and inherent dignity deserving to all

human beings (BC Association of Clinical Counsellors, 2014). While this may sound reasonable and even expected as a basic right in a health care environment, this is not the experience of many indigenous or LGBTQ Canadians (Citation needed).

As Mary Ellen Turpel-Lafond has alarmingly stated, British Columbia has a widespread and disturbing problem with Indigenous-specific racism and prejudice in BC's health care system that not only diminishes dignity, but risks safety when people are in the most vulnerable time of their lives (Bellrichard, 2020). Emergency room professionals betting on blood alcohol levels and assuming intoxication for a head injury that turned fatal are two examples that give insight into the day-to-day experiences of the indigenous population in Canada (Bellrichard, 2020). The stories of deep-seated and system racism are horrific and as Canadian's look ahead, they must consider that the hatred that underlies these beliefs places the vulnerable at greater risk. When seeking health care and support for a family member with NCD that may not even be met with respect or kindness, one would be remiss to not question safety. It is evident that the elderly Indigenous population and their families who seek counselling support and health care for loved ones with NCD may not receive even safe care, let alone supportive counselling.

It is estimated by the Alzheimer's Association that there were 350,000 LGBTQ+ individuals living with dementia in the United States in 2012 (Yarns et al., 2016), although it this statistic must be considered critically given the stigma and marginalization that pushes people underground into isolation. It may be that this number is much higher when considering that older LGBTQ+ adults have likely experienced much more mistreatment and discrimination due to the fact that much of their lives was lived prior to recent movements towards acceptance and inclusion (Yarns et al., 2016). The work of Yarns et al (2016) highlights the experiences of LGBTQ+ caregivers of being met with health care providers who are heterosexist or overtly homophobic and show a witnessing pervasive disregard for

the needs of these individuals. It is disturbing that individuals with dementia who identify as LGBTQ+ often give up their identity in response to a lack of cultural competence in health care workers (Yarns et al., 2016). This not only speaks to the need for education for health care workers, but also to the need to address this in therapeutic counselling for LGBTQ people living with dementia and their caregivers.

Multiple research studies carried out in the United States and in Europe demonstrate that transgender people are significantly higher than any other sexual minority to be victims of harassment, discrimination or violence (Prunas, et al., 2016). While one large survey conducted in the U.K. found that 73% of transgender people had experienced harassment in a public place and that 10% had experienced violent behaviour, it is most alarming that 36% of transgender people in the U.K. had reported at least one experience of discrimination and harassment in the work place, discrimination by a health care provider or violence (Prunas, et al., 2016). This is of concern as our population ages and Canada anticipates a growing number of people with NCD, some of whom will be transgender or gender nonconforming relying on health care providers for the most basic fundamental needs of daily living.

A client's cultural experiences and lived histories impact the client-therapist relationship, the treatments chosen, the building of rapport and therapy outcomes; therefore, it is crucial that the therapist aligns with the client's culture (Soto et al., 2018). Soto et al (2018) posit that therapists should not assume that their own self-evaluation regarding multicultural competence aligns with that of the client, which correlates to the requirements of the BC Code of Ethical Conduct for clinical counsellors. The BC Code of Ethical Conduct requires us to be aware of our own ethnic and cultural background, to actively engage in broadening our knowledge of ethnic and cultural experiences, to explore cultural differences in therapeutic situations and be aware of when a referral is appropriate for the client (BC

Association of Clinical Counsellors, 2014). When followed, the code guides a therapist to ensure appropriate therapy is provided to clients.

Alternative Ways to Think – Thinking Past the Canadian Mainstream

Aging at Home with Neurocognitive Disorder

It is well known that change and transition throughout our lives is stressful; moving from one home to another is particularly distressing, even when people are eager to do so (Stress, 2020). Let's now consider doing this when you are confused, have lost trust in your loved ones and are frustrated. With this in mind and with a compassionate heart, one is pushed to ask themselves if there is a better way to care for our elderly, in particular those with NCD. Elers, et al. (2018) posit that most older people prefer to age in place as a way to maintain independence and connect with friends and family who provide both practical and emotional support. Furthermore, they argue that moving into long term care can be detrimental for the elderly as they risk decreased mobility and loss of independence (Elers, et al., 2018). Additionally, there are no legislated requirements to provide family or informal caregivers with transitional support that would include psychotherapy during this time (Printer, 2020).

This stance is further supported by Bryanton (2018) who argues that to age in place means more than just staying in your house, but that our homes offer memories and emotions – a sense of safety and security. It could be argued that this is even more so important for those whose memories and emotional security is slowly lingering away. The work of Bryanton (2018) reveals the lived realities of women who are age 85 and older living in rural communities in Prince Edward Island, Canada, and prefer to live in their own homes. Her photo voice research piece (incidentally, that she completed as part of her doctoral studies in her 80's) allowed for these women to be heard and reveals active satisfying lives; women who drive their own cars, pay their own bills, prefer skype over the telephone, surf the net,

teach others and one woman in her nineties who uses a ride on mower to cut her lawn in the summer and keeps a fire going for heat in the winter. Of course, these particular activities may not be available eventually to those with NCD due to disease progression, but it is curious how this approach could be different and beneficial for those with NCD and their families. These women are amongst the fastest growing cohort of the aging population with this number expected to triple by 2031 in Canada (Bryanton, 2018).

The World Health Organization (WHO) has recommended that governments declare neurocognitive disorder (NCD) as a public health priority due to the increasing number of persons who will be facing this disorder (Hansen, Hauge, & Bergland, 2017). Globally, the majority of people living with neurocognitive disorder live at home including those in Norway where 50% of the 78,000 people with NCD live at home and often alone. Hansen et al., (2017) posit that the psychosocial needs of those with NCD has not been sufficiently explored and therefore studied how these needs are perceived, emphasized and met by home health care providers. It was concluded that there are major differences in how home health care providers perceived the psychosocial needs of persons with NCD and what their responsibilities were in meeting those needs (Hansen et al., 2017).

Hansen et al., (2017) posit that psychosocial needs are prioritized at a lower level than physical needs and that this finding is further supported by previous research. Health care providers considered that psychosocial needs were considered the responsibility of relatives and could be addressed outside of the home at senior day care centres. Sitting down and talking with the persons they were caring for was not considered care even when loneliness was expressed. Furthermore, even when persons were observed as having anxiety, depression or unrest, these needs were still not prioritized. In cases where sadness or loneliness were observed, relatives were contacted to meet these needs (Hansen et al., 2017).

This is a disturbing observation given how common these symptoms are in persons with NCD who live at home (Hansen et al., 2017).

While health care providers contribute this gap in care to time constraints, they also acknowledge a lack of competence which results in a feeling of insufficiency among health care providers (Hansen et al., 2017). It is of interest that how health care providers perceive how fulfilling psychosocial needs should be met and what interventions should be used determines how the fulfilment of these needs are met. As Canadians move forward to thoughtfully considering how persons with NCD and their families will be best supported while aging in place in Canada, the gaps highlighted here need to be addressed. Increased consciousness and competency in fulfilling psychosocial needs is essential to providing holistic care that allows people to age in place. This integral aspect of meeting psychosocial needs of those with NCD requires a shift in how one thinks about the priorities in providing care. As people with NCD age, they often struggle with maintaining relationships, resulting in isolation and social death prior to physical death (Watson, 2019). Watson posits that when care staff recognize and support the continuity of selfhood, that is how their past life is important to their present life and situation, they are able to better know how to care for them.

Aging at Home Infrastructure

To allow the elderly to age in their own homes with support of families, the infrastructure has to set up for them to succeed and be safe. Dobner et al., (2016) posit that the growing number of people aging in urban environments increases the demands for and creates challenges for urban development. As populations age and our independence begins to be threatened due in part to driving cessation, sensory decline, physical limitations and cognitive decline, the need for community supports becomes more evident. The availability of public transportation, care services in neighbourhood and community settings are two key pieces that need to be fit into the aging in place puzzle if this is to be available for people in a

meaningful way (Dobner et al., 2016). Fortunately, with the advancements of smart phones, internet access and virtual assistants such as Amazon's Alexa, opportunities to support independence are at a historical high.

Technology movement in the Netherlands allows for aging in place methods that includes videoconferencing with care providers, medical professionals, family and community and home health applications that report blood pressure and glucose monitoring (Dobner et al., 2016) This movement recognizes that people don't want to be dependent on a health care system; they want to be independent and have the freedom to live fulfilling lives rather than focus on their medical problems (Widen & Haseltine, 2016). It also is potentially less disruptive and confusing for those with NCD and allows for easier access to this health care. With the COVID-19 pandemic currently rampant in long term care, the use of technology has become significant as seen when video-calling on a tablet is often the only point of connection with loved ones even while actively dying. Budd et al., (2020) discuss how digital technologies are being harnessed during the COVID -19 pandemic worldwide including services for mental health and how public health will continue to become more digital in the future.

Global Approaches to Caring for Those with Neurocognitive Disorder

The Netherlands are regarded as leading the way in developing progressive approaches for long term care for people with NCD given the smaller home-like care environments and green care farms that are now alternatives to traditional nursing homes care (Bram de Boer et al., 2017). With over 1000 green care farms that serve individuals with psychological, learning or addiction problems, 200 of these serve those with NCD alone. Green care farms provide a unique environment for those with NCD that stems from developments within the agricultural sector. With activities such as preparing dinner, playing games, picking eggs, gardening, and feeding the animals, residents are free to wander and be

physically active on a daily basis which is in stark contrast to activities in institutional care where memory training, bingo and trivia are common (Bram de Boer et al., 2017). Some studies show that this psychosocial approach to care shows better nutritional status, more engagement in activities and a better quality of life, although other studies show no difference in quality of life when compared to larger traditional care homes (Bram de Boer et al., 2017). It is also of interest that informal caregivers are actively involved at green care farms, although there was no data available to show outcomes of social emotional health.

Widen & Haseltine (2016) report that in the Netherlands there is a strong focus of care on wellbeing, wellness and lifestyle choices for the elderly and that healthcare professionals focus on their patient's individual capabilities, freedom, autonomy and wellness. Home care organization allow for as much independence as possible and include family and community to support the elderly before nursing care is provided. The role of nursing and elder care is seen differently in the Netherlands than in North America, as there is emphasis on satisfaction and wellness and how elders feel in their home, which may include daily tasks such as watering their garden or taking out their garbage. Caring for the elderly emphasises the importance of freedom, personal autonomy, appreciation for wellness and vitality (Widen & Haseltine, 2016). This is in stark contrast to elderly care that is available in Canada that focuses mostly on institutionalized long-term care often operated by for profit businesses.

The Netherlands has alternatives to institutionalized long term residential care that includes the Apartments for Life model which places emphasis on social interaction and human happiness by creating a rich environment that includes restaurants, a zoo, internet café, a remembrance museum and healthcare. This model embraces four distinct tenets that include; *be your own boss, use it or lose it, care providers as extended family* and *yes culture* which refers to staff agreeing to new ideas or requests made by residents. Another alternative

is the Dementia Village Model which is a small self-contained village where later stage dementia residents can live relatively normal lives. There are smaller homes with 6 residents in each home, a shopping street, a recreation center, a theatre, a grocery store, restaurants, gardens and even a bar. The residents are free to wander at their own will and staff are dressed in normal clothing contributing to a sense of community (Widen & Haseltine, 2016). Amongst other differences, freedom to wander is one aspect of these models that is in stark contrast to the long-term care homes in Canada which embrace a clinical approach to care with secure units that prevent elopement. It is notable that as Canada prepares for increased institutional style long-term care homes as our population ages, the Netherlands has practiced these alternatives since the 1990's with success. Missing from the literature are explorations of whether these models in the Netherlands have similar number of instances of aggressive behaviour and elopement attempts, and whether loved ones report differences in social and emotional support.

Chapter 3 Analysis and Conclusion

It is evident from the literature review that caregivers and loved ones of those with NCD not only benefit from psychotherapy but actually require it to mitigate physical and mental health harm. This study has served as a foundation to establish what the structure of a therapeutic counselling program should look like to best support caregivers and loved ones of those with NCD throughout disease progression. After critical review of the issues that caregivers face and a look at what mainstream and alternative approaches are supportive, a vision for what modalities to utilize and how best to deliver these supports has become apparent. With the literature reviewed as a basis, I propose a program that is structured to service caregivers and loved ones from initial diagnosis through to grieving after death. The program will support caregivers regardless if their loved one is cared for at home or is transitioning or already transitioned into a public or privately funded long term care facility.

It is evident through this review, that the findings fit into three main areas of concern are: accessibility to clinical psychotherapeutic support throughout disease progression, social and emotional connection with other caregivers, health risks of caregivers and grief counselling. I argue that counselling services must be low barrier and inclusive to be utilized and affective for the community at large. Foley et al., (2017) posit that General Practitioners who are often the initial and only resource for caregivers, recognize their central role in providing support for family caregivers, yet their limited accessibility, time availability and lack of education in dementia and counselling leaves caregivers feeling isolated. This need for accessible counselling is further supported by Zmora et al., (2020) whose recommendations resulting from data analysis of an ongoing counselling trial, argue for psychoeducational and psychosocial interventions for caregivers of those with NCD while transitioning into long term care. Even finding what information is available and what relevant services are available is a barrier for caregivers (Macleod et al., 2017). Resources that are easy to find, low cost or free of charge, accessible (for example friendly for visually or hearing impaired and wheelchairs bound), inclusivity of culture, sexual identity and religion, are essential. This project has been developed with the intention that those most oppressed in the health care system will be supported including racialized, Indigenous, LGBTQ and low-income seniors. In conclusion, the reader will be provided with a therapeutic program that will address how caregivers and families of those living at home or in long term care with neurocognitive disorder are best supported.

Social Connection

This study highlighted the need for psychotherapy for caregivers long before transition into long term care is even considered and throughout disease progression. As previously discussed, Dam et al (2018) posit, that the need for social engagement is crucial for those in a caregiving role given the mental and physical health risks that are faced by

these individuals. For this reason, social connection must be afforded to caregivers from initial diagnosis through to post death grieving as needed and easily accessible. I propose that social connection be offered through government funded organizations much like parenting support groups are for pre and post-natal women and families with infants and up to 2 years of age (Delta Kidz, 2021). Just as a new parent group would have a qualified facilitator and relevant special guests such as public health nurses, nutritionists or sleep experts, a support group for caregivers would be facilitated by a registered clinical counsellor and have special guests such as a geriatric nursing specialist, a social worker specializing in long term care or peer counsellors with lived experience. Most supportive, however, might just be the opportunity to be in the company of others experiencing similar challenges. For this service to be non-barrier, it would be free of charge, accessible by transit and operated on a regular drop-in basis such as the first Tuesday evening of each month. Unlike parents who benefit from government funded programs for parenting support mentioned above, caregivers of those with NCD are not guaranteed access to some of the most basic mental health services and supports when needed (Canadian Mental Health Association, 2021).

Universal Mental Health Care

While Canadians pride themselves with our Universal Health Care, it falls far short to meet the mental health needs of Canadians when and where it is needed (Canadian Mental Health Association, 2021). There is a distinct disparity between meeting physical and mental health needs of Canadians for which over half of Canadians consider to be at epidemic proportions for anxiety and depression (Canadian Mental Health Association, 2021). Chronic underfunding of community accessible mental health services and a reliance on high-cost services such as psychiatrists and hospitals are partly to blame for lengthy wait times which is problematic when people are in crisis (Canadian Mental Health Association, 2021). Often Canadians seek support from family physician which is a limited resource and who may not

be able to meet their complex mental health needs (Canadian Mental Health Association, 2021). To address this concern in a meaningful way, more research funding is required to bring mental health research up to balance with physical health research. The Canadian Institutes of Health Research spends 4.3 percent of its annual research budget on mental health which mitigates any potential innovation or leveraging knowledge into practice to develop therapies appropriately (Canadian Mental Health Association, 2021). Canada could bring mental health care into balance if more research funding was available, if evidence-based therapies were publicly funding, if mental health care was accessible in a continuum of care, if investment was made to promote and support early interventions and supports and if equitable access were ensured (Canadian Mental Health Association, 2021).

Canada has signed or ratified several international human rights treaties including the International Covenant on Economic, Social and Cultural Rights, the International Convention on the Elimination of All Forms of Racial Discrimination, the United Nations Declaration on the Rights of Indigenous Peoples, the Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women which articulate a human rights approach to disability that ensures the ‘right to the highest attainable standard of mental and physical health’. Given this commitment that has been made, mental health care is not a privilege, but a right for all Canadians (Canadian Mental Health Association, 2021).

Proposed Program for Pre-placement in Long Term Care

The program proposed meets the Canadian Mental Health Recommendation as it is a non-barrier program that is accessible early when care is needed and is conducted with evidence-based therapies. Group counselling for caregivers, close family members and friends will be available on a drop-in on-going basis in the community (ie., community centre or health unit). The psychoeducation piece of this group in particular will focus on issues

specific to pre-placement, which differs from what will be offered in the post-placement group. The format of this service would be a semi-structured 2-hour session that ensures a positive, safe and encouraging environment. A Semi-structured format refers to the flexibility and room for responsiveness to meet the needs of the members of the group (Bernstein, 2015). Appendix A offers a schedule for this program.

Proposed Program for Post-placement in Long Term Care

As discussed, placement in long term care is met with much distress for caregivers and family members which speaks to the need for relevant and meaningful therapeutic counselling. I contend that this must be available within the care home environment on a regular and frequent basis if it is to truly meet the needs of caregivers and families; the needs of caregivers and families should be balanced with availability of services. The psychoeducation piece of this group in particular will focus on issues specific to placement in long term care such as loss of attachment, role change of caregivers, guilt, grief and loneliness. The format of this service would be the same as the pre-placement program, a semi-structured 2-hour session that ensures a positive, safe and encouraging environment. This will be ensured by having discussion and gain agreement at the time of intake with participants. A Semi-structured format refers to the flexibility and room for responsiveness to meet the needs of the members of the group. The social connection and support found in this group would contribute to the harmony of the residential care area as families will get to know the other residents as well. Appendix B offers a schedule for this program.

While one might initially think of social connection as being met through in-person face-to-face encounters, it may be more common to socially connect through the internet. As Bachmann (2020) posits, people are increasingly using social media to share information including caregivers. The flexibility is a significant benefit given the demands of being a caregiver and the limitations of being able to freely leave someone with NCD. Facebook

offers the option for closed groups where members with a particular need can pose questions, seek advice, give guidance, offer humour and generally support one another. A Facebook group would be a favourable extension for members who attend the in-person support group. However, it must be considered that neither the support group format, nor social media approach may fit for all caregivers and family members which may enhance the sense of isolation for these people. Scheduled telephone check-ins for these individuals from registered clinical therapists would offer mental health support and could be offered as an extension of the proposed program.

Advocacy for Service

As evidenced above, the experience of caregivers and family members is that there is currently a lack of low-barrier, accessible therapeutic clinical counselling. It is a disturbing reality that the provincial government of BC *requires* that long-term care facilities provide recreational staff for activities such as paintings, parties and games, but they do not require that facilities provide therapeutic clinical counselling for residents or their families that is in support of their physical and mental health (Government of British Columbia, 2021). It is not to say that recreational activities are not important for social emotional health, but there lies a void in legislative requirements to meet mental and physical health needs of caregivers and families in long term care in BC.

During this time, it would be remiss to write a paper about elder care and not recognize the devastation that is occurring in long term care homes during the COVID-19 pandemic. Long term care homes have been at the epicenter of this pandemic with residents representing 80% of the country's deaths (Stall, et al., 2020). It is alarming that during this pandemic, one of the largest for-profit chains in Ontario has asked for the rules to be relaxed, including the 14-day isolation period, which would result in decreased occupancy levels and ultimately decreased revenue and reduced payments to investors (Progress, 2020). It is of

interest that this particular chain is also one of the hardest hit by COVID-19 and declared a shareholder dividend of \$10.7 million during the pandemic (Employees, 2020) (Progress, 2020). For profit care homes have a history of demonstrating a lower standard of care as evidenced by more hospital admissions of residents due to quality-of-care related diagnoses (McGrail, et al. 2007). It is notable that in these cases when these elderly residents are needing emergency care, minimal standards of care are not being provided as that is all that is required by the Community Care and Assisted Living Act (Government of British Columbia, 2021). Canadian citizens, must ask themselves, why they are tolerating the government to contribute to this low standard of care?

Conclusion

In sum, caregivers of those with NCD are in need of more comprehensive resources to adequately support their mental health needs including therapeutic counselling which is currently not mandated in Canada (Canada, 2021, Printer, 2020). Through a critical review of the existing literature, the burden of caregiving on family members has become indisputable in a health care system where mental health needs are insufficiently addressed, yet the demand for family caregivers is expected to grow significantly (The Conference Board of Canada, 2015). Given the estimated 458,000 Canadian seniors who may experience unmet or under-met needs by 2046, it is preeminent that caregiver needs and best courses of service delivery be assessed to meet the intersectional needs of caregivers (The Conference Board of Canada, 2015). Lastly, as the COVID-19 pandemic has highlighted, the gaps that exist in how the elderly are cared for in long term care, the timing is auspicious to prepare for how the aging population and their caregivers will be best supported in the future (Progress, 2020).

Glossary of Terms

Ambiguous loss: Loss that is unclear, cannot be fixed and has no closure.

Care: Supervision that is provided to an adult who is vulnerable because of family circumstances, age, disability, illness or frailty, and dependent on caregivers for continuing assistance or direction in the form of 3 or more prescribed services (ie., meals, medication administration, personal care needs, clinical medical needs).

Caregiver: A person who provides direct care to another person to meet their emotional, physical, social and emotional needs.

Chronic sorrow: An ongoing response to losses that are continual and unending in nature

Community care facility: A premises in which a person provides care to 3 or more persons who are not related by blood or marriage.

Health authority: A body designated under section 4 of the British Columbia *Health Authorities Act*;

Indigenous: A collective name for the original peoples of North America and their descendants that recognizes three distinct groups: First Nations, Métis and Inuit.

Iterative Grief Model: A grief process involving three states – separation, liminality and re-emergence

LGBTQ: Lesbian, gay, bi-sexual, queer, trans-gender.

Living loss: Loss that is an ongoing presence in one's life.

Long term care: Residential care for persons with chronic or progressive conditions, primarily due to the aging process, governed by laws and regulations.

Low Income: Describes a person who earns below or not significantly above the poverty line.

Neurocognitive disorder: Dementia, delirium, amnesic and other organic cognitive disorders.

Nonfinite loss: Loss that is enduring in nature precipitated by an event that retains a physical or psychological presence in an ongoing manner.

Senior: A person age 65 years or older.

Appendix A

Schedule for Preplacement in Long Term Care Program for Caregivers

- | | |
|------------|--|
| 15 minutes | Welcome, introductions |
| 45 minutes | Group check in <ul style="list-style-type: none">• Participants introduce the loved one they are caring for – name, relationship, life highlights• Participants volunteer to check in on highs and lows since the last session |
| 45 minutes | Psychoeducation – Facilitator led topics, such as: <ul style="list-style-type: none">• Stages of Alzheimer’s – what to expect• Caregiving tips – ie., routines, personal care, recreation activities• Safety• Transitioning to Long Term Care• Self-care & self-compassion |
| 15 minutes | Closure <ul style="list-style-type: none">• Mindfulness Intervention• Provide resources |

Appendix B

Schedule for Preplacement in Long Term Care Program for Caregivers

- | | |
|------------|--|
| 15 minutes | Welcome, introductions |
| 45 minutes | Group check in <ul style="list-style-type: none">• Participants introduce their loved one – name, relationship, life highlights.• Participants volunteer to check in on highs and lows since the last session |
| 45 minutes | Psychoeducation – Facilitator led topics, such as: <ul style="list-style-type: none">• What to expect in the care home – routines, who to talk to about what, how to handle different situation, Resident Bill of Rights, licensing regulations• Grief• Nature of neuro-cognitive diseases and their progression• Self-care & self-compassion |
| 15 minutes | Closure <ul style="list-style-type: none">• Mindfulness Intervention• Provide resources |

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